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Paul Chappell, Merran Toerien, Clare Jackson, Markus Reuber



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Following the patient's orders?

Recommending vs. offering choice in neurology outpatient consultations

Paul Chappell^{ai}, Merran Toerien^{aii}, Clare Jackson^a, and Markus Reuber^b

^a Department of Sociology, University of York, Heslington, York, YO10 5DD, UK

Email addresses:

paulchappellmail@gmail.com

merran.toerien@york.ac.uk

clare.jackson@york.ac.uk

^b Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital,

Glossop Road, Sheffield, S10 2JF, UK

Email: markus.reuber@sth.nhs.uk

ⁱ Paul Chappell was Research Associate in Sociology at the University of York at the time the work was undertaken and is now Honorary Fellow in Sociology at York.

ⁱⁱ Merran Toerien is the corresponding author.

Abstract

The UK's Royal College of Surgeons (2016) has argued that health professionals must replace a 'paternalistic' approach to consent with 'informed choice'. We engage with these guidelines through analysis of neurology consultations in two UK-based neuroscience centres, where informed choice has been advocated for over a decade. Based on 223 recorded consultations and related questionnaire data (collected in 2012), we used conversation analysis (CA) to identify two practices for offering choice: patient view elicitors (PVEs) and option-lists. This paper reports further, mixed-methods analyses, combining CA with statistical techniques to compare the 'choice' practices with recommendations. Recommendations were overwhelmingly more common. There was little evidence that patient demographics determined whether choice was offered. Instead, decisional practices were associated with a range of clinical considerations. There was also evidence that individual neurologists tended to have a 'style', making it partly a matter of chance which decisional practice(s) patients encountered. This variability matters for the *perception* of choice: neurologists and patients were more likely to agree a choice had been offered if a PVE or option-list was used. It also matters for the outcome of the decision-making process: while recommendations nearly always ended in agreement to undertake the proffered course of action, option-lists and PVEs did so only about two-thirds of the time. While the direction of causality is unknown, this may indicate that patients are better enabled to refuse things they don't want when neurologists avoid recommending. We argue that our findings imply that neurologists tend to view choice as risky – in that the patient might make the 'wrong' choice – but that the inter-individual variation indicates that greater use of the more participatory practices is possible.

Keywords: UK; patient choice; doctor-patient interaction; neurology consultations; conversation analysis; mixed-methods; decision-making.

1. Introduction

Widely-publicized Royal College of Surgeons' (RCS, 2016) guidelines on consent specify that the aim "is to give the patient the information they need to make a decision about what treatment or procedure (if any) they want" (p. 4). The guidelines are responsive to the 2015 Supreme Court case of *Montgomery vs Lanarkshire Health Board* in which a woman was awarded damages because her obstetrician had not fully explained the risk of vaginal birth in her circumstances (small pelvis, large baby). Her baby – starved of oxygen for 12 minutes – was born with cerebral palsy. This case, according to the RCS, marks a radical shift in how the consent process is conceptualized:

From one in which the surgeon would explain the procedure to the patient and obtain their consent to proceed, to one in which the surgeon sets out the treatment options and allows the patient to decide (p. 15).

While recognizing that the UK's General Medical Council has "consistently supported patient autonomy", the RCS argues that "established clinical practice – and a large body of case law – [has typically] followed a more paternalistic approach" (p. 3). The *Montgomery* case thus necessitates "a change in attitude from surgeons in discussions about consent" (p. 3). Moreover, the RCS guidance is offered to "other

healthcare professionals” (p. 4), implying that similar changes may be needed in other specialties.

In this paper, we engage with these guidelines through our investigation of decision-making in neurology – a specialty where the RCS guidance should already be embedded, given that The National Service Framework (NSF) for long-term conditions (Department of Health, 2005), in place for over a decade, specifies that patients should “receive appropriate information before starting medication to enable informed choice” (p. 27). Although the NSF allows for more leeway than the RCS guidelines – acknowledging that “not everyone with a long term neurological condition will want to participate actively in their own care” (p. 21) – the documents share an emphasis on providing information about treatment *options*. Neurology offers an excellent site, therefore, for investigating how (and to what extent) health professionals are already acting in accordance with the consent process proposed by the RCS.

Our wider project – funded by the UK’s National Institute for Health Research – sought to explicate interactional practices used by neurologists to initiate decision-making with patients. Here, we compare three such practices: recommending, option-listing and patient view elicitors (PVEs). We argue that, relative to recommending, the latter two invite patients to take a more active role in decision-making, and align more with the RCS guidelines. It is striking, therefore, that recommendations were overwhelmingly more common, even in neurology.

2. What we already know about real-time decision-making in the clinic

Our project builds on previous research on real-time decision-making in the clinic. Much of this has focused on the treatment recommendation. Although recommendations may be designed in various ways, it is well-established that clinicians and patients understand recommendations to be proposals: they are subject to the patient's acceptance, and may be resisted (Costello and Roberts, 2001; Koenig, 2011; Stivers, 2005). Nevertheless, there is evidence showing how clinicians may persuade patients to accept the course of action they think is best (Quirk et al., 2012). Hudak et al. (2011) show how surgeons may build their recommendations to try to ward off resistance. Stivers (2005) found that parents were less likely to resist a non-antibiotic treatment recommendation for their child if this was framed as a positive recommendation (for a specific alternative), rather than as a recommendation against antibiotics. Opel et al. (2013) showed that significantly fewer parents resisted vaccine recommendations for their children when the provider used a "presumptive initiation format" (i.e. containing a linguistic presupposition of vaccination) as opposed to a "participatory" one (i.e. providing parents with more decisional latitude). This distinction maps closely onto the focus of our paper.

