Evaluating nuanced practices for initiating decision-making in neurology clinics: a mixed-methods study

Markus Reuber,¹ Paul Chappell,² Clare Jackson² and Merran Toerien²*

¹Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Sheffield, UK
²Department of Sociology, University of York, York, UK

*Corresponding author merran.toerien@york.ac.uk

Declared competing interests of authors: none

Published September 2018
DOI: 10.3310/hsdr06340

Scientific summary

Initiating decision-making in neurology clinics
Health Services and Delivery Research 2018; Vol. 6: No. 34
DOI: 10.3310/hsdr06340

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Scientific summary

Background

This report is based on follow-on research from our previous qualitative analysis of real-time interactional practices used to offer patients choice in the neurology clinic [Reuber M, Toerien M, Shaw R, Duncan R. Delivering patient choice in clinical practice: a conversation analytic study of communication practices used in neurology clinics to involve patients in decision-making. Health Service Delivery Res 2015;3(7)]. Our focus reflects the NHS’s emphasis on ‘patient choice’ and the lack of evidence-based guidance on how to enact it. Our previous research met its objective by identifying two interactional practices for offering choice, which we called ‘patient view elicitors’ (PVEs) and ‘option-listing’. Option-listing consists of an explicit listing of alternatives, from which the patient may choose one or more. PVEs incorporate a range of turn designs, which may invite the patient to express a preference or ask how they feel or what they think about a proposed course of action, and other variants on this theme. Although PVEs and option-lists position the decision as lying (at least partly) in the patient’s domain, recommendations convey the neurologist’s view on what is best. Our primary study was not designed to compare these three practices, nor did it analyse the consequences of selecting one over another. Hence, we conducted further qualitative and quantitative analyses of our data set in the follow-on research reported here.

Objectives

The study had four objectives, namely to:

1. map out (a) the three interactional practices that we have previously identified for initiating decision-making in the neurology clinic, together with (b) their interactional consequences (e.g. patient engagement or resistance and whether or not the patient ended up agreeing to a proffered course of action)
2. identify, qualitatively and quantitatively, any interactional patterns across our data set (e.g. to assess whether or not, and how, different interactional practices led to patient acceptance/resistance)
3. statistically examine the relationship between the interactional practices and the self-report data collected as part of the primary study (i.e. patient satisfaction data 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.

The practical goal motivating this work was to provide evidence-based and contextualised (as opposed to abstract) guidance regarding how these practices work, to enable clinicians to use them in ways that are sensitive to the nuances of interaction (as opposed to mechanistically).

Design

Our previous study used the qualitative, micro-analytic approach called conversation analysis (CA) to identify and evaluate the practices whereby neurologists offer patients choice. Our main data set consisted of 223 audio- and video-recorded consultations. We also collected, via self-report questionnaires, a range of clinical, demographic and patient satisfaction data [using the Medical Interview Satisfaction Scale (MISS-21)] and patients’ and neurologists’ perceptions of whether or not choice had been made available during a consultation. Our current research, informed by public and patient involvement throughout,
was based on mixed-methods secondary analysis of our set of interactional and questionnaire data to explore the nature and effects of the three interactional practices.

We developed a codebook and mapped out every recommendation, PVE and option-list together with a range of variables internal to each consultation (e.g. patients’ immediate responses and whether or not a course of action was agreed) and external to the consultation (e.g. patient satisfaction and perception of whether or not a choice had been offered). The resulting matrix captured the qualitative data related to each decision as well as associated quantitative data, powerfully facilitating extensive analyses of the three practices and their relationships with a wide range of variables.

**Setting and participants**

The original study was conducted in neurology outpatient clinics in Glasgow and Sheffield. A total of 14 neurologists, 223 patients and 114 accompanying others took part. Neurology is an ideal setting for addressing the study aims because a ‘person-centred service’ is a quality requirement and two neurological conditions (epilepsy and multiple sclerosis) have been identified by the UK’s Department of Health and Social Care as well suited to a participatory approach. Thus, we had reason to expect patient choice to be captured in this setting. However, although the content of a decision may be condition specific, practices for making choice available in interaction with patients are not. The findings reported here should therefore be of relevance to clinicians working in other settings.

**Key findings**

**The distribution of the three practices**

Despite long-standing guidance that patients should be enabled to make an informed choice, we found that recommending was the most common approach to decision-making in our data set: 91% of the 144 consultations with one or more decision point contained at least one recommendation, whereas just over half contained a PVE and only 16.7% contained an option-list. Recommendations were also by far the most common practice across all decision points, giving a ratio of 1.0 : 4.3 : 12.8 for option-lists to PVEs to recommendations. In other words, there were around 13 recommendations for every option-list.

