

<b>Institution:</b> University of York		
<b>Unit of Assessment:</b> 21 - Sociology		
<b>Title of case study:</b> Patient choice in practice: translating research findings into training and national guidelines for medical students and practitioners		
<b>Period when the underpinning research was undertaken:</b> 2011-2018		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr Merran Toerien Dr Clare Jackson	Senior Lecturer Senior Lecturer	2007 - present 2013 - present
<b>Period when the claimed impact occurred:</b> 2019-2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>Two collaborative applied conversation analytic studies undertaken at the University of York, have led to a transformative programme of impact activities, reaching across numerous medical specialties in four countries: Brazil, The Netherlands, Norway and the UK. This includes translation of the research findings into Brazilian Portuguese, Dutch and Norwegian. The research identified, for the first time, the specific communication skills needed to offer patients choice effectively. By producing innovative face-to-face and online training with international reach, the research team, led by Dr Toerien, has trained over 200 medical students and practitioners in these skills directly. The value of the research for improving medical training and practice has been widely recognised by medical educators and guideline producers, ensuring the breadth and longevity of the research impact well beyond those directly trained. The key impacts are:</p> <ul style="list-style-type: none"> <li>• A documented, positive change in medical students' and practitioners' awareness, understanding and practice regarding how best to offer patients choice;</li> <li>• Direct influence on the content of medical training curricula, and on how medical educators train students in shared decision-making;</li> <li>• Inclusion of the findings in two national clinical communication guidelines: for the Dutch College of GPs and the UK's National Institute for Health and Care Excellence.</li> </ul>		
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>Conducted between October 2011 and September 2018, the research used an innovative blend of conversation analysis (CA) and statistical techniques to compare different approaches to decision-making identified in NHS-based neurology consultations. Co-investigators Drs Toerien and Jackson led on the CA component, which is critical to the impacts described. The Chief Investigator was consultant neurologist, Professor Markus Reuber (University of Sheffield). An extensive pre-project literature review revealed only two studies investigating choice in practice, neither of which considered doctor-led care. The research thus makes a substantive, empirical contribution by demonstrating which interactional practices work best for enabling patients to <u>firstly</u>, recognise that they have a choice and, <u>secondly</u>, engage more actively in decision-making. The research dataset consists of 223 recorded neurology consultations, plus pre- and post-consultation questionnaires, giving unprecedented insight into what really happens when clinicians offer choice, and how this is experienced by patients.</p> <p>The ideal of shared decision-making has been endorsed for over 40 years and is embedded in the NHS Constitution, required by the UK's General Medical Council, and recommended by the National Institute for Health and Care Excellence (NICE). Yet research – including that underpinning this case study [A][B][D][E] – repeatedly shows that clinicians struggle to enact the ideal in practice. This matters because patients report wanting to be more involved in decision-making and because there is good evidence for a host of positive outcomes when they are [A][B]. There is agreement that better communication skills are key to making shared decision-making a reality, but conventional training has been criticised – by medics themselves – for having “<i>ignored insights from conversation analysis</i>” (Gulbrandsen, letter in the BMJ, 2020). Seeking to address such short-comings, the ‘Patient Choice in Practice’ project [A][B] – funded by two National Institute for Health Research (Health Services and Delivery) grants (10/2000/61</p>		

& 14/19/43) – sought to understand the *specific* communication skills needed to offer patients choice most effectively.

The research showed that, despite the long-standing guidance that patients should be enabled to make an ‘informed choice’, recommending remains overwhelmingly more common than offering choice [B][D][E]. However, the research also identified two effective practices for offering choice: (1) *Option-listing*, which involves explicit listing of alternatives from which the patient may choose [A-E]; and (2) *Patient view elicitors (PVEs)*, which include formats that invite patients to express a preference, how they feel about an option, and variants on this theme. PVEs may be used alone or with option-lists to give patients opportunities to direct the decision-making according to their own views [A][B][E]. By comparing these two practices with the standard practice of *recommending* a single option, this research found that:

1. Full-form option-listing, which includes three components – summarised as ALF: Announcing a decision is to be made, Listing the options, Finding out what the patient wants using a PVE – was the most effective way for clinicians to actively invite patients’ involvement in the decision-making [A][B][C];
2. However, option-listing was remarkably rare [B][E] – a striking finding given that this is core to shared decision-making and described specifically as the ‘gold standard’ in some guidelines (e.g. Royal College of Surgeons, 2016).
3. Clinicians and patients were significantly more likely to agree that a choice had been offered if a PVE or option-list (as opposed to a recommendation) was used, indicating their effectiveness for enabling patients to recognise they have a choice [B][E].
4. Whilst recommendations nearly always ended in agreement to undertake the clinician’s preferred course of action, option-lists and PVEs did so only about two-thirds of the time (a statistically significant difference) [B][E].