Collins et al. (2005) drew a related distinction, demonstrating a continuum of approaches to decision-making, ranging from 'unilateral' (or clinician-determined) to 'bilateral' (or shared). Illustrating the 'bilateral' approach, they showed how clinicians sometimes replace the treatment recommendation with efforts to include patients actively by, for example, "signposting options in advance of naming them; eliciting displays of understanding and statements of preference from the patient" (p. 2625).

Extending this research, our primary study used conversation analysis (CA) to identify two key practices whereby clinicians might invite patients to contribute, actively, to decision-making about treatment, investigation or referral options. We call these ‘option-lists’ and ‘patient view elicitors’ (PVEs) (Reuber et al., 2015). In brief, option-listing – illustrated below – consists of an explicit listing of alternatives (lines 2-3, 5-6) from which the patient may choose. This includes an initial announcement that there is a decision to be made (line 1).

Example of option-listing (G018; Multiple Sclerosis)

- 01 Neu: And **there’s two ways of dealing with this. If you don’t feel** that
02 things are absolutely back to normal... then **I can give you some**
03 **steroid treatment** for a short while.
- 04 Pat: Mm hm. ...
- 05 Neu: **Alternatively I could arrange for you to be seen by one of our**
06 **MS specialists.**
- 07 Pat: Uh huh.
- 08 Neu: ... see if they think that the inflammation...would benefit from some
09 other forms of treatment

The identifiers in this paper show where the recording was made (Glasgow or Sheffield) and the recording number (numbered consecutively at each site from 001). For ease of reading we have not used Jeffersonian transcription notation here, given our primary focus on the quantitative analysis.

The term ‘patient view elicitor’ incorporates a range of turn designs, which invite the patient to express:

- A preference; e.g. *Do you want to try a new drug?* (G075)
- How they “feel” about an option; e.g. *What are your own feelings?* (G092)
- Their “thoughts” on a proposed course of action; e.g. *What do you think about drugs like interferon?* (S084)
- And other variants on this theme; e.g. *Is that bad enough that you’d want to change drugs?* (S060).

All three practices may be designed in varying ways with implications for what sort of response is relevant next. The crucial contrast, for our purposes here, is the way in which option-lists and PVEs orient to the decision as lying in the patient’s domain. Both seek the patient’s active voicing of their position with respect to the option(s), while recommendations designedly make explicit which option the neurologist thinks is best, only seeking the patient’s acceptance thereof (see Toerien et al., 2013).

The following examples, together with the option-listing example, above, illustrate this contrast by showing the same decision type (whether to take steroids) handled using each practice. We have seen steroids listed as one option among two alternatives. In the following turn, the neurologist also constructs steroid use as optional, this time using a PVE, which foregrounds the patient’s wishes:

D’you want to try some steroids? (S080)

In our final example, the neurologist, having provided some diagnostic information about the patient's symptoms (not shown), builds on this to justify steroids as his recommended course of action, thereby foregrounding his opinion.

*And that's why **I want to** get the trial of steroids... It kind of depends on how things go, but I think five days of steroid tablets, you know, a short sharp course... should give us enough information to see whether or not we need to do anything else with it (G042).*

We understand these three practices as alternative approaches to the same activity: initiating – and, for later decision-points, pursuing – a decision about some possible treatment, investigation or referral, introduced by the neurologist.

As we have argued previously, although option-lists and PVEs seldom set up an entirely open (or neutral) decision, they can be said to offer the patient more of a say in the decision-making than recommendations (Reuber et al., 2015). This is for two, interrelated reasons. First, recommendations seek acceptance of a conclusion already reached by the clinician. Second, although recommendations can be formulated to carry different levels of deontic force (Stevanovic and Peräkylä, 2012) – ranging from a pronouncement that a particular treatment is necessary, through to a highly mitigated suggestion that a treatment might be helpful – recommendations unavoidably position the patient as having to respond to an 'expert opinion'. To resist a recommendation is to go against that expertise.

As a practice for initiating decision-making, then, recommendations fall on the ‘old’ side of the RCS’s distinction: the approach to consent “in which the surgeon would explain the procedure to the patient and obtain their consent to proceed” (p. 15). Option-listing, by contrast, maps closely onto the advocated ‘new’ approach, “in which the surgeon sets out the treatment options and allows the patient to decide” (ibid.). PVEs lie closer to the ‘new’ approach, in that they also seek the patient’s active involvement in the decision-making. In our primary study, we focused on how these two practices could be used to facilitate patient choice (Reuber et al., 2015). In the present study we coded our dataset for quantitative analysis to explore the distribution of these practices, and how they compare with recommendations. Our aim, following the example of Opel (2013), Robinson (2007) and Stivers (2015), was to reduce the interactional data - for quantitative analysis - without sacrificing a CA sensibility. We therefore worked iteratively from the recordings and retained as much interactional information as possible by maintaining sequential ordering and capturing both neurologists’ initiating turns and patients’ immediate responses (see Reuber et al., 2015 and forthcoming for analysis of the latter) across often extended decision-making trajectories.