In asking what variables are associated with the selection of decision-making practices, we found that the practices were employed at different frequencies depending on the type of decision being made. Investigations tended to involve recommendations, whereas treatment and referral decisions were relatively more likely to involve the explicit elicitation of the patient’s viewpoint (in the form of a PVE or option-list). However, there was a large degree of distinctive variation among individual neurologists, suggesting that some neurologists have a decisional ‘style’, such that whether or not patients get offered a choice depends partly on which neurologist they see. This appears to at least partly explain the regional differences we found: patients seen in Sheffield were more likely to be offered choice.

Patient demographics did not appear to play a key role in patterning decisional practice. It therefore appears unlikely that neurologists were deciding to use certain practices with certain social groups. There is one intriguing exception to this: option-lists were more commonly used with younger people.

Several clinical factors did show associations with decisional practice. Neurologists were more likely to use option-lists or PVEs (1) when they were more certain about a diagnosis, (2) when the symptoms were medically explained and (3) in follow-up appointments (as opposed to first appointments).
Consequences of using each practice
The external consequences of interactional practices were examined using two main variables: (1) perception of choice and (2) patient satisfaction scores. We found that neurologists and patients, separately, were far more likely to report that a choice had been offered when a PVE or option-list was used. The patterns were especially striking when examining the extent to which neurologists and patients agreed whether or not choice had been offered: there was agreement that a choice was offered in 71.2% of consultations containing an option-list or PVE, but in just 33.9% of cases without either.

There was no significant difference in overall patient satisfaction, no matter which of the practices were employed. Scores on the rapport and Distress Relief subscales also did not differ depending on decisional practice. Clinician numbers were too small to conduct meaningful tests for significant differences at the individual level. However, it is intriguing to note that the neurologist who routinely used PVEs scored the highest on all measures of patient satisfaction. By contrast, the neurologist who most commonly used recommendations scored below average for the equivalent measures.

We addressed relationships between interactional practices and their consequences internal to consultations in two ways. First, we examined the immediate responses to the different forms of practice. Second, we examined which of the practices were most likely to end up with a proffered course of action agreed (that it was going to happen in principle) at the end of the decision-making process.

We found that immediate acceptance of a proffered course of action was less common, for all practices, than some form of non-acceptance. However, the latter does not necessarily indicate resistance. Of the three practices, recommendations stood out for most commonly including no opportunity to respond. Although, in contrast to PVEs and option-lists, recommendations are not necessarily designed to invite the patient’s active involvement in decision-making, recommendations can be understood as initiating turns, which means that they do make relevant a response from the patient. Thus, it is noteworthy when an opportunity to respond is not given. PVEs, which are explicitly set up to invite the patient’s response, tend to be met by either some type of non-acceptance (around 50% were classified as such) or agreement to the proffered action (just under 50% were classified as such). Option-lists were nearly always followed by some form of non-acceptance (90% of the time); however, this relates to the option-list format. As option-lists are, by definition, lists of alternatives, patients typically respond first (usually minimally) to the individual items on the list, and only move to select from/comment on the whole list when expressly invited to do so, which was often achieved through a subsequent PVE.

In examining whether or not decisional practices were related to a course of action happening (in principle), we found a strong association between agreement to go ahead with a proffered course of action and decisional practice: agreement occurred in 98.6% of decisions including only recommendations but in only 68.6% of decisions where a PVE or option-list was used. Option-lists often led to deferred decisions, which accords with their use in making ‘major’ decisions, when neurologists regularly encouraged patients to seek additional support with the decision-making process (e.g. from a specialist nurse).

Importantly, there was no relationship between length of consultation and the form of decisional practice employed, even though PVEs (used as first decision points) tend to lead to the fewest number of subsequent decision points and option-lists tend to lead to longer chains.

Further conversation analytic insights
The clear difference in acceptance rates when comparing PVEs and option-lists with recommendations raises an important question for clinical practice: is the lower level of uptake following some form of choice an indicator that the patient-choice agenda is working (i.e. patients are successfully refusing courses of action they do not want)? Or is there reason to be concerned that patients might be failing to receive
whatever they really need owing to the use of more participatory practices? Our study could not answer this question fully because it was not designed to test the medical appropriateness of the decisions or patients’ subsequent adherence. However, undertaking further conversation analytic work, we approached the question from an interactional perspective, seeking to understand some of the patterns that underpin the quantitative findings.