These findings imply a dilemma: on the one hand, there has been an emphasis in NHS policy on increasing patient choice since at least 2000; on the other hand, clinical guidelines may indicate that a particular treatment option is recommended. Toerien *et al.* thus argue that it is too simplistic to suggest (as the Royal College of Surgeons does) that recommendations should be abandoned in favour of option-listing [E]. Rather, **clinicians need to be aware of the advantages and risks of each approach to decision-making in order to balance their duty of care with their responsibility to empower patients to make their own decisions**. This is not an easy task, hence the need for nuanced, specific communication training, grounded in how decision-making actually works. The research demonstrated that the communication skills identified work effectively to offer patients choice on the frontline. Moreover, the rich evidence base of recorded consultations provides – for the first time – best practice examples of patient choice, rooted in the complexities of real clinical interaction.

### 3. References to the research (indicative maximum of six references)

[A] Reuber, M., Toerien, M., Shaw, R., & Duncan, R. (2015) Delivering patient choice in clinical practice: a conversation analytic study of communication practices used in neurology clinics to involve patients in decision-making. *Health Services and Delivery Research*, 3(7) (returned to REF2021, report from grant funded by NIHR) <https://doi.org/10.3310/hsdr03070>

[B] Reuber, M., Chappell, P., Jackson, C. & Toerien, M. (2018) Evaluating nuanced practices for initiating decision-making in neurology clinics: a mixed-methods study. *Health Services and Delivery Research* 6(34) (report from grant funded by NIHR) <https://doi.org/10.3310/hsdr06340>

[C] Toerien, M., Shaw, R. & Reuber, M. (2013) Initiating decision-making in neurology consultations: ‘recommending’ versus ‘option-listing’ and the implications for medical authority’ *Sociology of Health & Illness* 35(6) pp.873-890 (returned to REF2014) <https://doi.org/10.1111/1467-9566.12000>

[D] Toerien, M., Reuber, M., Duncan, R. & Shaw, R. (2018) ‘Generating the perception of choice: The remarkable malleability of option-listing’ *Sociology of Health & Illness* 40(7) pp.1250-1267 (returned to REF2021) <https://doi.org/10.1111/1467-9566.12766>

[E] Chappell, P., Toerien, M., Jackson, C., Reuber, M. (2018) Following the patient’s orders? Recommending vs. offering choice in neurology outpatient consultations. *Social Science & Medicine* 205 pp.8-16 <https://doi.org/10.1016/j.socscimed.2018.03.036>

[F] Toerien, M. (2018). Deferring the Decision Point: Treatment Assertions in Neurology Outpatient Consultations. *Health Communication*, 33(11):1355-65. (returned to REF2021) <https://doi.org/10.1080/10410236.2017.1350912>

#### 4. Details of the impact (indicative maximum 750 words)

Through a multi-pronged programme of impact activities, the research has:

1. Been used to train medical students and practitioners in communication skills.
2. Directly influenced medical curricula and medical educators.
3. Been included in two sets of national clinical communication guidelines (Netherlands and UK).

These impact activities are highly significant because, as noted above, involving patients in decision-making is a widespread 'best practice' requirement, but there is extensive evidence that clinicians find it difficult to do. The impact activities have achieved notable reach, having made a positive difference in four countries across two continents (Brazil, the Netherlands, Norway, the UK), reaching four types of beneficiary: medical students, medical practitioners, healthcare educators and medical guideline producers. The research findings have been used across multiple specialties, including neurology, general practice, ophthalmology, and emergency medicine.

#### **Impact 1. A documented, positive change in medical students' and practitioners' awareness, understanding and practice regarding how best to offer patients choice.**

This was achieved by delivering evidence-based communication skills training, in person, to over 200 medical students and practitioners, including end-of-project NIHR-funded workshops for neurologists in the UK (Glasgow and Sheffield), and invited workshops for psychiatrists in Glasgow, medical students and practitioners in Brazil, and ophthalmic practitioners and trainees in Belfast. These have been described as a "*perspective-changing learning experience... not just for the future profession but for their next-day practice already!*" (Medical Educator, Brazil)

[1a]. Student participants reported rapidly utilising what they had learnt, despite this often being at odds with what they observed their supervisors doing [1b][1c][1d]. One drew upon the training to counter a professor's suggestion that they tell a patient what to do: "*In that moment all my studies of patient choice made complete sense and I said, 'why don't we ask the patient what she would like?'*" The professor agreed, and the patient's positive response has convinced the student to implement patient choice in her future practice [1d]. Experienced medical practitioners reported "*more awareness of my own practice*" (Optometrist, Belfast) [1e] and positive changes following the training: "*I used to think that my practice included patient's choice. But now I am beginning to realize that there are many more situations, such as decisions about medical procedures, exams, besides treatment!... It has already started! Today in my practice I have realized my opportunities to introduce choices in medical decisions!*" (Neurologist, Brazil) [1e].