3. Methods

3.1 Recruitment and data collection

Our primary dataset of 223 audio/video recordings of neurology outpatient appointments was collected in 2012 in two major clinical neuroscience centres (in Glasgow and Sheffield). Neurologists and patients also completed questionnaires before and after their recorded consultation. Fourteen neurologists (seven at each

site), 223 patients (114 in Glasgow, 109 in Sheffield), and 114 accompanying others (63 and 51, respectively) took part. Clinicians opted in to the study, providing written consent. Patients received advance, written information about the study. Dedicated study research assistants conducted informed consent discussions with patients (and accompanying others), taking written consent as appropriate. All participants were 16 years or older and able to consent in English. All could choose whether their consultations were audio- or video-recorded. The research assistants operated the recording equipment and provided help with the questionnaires, but were not present during the consultations. Ethics approval was granted by the National Research Ethics Service Committee for Yorkshire & the Humber (South Yorkshire) on 11 October 2011 and by the Proportionate Review Sub-committee of the NRES Committee North West (Greater Manchester South) on 20 July 2015.

3.2 Coding the recordings

This study was designed to compare neurologists' recommendations, option-lists and PVEs. Based on our previous qualitative findings (Reuber et al., 2015), we produced a coding scheme through an iterative bottom-up process to capture what was going on in the interactions. Hence, we developed a set of inclusion criteria based on the three focal practices and three recurrent types of decision: treatments, investigations and referrals. We developed a codebook and extraction form (available from the corresponding author). Working from the audio recordings (because we had those for all cases) in conjunction with their verbatim transcripts, the following were identified:

- All *decisions* about treatments, investigations or referrals initiated by the neurologist using one of our three core practices.

- Many decisions entailed extended sequences, with multiple *decision-points* (e.g. a recommendation followed by an option-list, then a PVE). We coded every option-list, PVE or recommendation that occurred across each decision type meeting our inclusion criteria. Our coding retained the sequential ordering, allowing us to compare first decision-points with later ones.
- For each decision, we noted whether one or more of the possible courses of action had been *agreed upon* by the end of the consultation. Coders could select ‘yes’, ‘no’ or ‘decision deferred’. The goal was to note whether a proffered course of action was going ahead in principle (we do not have the data to assess whether these actually occurred). For option-listing, if *any* listed option was agreed upon, coders selected ‘yes’. For PVEs, if the patient opted for a course of action proffered through the PVE – be that specific (e.g. a named drug) or general (e.g. ‘treatment’ for their condition) – then coders selected ‘yes’. To handle recommendations against doing something, coders recorded ‘yes’ if the decision was in favour of a ‘negative’ course of action (e.g. agreeing not to change a medication).
- For each decision-point, we identified how the patient and/or accompanying other *responded* in next position. Due to space constraints, we do not report analyses of this here (see Reuber et al., forthcoming).

The resulting spreadsheet contained our interactionally-grounded quantitative codes and the relevant data extracts, facilitating our ability to move between a qualitative and quantitative approach. The figure provided as a ‘Supplementary File’ illustrates our coding process, showing how a single consultation might have more than one decision and how decisions may have one or more decision-point. Given that our aim

was to compare recommendations, option-lists and PVEs, we did not attempt to code all possible ways in which a decision might be negotiated. To ensure we were comparing neurologist-initiated decisions, we excluded patient-initiated ones.

3.3 Inter-coder reliability

To test the reliability of our coding, three coders independently coded 20 consultations, sharing 10 with each of the others (30 consultations, or 13.5% of the dataset). Inter-coder agreement of the 39 first decision-points across the 30 consultations was checked. Agreement on when the first decision-point occurred was 74% - a large majority of cases. Percentage agreement and Kappa scores were calculated for each variable. Of the variables pertinent for this paper, agreement was 79.4% for the classification of decision-points (Kappa = 0.70) and 97.4% for the agreed outcome variable (Kappa = 0.92). This shows that there was some disagreement, indicative of the nuanced ways that decisions are initiated. However, these kappa values indicate 'substantial' and 'outstanding' agreement respectively (Landis and Koch, 1977), sufficient for quantitative analyses.

Coders subsequently negotiated agreements on all aspects of coding for the 30 cases before the remainder of the coding was conducted. The resulting quantitative data were then recoded into forms suitable for analysis.

3.4 Coding the questionnaires

Participant demographics and variables recording aspects of the patient's condition were derived from the questionnaire responses. These included the extent to which

neurologists considered patients' symptoms to be medically explained ('completely/largely explained', 'partly explained/partly unexplained' and 'completely/largely unexplained') and how certain they were of the diagnosis (rated from very uncertain (1) to very certain (10)). We employ variables that record the length of the consultation, which neurologist provided the consultation, and whether it took place within a general neurology or specialist clinic (e.g. Multiple Sclerosis or Epilepsy clinics). The six neurologists who recorded fewer than eight consultations each were combined into 'remainder' groups from Glasgow (three consultants) and Sheffield (three consultants). In post-consultation questionnaires, patients were asked: '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', and neurologists were asked: 'Did you give the patient a choice about treatment or further management?' A variable that described patient and neurologist agreement on whether choice had been offered was derived. Descriptive details for these variables can be seen in Tables 3, 4, and 5.