We showed that recommendations are not a homogeneous category. Although, by definition, recommendations convey decisions as being within the clinician’s domain (based on medical expertise), the interactional ‘push’ towards this domain varies across the different recommendation formats. We analysed the extreme end (those formulations that strongly place decisions with neurologists) and we identified three such formulations: those based on neurologists using ‘I/we will’, ‘I am going to’ and ‘I/we need/have to’. These turn designs appeared to operate differently. ‘Going to’ is used for treatment and investigations but ‘will’ and ‘need to’ are used mostly for investigations. ‘Going to’ and ‘will’ tend to presume agreement from the patient and engender, apparently unproblematically, the least active responses from patients. In contrast, ‘need to’ is often invoked in the context of possible resistance or otherwise problematic environments, and neurologists do pursue active agreement.

Next, we further explored the interactional trajectories following offers of choice. First, we showed cases for which neurologists offered choice and then readily accepted whatever the patient decided. Second, we showed how neurologists sometimes offered choice but then pursued a particular outcome when it was not forthcoming. Third, we considered the possibility that some choice formats may actually, perhaps inadvertently, bias patients towards rejecting the proffered course of action. We argue that our data set strongly supports an understanding of patient choice in practice as a form of ‘managed optionality’: patients were (at times) given the opportunity to make their own choice but within limits that were deemed to be clinically acceptable by the neurologist.

**Discussion**

Our distributional findings provide an indication that decision-making practices are not used randomly and, furthermore, that decisions are not routinely being made in ways that accord closely with current NHS policy on patient choice. Our findings suggest, instead, that current practice entails a blend of individual neurologists developing their own style, which they tend to favour regardless of the patient’s demographics and clinical characteristics, and a delicate balancing act regarding the specific decision. We argue that when the neurologists did tailor their practices, they were attending to a potential conflict between their perceived duty of care and the expectation that they minimise the exercise of their authority. Clinicians may resolve this by electing to recommend when they believe that there are compelling clinical reasons to favour their duty of care over the guidelines on giving choice. Hence, choice tends to be offered when it is deemed to be clinically acceptable – a form of managed optionality for patients.

**Conclusions**

Patient choice is harder to enact than policy directives acknowledge. Although there is good evidence that neurologists are seeking to enact patient choice, they are still more likely to make recommendations. This appears to be partly owing to concerns that choice might conflict with doctors’ duty of care. Future guidance needs to draw on evidence regarding choice in practice to support doctors and patients to achieve the wider goal of shared decision-making (SDM).
Future work

On the basis of this study, we recommend four directions for future research:

1. Investigation of longer-term, external outcome factors (such as adherence) to advance understanding of how the use of different practices within the interaction might matter beyond the clinic.

2. To further understand associations between practice employed and characteristics of decision, a study that includes some measure of the ‘weight’ of the decisions made (e.g. ratings by an expert panel) to enable comparisons between those decisions judged to be more or less ‘serious’ or ‘necessary’ with respect to patients’ health outcomes.

3. The extension of our methodological approach to investigate other interactional practices of relevance to the broader ideal of SDM (including those used in activities other than decision-making per se, e.g. open questions and practices used to give patients opportunities to ask questions).

4. The extension of our methodological approach to other clinical settings to build a more complete picture of the ways in which patient choice is being enacted on the ‘front line’.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.
Criteria for inclusion in the *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 14/19/43. The contractual start date was in August 2015. The final report began editorial review in May 2017 and was accepted for publication in October 2017. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care.

© Queen’s Printer and Controller of HMSO 2018. This work was produced by Reuber et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
**NIHR Journals Library Editor-in-Chief**

**Professor Tom Walley** Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

**NIHR Journals Library Editors**

**Professor Ken Stein** Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

**Professor Andrée Le May** Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

**Dr Martin Ashton-Key** Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck** Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

**Dr Tessa Crilly** Director, Crystal Blue Consulting Ltd, UK

**Dr Eugenia Cronin** Senior Scientific Advisor, Wessex Institute, UK

**Dr Peter Davidson** Director of the NIHR Dissemination Centre, University of Southampton, UK

**Ms Tara Lamont** Scientific Advisor, NETSCC, UK

**Dr Catriona McDaid** Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

**Professor William McGuire** Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads** Professor of Wellbeing Research, University of Winchester, UK

**Professor John Norrie** Chair in Medical Statistics, University of Edinburgh, UK

**Professor John Powell** Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

**Dr Rob Riemsma** Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

**Professor Helen Roberts** Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

**Professor Jonathan Ross** Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

**Professor Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

**Professor Martin Underwood** Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

**Editorial contact:** journals.library@nihr.ac.uk