A two-hour e-learning package, called 'Patient Choice in Practice', was developed to augment the face-to-face workshops that were curtailed by the COVID-19 pandemic, as well as to ensure longevity and reach of the training (see also Impact 2, below). This was piloted in 2020 with 55 medical students in Brazil, who also received a three-hour online workshop (delivered twice by Toerien), with real-time translation into Brazilian Portuguese. Positive evaluations by participants were publicly reported on the Unisinos news pages: "*I was able to deepen and solidify my knowledge... how to bring these options... giving space for the patient to bring their thoughts, values and desires in relation to that decision... the knowledge acquired in the workshop makes my practice even more respectful, sensitive to the other*" [2]. Formal evaluation was conducted using pre- and post-training questionnaires. **These showed that the training led to a statistically significant increase (Wilcoxon Sign rank test) in participants' confidence in how to offer patients choice [3]**, particularly through the skills taught around option-listing and seeking patient views: "*The most important thing I learned was how to include the patient in the decision (through the use of ALF and, mainly, PVEs). After the workshop, I concluded that, during our practices, we disseminated many more recommendations than shared decision-making processes, without even realizing it. So, I leave this workshop much more aware of this*" [3]. **The majority of participants (80%) reported that they would now offer choice in situations when they would not have done so before the training [3].**

**Impact 2: A lasting change in medical curricula and medical educators' approach to communication skills training.**

The repeat invitation to Toerien (2019 and 2020) to provide training on patient choice to the medical students at Unisinos (Brazil) represents a lasting change to the curriculum. This will continue directly through the Patient Choice in Practice e-learning package, which has been adopted for ongoing use at Unisinos [1a][4], Queen's University Belfast [5] and Manchester Medical Schools. As a medical educator at Manchester Medical School notes: *"The Patient choice in Practice eLearning package addresses a crucial part of communication in clinical care. Rather than training based on simulated clinical practice, it uses real clinical encounters to encourage participants to think critically about how to balance patients' right to choose with the practitioner's duty of care. This will provide clinicians with greater authenticity in the teaching presented to them and greater clinician acceptance of the learning it provides. The package dovetails with other areas of communication training and addresses a curriculum gap"* [6]. The medical educators also report how the research has influenced their own teaching: *"the workshop Patient Choice in Practice generated impact on my teaching to second year-med students... I, along with the lead tutor of Language and Interaction in Healthcare, have referred to [Toerien et al's] work in class... and we agreed to permanently incorporate [their] work on the syllabus we will be offering"* [4].

Educators in Norway have incorporated the research in continuing professional development training: *"Findings from [Toerien et al's] research have been amongst the key take home messages in lectures I've delivered on how to achieve patient choice and shared decision making in practice. This is one of the most challenging communicative tasks in modern health care, and [Toerien et al's] empirical findings are powerful in demonstrating how it can be accomplished in practice"* (educator responsible for training over 200 Norwegian specialists in general medicine and ophthalmology, at Stavanger University Hospital) [7]. For those who teach and practice medicine, the research has had a double impact. *"[Toerien et al's] papers on patient choice have greatly influenced my thinking and knowledge around (shared) decision making, both with regards to my own research, clinical practice and my teaching these subjects at UiT the Arctic University of Norway's medical school... students have been very engaged with the issues [Toerien et al have] raised, prompting important learning about and hands-on training in communicating with 'difficult' patients... and patients with chronic disease"* (Head of the Emergency Department of Nordland Hospital) [8]. The research impact in Norway will have longevity because the *"findings about what constitutes patient choice have also been given a prominent place in the first conversation analytic introductory book in Norwegian, focusing on conversation as a tool for professional practice"* [7]. This includes a translation of material from the final report [A].