3.5 Analytic approach

Quantitative analysis consisted of a three-stage descriptive, exploratory process. First, we mapped the distribution of the three practices across consultations, decisions, and decision-points (Figure 1 and Table 1). Second, the bivariate links between interactional practices and demographic and clinical variables were investigated (Tables 2, 3, 4, and 5, and 7) and two binary logistic regression models were estimated (Table 6), using Generalized Estimating Equations Modelling to adjust for the clustered nature of the data. The dependent variable in both models is the binary variable classifying each consultation as either containing at least one PVE

and/or option-list or only containing recommendations. For independent variables, we included all demographic and clinical variables showing an association (at the 0.2 level) with interactional practices, in order to identify independent predictors of these practices, excluding the individual neurologist variable, as this led to overfitting. Specification 1 includes all relevant variables, whereas Specification 2 excludes the variables with greater than 5% missing values from the analysis, in order to preserve a higher N. Third, we investigated the bivariate links between practice and outcomes to explore the extent to which different practices may lead to differing levels of take-up of the options proffered by the neurologist (Table 8). Bivariate associations were investigated using contingency tables, Chi square tests, ANOVA, and correlation, as appropriate. In all analyses, we report p values at 0.1, 0.05, 0.01 and .001 levels and consider p-values below 0.05 to indicate statistical significance.

Some participants did not fully complete the questionnaires. Additionally, not all consultations contained a decision, as defined by our coding scheme. To deal with missing data, we took the 144 recordings with at least one decision meeting our inclusion criteria as our working sample, and used listwise deletion for the remainder of our analyses. The frequency of missing values for each of the different variables is shown in Tables 3 and 4.

4. Findings

4.1 Decisions and decision-points

Most consultations (144/223 or 65%) included at least one decision initiated by the neurologist through an option-list, PVE or recommendation. Figure 1 shows the

frequency of decisions across the 144 consultations with at least one decision, and the frequency of decision-points per decision. Decisions per consultation ranged from 1 to 4 (median 1), with single-decision consultations making up 51.4% of consultations. Decision-points per decision ranged from 1 to 11 (median 2). A large majority (96.4%) included 5 or fewer decision-points. At a gross level, the number of decision-points can indicate patient resistance. The longest chain, for example, involved a patient's resistance to, and neurologist's pursuit of, a recommendation for further investigations. We do not report analyses of decision-points here (but see Reuber et al., forthcoming). However, it is worth noting that option-lists have a higher average number of follow-up decision-points (2.5 per decision) than recommendations (1.6) and PVEs (1.2).

Figure 1 here

4.2 Distribution of practices across consultations, decisions, and decision-points

Table 1 shows the distribution of option-listing, PVEs and recommendations across the sample. By far the most common practice was the recommendation, followed by the PVE, then the option-list, which was comparatively rare. This was the case whether considering the percentage of consultations, decisions, decision-points, or first decision-points.

Table 1 here

4.3 Distribution of practices across decision types (treatments, investigations, referrals)

Treatment decisions were most common (over 60%), 29% were investigation decisions, and less than 10% referral decisions. Only a very small proportion of decisions (n=2, 0.8%) included more than one decision type (for example option-lists that included an investigation and treatment option). Table 2 shows the distribution of the practices across decision types, at decision level. Cases with multiple types of decision are excluded because of the low numbers. Table 2 reveals that recommendations were the most common practice across all decision types and option-lists were the least common. However, the proportions of the practices used for different decision types differed significantly. Investigations were characterised by very high numbers of recommendations, whereas treatment and referral decisions were relatively more likely to include option-lists and PVEs.

Table 2 here

4.4 Perception of choice

Table 3 shows relationships between interactional practice and perceived choice. Both neurologists and patients were more likely to report that a choice had been offered in consultations containing at least one option-list or PVE. There is a particularly strong relationship between perception of choice and use of option-lists or PVEs when the participants *agreed* choice was offered (see Reuber et al., forthcoming). These findings indicate that the understanding of option-lists and PVEs as mechanisms for offering choice is not just an analytic judgement; participants themselves typically perceived consultations containing these practices as offering choice, and those containing only recommendations as not offering choice.

Table 3 here***4.5 Geographic, patient demographic and clinical factors***

Tables 4 and 5 show the links between decisional practices and geographic, patient demographic, and clinical factors (there were too few neurologists to conduct tests based on their demographic characteristics). More PVEs and option-lists were used in the Sheffield consultations and more recommendations in the Glasgow consultations. We do not report other geographical differences in detail because we have done so previously for the full sample (n=223) (Wiseman et al., 2016) and the characteristics of the working sample (n=144) are very similar. To summarize the differences, Glasgow consultations were more likely to be held in general clinics and tended to be shorter. Symptoms were more likely to be “medically explained” in Sheffield consultations.

Table 4 here

Tables 4 and 5 demonstrate that the practice employed was largely unrelated to patients’ demographic characteristics. Different practices were no more or less likely to be employed based upon patients’ gender, ethnicity, educational level (which can be seen as a proxy for social class (Galobardes et al., 2007)) or work status. However, one of the two multivariate analyses (Specification 2, Table 6) indicates that younger patients were more likely to be given option-lists or PVEs, after other variables were controlled for.

By contrast, clinical factors and factors relating to the type of consultation were more commonly related to the practice employed. Bivariate analyses show neurologists were more likely to use option-lists or PVEs when they were more certain about a diagnosis and when the symptoms were medically explained. They were also more likely to use these two practices in follow-up (than first) appointments. There was some evidence that PVEs and option-lists were more likely to be used in specialist (than general) clinics, although this difference was not significant at the 0.05 level. There was no relationship between consultation length and the practice employed. Most of these associations do not remain significant after controlling for other variables (Table 6), but PVEs or option-lists were still more likely to be employed in consultations where neurologists were more certain of their diagnoses.

Tables 5 and 6 here

4.6 Individual differences between neurologists

Table 7 shows the differences between neurologists regarding their use of the three practices. We have insufficient sample size to employ inferential statistical (chi square) tests to investigate the differences between neurologists for one or more option-list vs. no option-list. Nevertheless, it is clear from the descriptive statistics and comparisons between 1 or more PVE and no PVE that there were large differences between neurologists in how often they employed PVEs or recommendations. Two contrasting cases highlight how individuals may exhibit a 'style' of decision-making: Sheffield 4 recorded no consultations containing only recommendations, and employed PVEs in all 19 consultations, whereas Glasgow 1

used recommendations in all 14 consultations, and used a lower combined proportion of PVEs and option-lists than any other neurologist.

Table 7 here

One potential explanation is that certain subspecialties may be more suited to certain forms of decision-making. However, a specialism-based explanation of individual differences does not appear to offer a good account for the patterning seen here, because, as Table 4 shows, there is no significant link between specialism and decisional practices. The above examples again illustrate this point: both Sheffield 4 and Glasgow 1 are from the same subspecialty.

4.7 Outcome: is the proffered course of action going ahead in principle?

Table 8 shows the links between practices and an important outcome measure: whether agreement was reached that a course of action made available by the neurologist was going to be acted upon by the patient. Crucially, when only recommendations were used, nearly all (98.6%) decisions concluded with the recommended course of action agreed in principle. By contrast, agreement was reached in only 68.6% of cases with a PVE or option-list. Thus, rejection of the proposed course of action – or deferral of a decision – was far more likely when PVEs or option-lists were employed (although the direction of causality is unknown).

Table 8 here

5. Discussion

The recent RCS (2016) guidance on consent proposes, in effect, that health professionals should (largely) abandon recommending in favour of option-listing together with a PVE to invite the patient's selection from the list. Our findings show that, despite long-standing guidance that patients should be enabled to make an "informed choice" (Department of Health, 2005, p. 27), recommending remains the primary means through which neurologists initiate decision-making. Moreover, option-listing was rare: there were around 13 recommendations for every option-list. On our measures, patients were offered choice in only about half the recorded consultations. Current practice in neurology thus appears to map more closely onto the 'old' approach articulated by the RCS – where clinicians explain the procedure and seek consent – than the practice advocated: where clinicians set out the options and let patients decide. This coheres with a range of findings regarding the inconsistency of participatory decision-making more broadly (e.g. Couët et al., 2015; Elwyn et al., 2013; Jones et al., 2014), and in neurology specifically (e.g. McCorry et al., 2009; Palace, 2013; Pietrolongo et al., 2013).

We explored whether our findings might be explained by clinician 'bias' regarding patients' sociodemographic status (cf. Aelbrecht et al., 2015; Waitzkin, 1989; Willems et al., 2005). However, apart from younger patients being more likely to be offered 'choice' – which might reflect an assumption that young adults prefer choice and elderly people prefer to be told what is best (e.g. Levinson et al., 2005) – we found no significant relationships between the practices and patient demographics. Rather, three factors seem to be most relevant:

- 1) Clinic location – option-listing and PVEs were more commonly used in Sheffield than Glasgow;
- 2) The individual clinician;
- 3) Clinical considerations. Option-lists and PVEs were more commonly used for treatment than investigation decisions and if there was greater certainty about the diagnosis. Bivariate analyses also indicated PVEs and option-lists were more likely to be used if symptoms were medically explained, and in follow-up appointments.

It is hard to pick apart the relative importance of these factors because we were unable to properly control for the influence of individual clinicians in our multivariate analyses. However, the most convincing reading of our descriptive analyses is that the first factor – geographical differences – may not represent ‘cultural’ differences between Glasgow and Sheffield. Rather, the importance of geography is likely explained by the idiosyncrasies of the individual neurologists and the clinical situations common in those clinics, because both of these factors contribute to skewing the distribution of practices in favour of more ‘choice’ in Sheffield.

The evidence for individual decision-making ‘styles’ among neurologists in our sample is strong, even within subspecialties; whether patients are offered a choice is partly based on which neurologist they see. This is key in the UK context of secondary care, which operates a referral system via the patient’s general practitioner. Although patients do have (limited) rights to choose their consultant, the allocation is typically made for them. Our study shows that this variability matters, firstly, for the *perception* of choice, since neurologists and patients were far more likely to report

that a choice was offered in consultations where option-lists or PVEs were employed. Secondly, while our data do not allow for definitive conclusions regarding the direction of causality, our findings also suggest that option-lists and PVEs may enable choice *in practice*. Given that recommendations nearly always ended in agreement that the proffered course of action would go ahead, but option-lists and PVEs ended in agreement only about two-thirds of the time, it may be that the latter practices facilitate more independent decision-making by patients. This may explain the more even split between agreement and refusal in response to option-lists and PVEs relative to recommendations, where patients might be more likely to ‘go along with’ the expert opinion. This interpretation is supported by Opel et al.’s (2013) finding that ‘participatory’ approaches were less likely than ‘presumptive’ approaches to lead to parents agreeing to vaccinate their children (the option clinicians thought best).

However, it is also possible that neurologists are more likely to use option-lists and PVEs when they already have reason to think patients might resist the proffered course of action (e.g. they know the patient’s treatment preferences). Moreover, since our study was not designed to assess the relative clinical significance of decisions, we cannot be sure whether the neurologists – insofar as they departed from their individual styles – were selecting practices based on some form of risk/benefit analysis. Certainly, the complex combination of clinical factors associated with whether the neurologists opted to recommend (*vs.* offering choice) suggest that they perceive choice as risky – the patient might choose what they consider to be the ‘wrong’ option. Clinicians may therefore choose a more directive approach if they believe the clinical stakes are too high.