**Impact 3: Inclusion of the research findings in two national clinical communication guidelines (in The Netherlands and the UK).**

As a result of delivering the keynote based on her research – described as an "eye-opener" [9a] – at the 2019 Dutch GP Science Day, Toerien was invited to provide "expert input" [9a] into the first clinical communication guidelines, developed by the Dutch College of General Practitioners (Nederlands Huisartsen Genootschap; NHG). Toerien delivered findings from the research on patient choice as well as an overview of CA findings on GP consultations in a 45-page report [9b] and 6 hours of discussion of the evidence with the NHG Programme Manager for Person-Centred Care. She reports: *"I am extremely pleased with the way [Toerien] was able to apply [her] scientific knowledge on CA to day-to-day GP practice. I learned a lot about patient choice in practice, which is a very important step for shared decision-making... [Toerien's report] provides a sound basis and it will be easy to translate the evidence into the communication modules"* [9a]. The final production of the guidelines has been delayed due to COVID-19, but **it has been confirmed that Toerien's input will definitely be included** [9a]. The guidelines will be applied in e-learning programmes developed by the NHG in order to make current knowledge on communication easily accessible to all Dutch GPs. *"The goal is to improve the clarity of GPs' communication – making it easier for patients to understand their diagnosis and any treatment options – and to equip GPs to know how to solicit patients' own concerns and preferences as the basis for a patient-centred approach to healthcare"* [9a]. In contributing so extensively to the development of these guidelines, then, the research will benefit not only all Dutch GPs but the patients with whom they communicate on a daily basis.

The e-learning materials have also been accepted for inclusion in a comprehensive set of training resources to support clinicians across the UK to enact the NICE Shared Decision-Making (SDM) Guidelines [10]. NICE will publish these guidelines in June 2021 but recognise that guidelines alone are not sufficient to counter the difficulties clinicians experience in enacting SDM. Acknowledging that “much centres on consultation skills” and that the current approach to training is inadequate, the NICE team see significant benefits to the novel approach taken in the e-learning package: *“we were delighted to be made aware of the York research and resources. They have the capacity to re-energise the rather ‘stuck’ consultation skills teaching and learning silo, and link that with shared decision making, which is under-done in practice. We were also delighted to see ‘Three things to remember’ as opposed to 78 items in the Calgary Cambridge consultation model. The tone of the materials is just excellent, especially the approach of adaptation by learners of their natural style rather than an external imposition of some standardised approach”* [10]. Agreement has been reached to include *“highlighted edits from the existing [e-learning] content in the Keele/NICE SDM resources”* as well as a link enabling learners to access the full package [10]. The use of these materials by NICE will ensure that clinicians across the UK are supported to enact patient choice in the most effective way. As with the Dutch GP guidelines, this will not only benefit clinicians by enhancing their professional conduct but will help to realise the NHS’s goal for patients to be active partners in decision-making, summarised in the well-publicised phrase: *“no decision about me, without me”* (Department of Health, 2012).

Toerien and Jackson’s pioneering research-based training in specific, practical communication skills has had a demonstrable, positive impact on medical students’ and practitioners’ ability and willingness to give patients choice. The longevity and reach of the impact has been secured through the e-learning package and by the uptake of the research findings by high-profile medical professionals and governing bodies including those with direct responsibility for medical training and guideline development. This ensures that the research will continue to help practitioners – internationally and across medical specialties – transform shared decision-making from an ideal to a reality in their daily interactions with patients.

##### 5. Sources to corroborate the impact (indicative maximum of 10 references)

- [1] (a) **Testimonial** from Professor of Applied Linguistics and Medical Education, Universidade do Vale do Rio dos Sinos (Unisinos) medical school, Brazil, 14 June 2020; (b) **Testimonial** from medical student at Unisinos medical school, Brazil, 26 January 2021; (c) **Testimonial** from medical student at Unisinos medical school, Brazil, 26 January 2021; (d) **Testimonial** from medical student at Unisinos medical school, Brazil, 23 March 2020; (e) Collated feedback from workshops held at Queen’s University, Belfast (December 2019) and Unisinos medical school, Brazil (November 2019)
- [2] Email from Professor of Applied Linguistics and Medical Education, with link to [Unisinos news page report on the workshop](#) (in Portuguese)
- [3] ‘Patient Choice in Practice: Brazil online workshop evaluation report’, Analysis and Report (University of York), January 2021
- [4] **Testimonial** from medical educator at Unisinos medical school, Brazil, 18 June 2020
- [5] **Testimonial** from Ophthalmologist and medical educator, Centre for Medical Education, Queen’s University of Belfast, 26 January 2021
- [6] **Testimonial** from GP and medical educator at Manchester Medical School, 3 June 2020
- [7] **Testimonial** from medical educator at University of Oslo, Norway, 26 January 2021
- [8] **Testimonial** from Head of Emergency Department of medical educator at Nordland Hospital, Norway, 8 July 2020
- [9] (a) **Testimonial** from Programme Manager for Person-Centred Care in the Dutch College of General Practitioners (Nederlands Huisartsen Genootschap; NHG), 18 September 2020; (b) Toerien’s report to Dutch College of General Practitioners (2019)
- [10] **Testimonial** from Professor of Evidence-informed Decision-making, Keele University (an influential member of the team devising resources to support NICE SDM guideline), 24 January 2021