Our qualitative analysis provides support for this. For example, we have observed a two-step process for anti-epileptic drug decisions, where the neurologist recommends *that* a patient with poorly controlled epilepsy try a different drug, but switches to option-listing regarding *which* drug to try. This is an example of choice being offered where the diagnosis is certain and medically explained, typically in a specialist clinic, at a follow-up appointment, with a patient who may well have prior experience of choosing between anti-epileptics. Nevertheless, choice is offered for that part of the decision for which the neurologist has: a) less evidence regarding which option is best, and b) good reason to seek the patient's views given that drugs have different risks. With respect to the decision to change drugs, the neurologist prioritises the 'duty of care' over offering choice. This aligns with Quirk et al.'s (2012) finding that there was a somewhat higher level of risk associated with more pressured and directed decisions (*vs.* more open ones) in UK psychiatric consultations.

The strong tendency for neurologists to recommend when making decisions about investigations (*vs.* treatments and referrals) may also be understood as supporting this analysis. Given that patients have as much legal right to refuse investigations as they have to refuse treatment (Department of Health, 2015) one might expect no such relationship between practice and decision type. However, it seems that neurologists regularly prioritise their view of what is best over the 'informed choice' policy when they consider there to be sufficient diagnostic uncertainty to warrant (further) testing. In such cases, not only is there often the risk of missing a serious diagnosis, but testing is typically positioned as a precursor to identifying a solution to the patient's complaint. Foregrounding the patient's right to choose whether to test might thus be

viewed as risky – particularly if treatment differs depending on the diagnosis (e.g. for epileptic *vs.* non-epileptic seizures).

Thus, we appear to be seeing a complex interplay between the exercise of epistemic (Heritage, 2012) and deontic authority (Stevanovic & Peräkylä, 2012), with neurologists being more likely to tell patients what to do when less certain of the diagnosis, and more likely to give patients a choice when they are better placed to weigh up the risk/benefit ratio of doing so. This may be understood as another instantiation of the ‘risk-choice paradox’, compellingly demonstrated in maternity care (Symon, 2006), where there is, simultaneously, a strong emphasis on avoiding risk and enabling choice for the woman in labour.

Our ongoing qualitative analysis also suggests that neurologists and patients orient to decisions about investigations as lying predominantly in the neurologist’s domain, while treatment decisions are understood as more open to joint negotiation (e.g. Costello and Roberts, 2001). This may be partly because investigations are understood as a component of the diagnostic activity – which is treated as largely a matter for the ‘experts’ (Heath, 1992) – and partly because the responsibility for carrying out tests lies with the healthcare service. Moreover, many tests are one-offs, carrying little risk of serious side effects for the patient, thus making their conduct relatively straightforward from a medical point of view. By contrast, many treatments require the patient to take responsibility for self-administering injections or tablets (often at a particular time) and may necessitate strategies for dealing with ongoing side effects. Thus, in addition to the evidence that neurologists appear to be using different practices based on their assessment of the risk associated with a ‘wrong’

choice, it appears that they are also attuned to the relative rights and responsibilities of each party regarding the decision being made.

Nevertheless, our findings clearly demonstrate that the same activity – decision-making – and even the same decision regarding the same condition in the same subspecialty, can be handled differently. This shows the more participatory practices can be used even in (some) situations where some clinicians routinely recommend. Our findings have three key implications: i) Given that recommending is overwhelmingly common, even in neurology, this is likely to be so across a range of specialties. The RCS guidance is right, then, to suggest that a more ‘paternalistic’ approach – where the doctor advises the patient to do what s/he considers best – remains part of established practice; ii) We believe that this is partly explained by doctors’ concerns that choice may be risky for patients (they may make the ‘wrong’ choice); iii) Nevertheless, some neurologists have developed a more ‘choice-oriented’ style, and here we note that the neurologist who offers most choice works in a specialist clinic, with patients whose symptoms are medically explained, and hence has exactly the basis for offering choice suggested by our findings. Further, all the neurologists do – at least on occasion – offer choice. Thus, the potential to expand the implementation of patient choice (should this be appropriate) is already within neurologists’ ‘repertoire’.

To our knowledge, our study is the first to map out, across a relatively large dataset of recorded consultations, the relationship between recommendations and practices that are demonstrably understood as offering choice, and a complex array of demographic and self-report variables of clinical relevance. This has allowed for a nuanced

understanding of how neurologists initiate decision-making in real-time. The study has its limitations, including those imposed by sample size (e.g. we were unable to conduct inferential analyses of neurologists' demographics), and the nature of our dataset. For example, we were able only to judge 'outcomes' based on conversational and self-report data. We have not tracked what happened following the consultations and do not have measures of physical or mental health that might have been a consequence of decisions taken. Further research is warranted.

We are also aware that the concept of 'choice' is contested and relatively poorly understood in interactional practice (Pilnick, 2008). We have focused on option-listing and PVEs because: a) our qualitative work showed how they were used to create explicit moments of choice; b) participants reported perceiving choice in those consultations where these practices were used; and c) option-lists and PVEs map onto the 'informed choice' ideal as articulated in NHS policy and guidance documents. Nevertheless, other practices will undoubtedly play a role in the perception of choice and its enactment. Moreover, as our qualitative work has shown, these practices do not *guarantee* that patient choice is enabled, and can be used as strategies to pursue the neurologist's agenda (Reuber et al., 2015). Such complexities, while making further qualitative work necessary, underscore the significance of our quantitative findings: despite the potential for all three practices to be used in atypical ways, the evidence strongly supports our claim that option-lists and PVEs, but not recommendations, are understood as making choice available.

In summary, neurologists do not appear to be adhering, systematically, to the guidelines on patient choice. However, 'one-size-fits-all' guidelines that uphold a

particular practice are, we would argue, unhelpful, both because they fail to take into account the complex balancing act that clinicians are demonstrably performing when selecting between alternative practices, and because these are not always enacted as policy-makers might intend. To enact a patient-centred approach in a meaningful way requires health professionals to engage, not in rote-learning of a formula for consent, but in reflective practice. This should include understanding the implicit *interactional* decisions (e.g. using an option-list, PVE and/or recommendation) they must make every time they initiate a substantive decision-making trajectory with a patient.

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Figure caption

Figure 1. Frequency of decisions per consultation (only including consultations with at least 1 decision) (left, n=246) and frequency of decision-points per decision (right, n=623).

Tables

Table 1. Distribution of the practices across consultations, decisions, and decision-points (row %)

		Recommendations	PVEs	Option-lists	PVEs or option-lists	No PVE or option-list (only recommendations)	Total
Consultations	n	131	77	24	80	64	144
	%	91%	53.5%	16.7%	55.6%	44.4%	n/a
Decisions	n	207	105	27	105	141	246
	%	84.1%	42.7%	11.0%	42.7%	57.3%	n/a
All decision-points	n	439	149	34	183	439	623
	%	70.6%	23.9%	5.5%	29.4%	70.6%	100%
First decision-points	n	173	58	15	73	173	246
	%	70.3%	23.6%	6.1%	29.6%	70.3%	100%

Table 2. Forms of practice used for different types of decisions (column %)

		Investigation	Treatment	Referral	Total
Decisions					
At least one recommendation	Count	64	124	17	205
	%	90.1%*	82.7%*	73.9%*	84.0%
At least one option-list	Count	1	20	4	25
	%	1.4%*	13.3%*	17.4%*	10.2%
At least one PVE	Count	17	67	14	98
	%	23.9**	44.7**	60.9**	40.2
At least one PVE or Option-list	Count	17	71	15	103
	%	23.9%***	47.3%***	65.2%***	42.2%

*** $p \leq 0.001$

** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Statistical tests show comparisons between 1 or more recommendation and no recommendation; 1 or more PVE and no PVE; 1 or more option-list and no option-list; and at least 1 PVE or option-list and no PVE or option-list.

Table 3. Decisional practice and perception of choice (column %)

	Option list or PVE	No Option list or PVE	Total
N	80	64	144
Patient choice	n=75	n=59	n=134
Choice	81.3%**	59.3%**	71.6%
No choice	18.7%**	40.7%**	28.4%
Clinician choice	n=78	n=63	n=141
Choice	83.3%***	52.4%***	69.5%
No choice	16.7%***	47.6%***	30.5%
Patient-doctor agreement on choice	n=73	n=59	n=132
Agree choice	71.2%***	33.9%***	54.5%
Agree no choice	6.8%***	22.0%***	13.6%
Patient no doctor yes	12.3%***	18.6%***	15.2%

Patient yes doctor no	9.6%***	25.4%***	16.7%
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p ≤ 0.001

** p ≤ 0.01

* p ≤ 0.05

~ p ≤ 0.1

NB. Statistical tests show comparisons between at least 1 PVE or option-list and no PVE or option-list.

Table 4. Distribution of patients from different demographic groups and with different clinical characteristics, and distribution of different types of consultations, across consultations containing different decisional practices. Categorical variables. (row %)

	At least 1 PVE or option-list	No PVEs or option-lists (only recs)
All	55.6% (n=80)	44.4% (n=64)
Location		
Sheffield	67.1%**	32.9%**
Glasgow	43.7%**	56.3%**
Clinic type		
Seen in general clinic	41.7%~	58.3%~
Seen in specialist clinic	58.3%~	41.7%~
Specialism		
General (n=25)	44.0%	56.0%
Epilepsy (n=37)	54.1%	45.9%
Headache / vascular (n=11)	45.5%	54.5%
MS (n=42)	64.3%	35.7%
Neuromuscular (n=10)	50.0%	50.0%
Other sub specialism (n=19)	63.2%	36.8%
Patient Accompanied?		
Accompanied	54.1%	45.9%
Alone	57.1%	42.9%
First appointment?	n=67	n=45
First appointment	45.5%*	54.5%*

Follow-up appointment	65.8%*	34.2%*
Symptoms		
Completely / largely explained	61.8%*	38.2%*
Partly explained	44.1%*	55.9%*
Completely Unexplained	37.5%*	62.5%*
Patient's Gender		
Female	53.9%	46.1%
Male	58.2%	41.8%
Ethnicity		
White British	56.1%	43.9%
Other	50.0%	50.0%
Post-school quals? (n=119)	n=67	n=52
Post-school quals	60.0%	40.0%
No post-school quals	53.6%	46.4%
Work status (n=143)	n=79	n=64
In work / education / other	57.5%	42.5%
Not working due to ill health	48.6%	51.4%
Employment		
Employed	61.5%	38.5%
Not employed	52.2%	47.8%

*** $p \leq 0.001$

** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Statistical tests show comparisons between at least 1 PVE or option-list and no PVE or option-list.

Table 5. Distribution of patients from different demographic groups and with different clinical characteristics, and distribution of different types of consultations, across consultations containing different decisional practices. Continuous variables.

		At least 1 PVE / or option-list	No PVE or option-list (only recs)	All
Patient age	Mean	44.5	48.1	46.1
	S.D.	14.1	15.6	14.8
Certainty	Mean	8.74*	8.0*	8.41
	S.D.	1.7	1.9	1.8
Duration	Mean	22.3	20.1	21.3
	S.D.	10.9	11.6	11.2

*** $p \leq 0.001$

** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Statistical tests show comparisons between at least 1 PVE or option-list and no PVE or option-list.

Table 6. Multivariate predictors of decisional practice (Odds ratios of consultation containing at least one PVE or option-list)

		Specification 1 (n= 112)		Specification 2 (n= 144)	
		OR	95% CI	OR	95% CI
Site	Glasgow	0.45	0.17 - 1.31	0.37*	.15 - .91
Clinic type	General	0.42	0.12 - 1.40	0.68	0.23 - 2.02
Symptoms	Completely unexplained	1.31	0.29- 5.83	2.3	.70 - 7.45
	Partly explained	0.94	.33 - 2.67	1.44	.55 - 3.76
First appointment?	First	0.46	.16 - 1.31	--	--
Certainty		1.59*	1.20- 2.09	1.30~	.97 - 1.7
Age		0.98	.95 - 1.01	0.91*	.95 - 0.99

*** $p \leq 0.001$

** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Dependent variable reference category is no PVE and/or option-list (only recommendations).

Table 7. Individual neurologists' use of different decisional practices (row %)

	At least one recommendation	At least 1 PVE	At least 1 Option-list
All	91.0%	55.6% (n=80)	44.4% (n=64)
Neurologist			
Sheffield 2 (n=10)	90%**	50.0%**	0.0% ^a
Sheffield 3 (n=14)	85.7%**	50.0%**	7.1% ^a
Sheffield 4 (n=19)	73.7%**	100.0%**	36.8% ^a
Sheffield 6 (n= 12)	100.0%**	41.7%**	25.0% ^a
Sheffield rest (n=18)	83.3%**	72.2%**	22.2% ^a

Glasgow 1 (n=23)	100.0%**	30.4%**	4.3% ^a
Glasgow 2 (n=13)	92.3%**	38.5%**	0.0% ^a
Glasgow 4 (n=12)	100.0%**	41.7%**	41.7% ^a
Glasgow 5 (n=14)	100.0%**	35.7%**	21.4% ^a
Glasgow rest (n=9)	88.9%**	66.7%**	0.0% ^a

^aSignificance testing not employed for this comparison

*** $p \leq 0.001$

** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Statistical tests show comparison between at least 1 recommendation and no recommendation; and at least one PVE and no PVE.

Table 8. Forms of decisional practice used and whether recommended courses of action are agreed to happen in principle (column %)

	At least 1 PVE or option-list	No PVE or option-list (only recs)	Total
N	105	141	246
Decision deferred	11.4%***	0.0%***	4.9%
No	20.0%***	1.4%***	9.3%
Yes	68.6%***	98.6%***	85.8%

*** $p \leq 0.001$

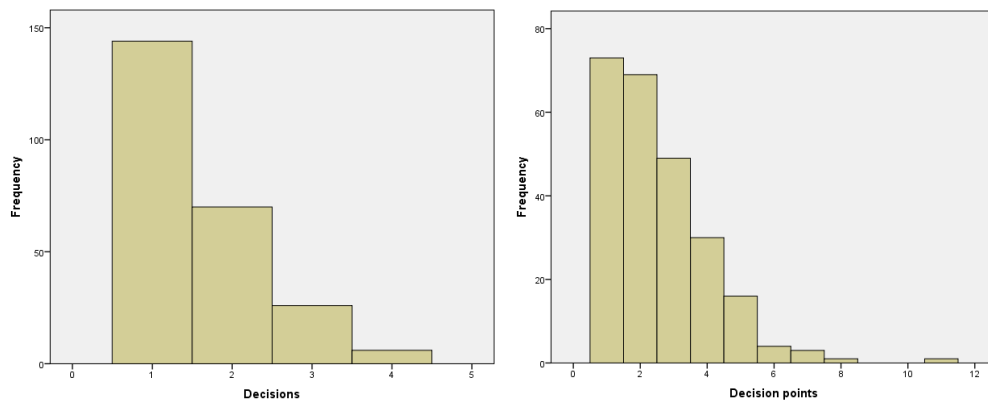
** $p \leq 0.01$

* $p \leq 0.05$

~ $p \leq 0.1$

NB. Statistical tests show comparisons between at least 1 PVE or option-list and no PVE or option-list.

Figure 1.



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Acknowledgements for:**Following the patient's orders?****Recommending vs. offering choice in neurology outpatient consultations**Paul Chappell^a, Merran Toerien^a, Clare Jackson^a, and Markus Reuber^b^a Department of Sociology, University of York, Heslington, York, YO10 5DD, UK

Email addresses:

paulchappellmail@gmail.com

merran.toerien@york.ac.uk

clare.jackson@york.ac.uk

^b Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital,

Glossop Road, Sheffield, S10 2JF, UK

Email: markus.reuber@sth.nhs.uk

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Research highlights

- Recommendations were far more common than patient view elicitors or option-lists.
- Use of the practices was largely not associated with patient demographics.
- Whether patients were offered choice partly depended on which neurologist they saw.
- Recommendations were more likely to end in agreement to treat/investigate/refer.
- Neurologists treat 'choice' practices as risky but could expand their use thereof.