

# Kent Academic Repository

## Full text document (pdf)

### Citation for published version

Gabe, Jonathan and Harley, Kirsten and Calnan, Michael .W. (2015) Healthcare choice: Discourses, perceptions, experiences and practices. *Current Sociology*, 63 (5). pp. 621-635. ISSN 0011-3921.

### DOI

<https://doi.org/10.1177/0011392115590061>

### Link to record in KAR

<http://kar.kent.ac.uk/54213/>

### Document Version

Author's Accepted Manuscript

#### Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

#### Versions of research

The version in the Kent Academic Repository may differ from the final published version.

Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

#### Enquiries

For any further enquiries regarding the licence status of this document, please contact:

[researchsupport@kent.ac.uk](mailto:researchsupport@kent.ac.uk)

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>

## **Health Care Choice: Discourses, Perceptions, Experiences and Practices**

**Edited by Jonathan Gabe, Kirsten Harley and Michael Calnan**

**published in *Current Sociology Monograph* (2015) 63(5), 621-635.**

### **Background: policy context**

The notion of choice is at the heart of neoliberalism, which has driven much health system reform over recent decades (Clarke et al., 2006). For example, recent government health service policy in Western European countries such as Sweden and England (Peckham and Sanderson, 2012; Fotaki, 2007) has emphasised the need to introduce principles of marketisation such as increased competition and choice into health systems which are predominantly publicly funded and traditionally associated with egalitarian or communitarian values. Other countries such as New Zealand have also seen the recent introduction of individual patient choice where there has been little history of such a policy and where decisions have traditionally been made by primary care clinicians acting as gatekeepers and/or care coordinators on behalf of the patient (Fotaki, 2013).

Not all of these choice policies, however, have been explicitly tied to marketisation. They may have been portrayed, at least in the first instance, as aiming to make health services more responsive to patient needs and preferences, alongside policies designed to increase patient access and partnership. This illustrates that responsiveness can be achieved through different means and not necessarily solely through individual choice and market mechanisms (Greener, 2009). An analysis of policy in the British National Health Service (NHS) from 1944 to 2000 (Greener, 2009) showed that the focus on choice in health service policy was not new and that its introduction has been a slow and gradual process, though the models that it was associated with have changed. For example, in the very early years of the NHS choice was referred to in the context of patient choice of general practitioner (GP), or family doctor, but was based on an associational relationship that was long-term and

continuous, favouring loyalty between GPs and patients. Later, in the 1980s, choice had a stronger visibility in policy both in terms of encouraging the option of exiting to the private sector and with GPs playing a key role in enhancing patient choice, suggesting a co-production or collaborative model. The latter model, according to Greener (2009), was superseded in the late 1990s by a consumerist model with an emphasis on informed choice and greater information, although there was a broadening of the term to include not only choice of treatment but also of lifestyle. This analysis also identified two different models of consumerism which were evident in the literature. The first was the one traditionally associated with neo-liberalism with consumers portrayed as active, rational actors and rational choosers while the second one was where consumers were more passive victims open to exploitation and manipulation, which seems to parallel consumerist interest in protecting vulnerable patients and promoting their rights as a group (Greener, 2009).

Choice policies might be seen, therefore, as part of a more general set of policies aimed at patient-centred care (Milewa, 2009). For example, in England this was the approach taken by the New Labour government in the early part of this century but it became part of a more explicit marketisation policy later in its administration (Clarke et al., 2006) and has certainly been accelerated under the Conservative and Liberal Democrat coalition government (Gabe, 2013; Ham et al., 2015). Under neoliberalism, choice is promoted in two ways: first as valuable in itself as a way of meeting patient wishes, at least for some groups of patients, to enhance their control and autonomy (Fotaki, 2013); and second as a means to enhance quality and efficiency through the creation of competition between providers and funders. For some writers, such as Le Grand (2007), linking choice to competition mechanisms provides the necessary incentives for enhancing and maintaining improvement in the performance of health services. It is based on neo-classical economics as it takes for granted that individuals are rational actors who can and do exercise choice on the basis of informed knowledge and calculations designed to maximise self-interest and minimise loss. The ideal patient is depicted as responsible and informed and as someone who both wants and exercises choice. As "discriminating customers" who are responsible for their own health, failure to act responsibly then becomes their responsibility alone (Newman and Clarke, 2009; Smart, 2010). Such developments are also associated

with Post-Fordism brought about by socio-economic change where consumers rather than producers call the tune and the consumer is sovereign (Gabe, 2013). From this standpoint health and health services are viewed as commodities to be purchased by consumers in the market like any other good.

### **Choice and the problem of commodifying health care**

The appropriateness and relevance of this political discourse about choice for health and welfare may be generally contested. However, it appears particularly problematic in the context of healthcare because the nature of health care choice is entwined with questions about whether such care can be commodified given the uncertainties and unpredictabilities associated with it, the availability of competing evidence on which to make judgements and the role of trust in experts and people's different capacities to choose. Titmuss (2004) suggested that there are various limits to the idea of consumerism (voice, choice and exit by patients) in relation to health care. For example, most patients enter the doctor-patient relationship on an unequal basis in terms of status, knowledge and access to resources (such as medications and referral to other experts) and many patients do not know in advance exactly what medical procedures and drugs they will need - they rely on doctors for advice. Similarly, unless a patient and/or their advocate keeps going to the doctor with the same problem, such as with some chronic illnesses (potentially becoming a 'lay expert'), he or she will often find it difficult to reach a judgement on the effectiveness of different types of treatment. This argument is taken forward in the discourse analysis of Nordgren (2010). He suggests that health policy discourses have employed an overly simplistic language about choice which neglects the important issues of patient vulnerability, their lack of knowledge, the asymmetrical relationship with their physician, dependency and the need for care and the patient's varying capacity to make choices. These tensions also appeared evident in McDonald and colleagues' (2007) analysis of primary health care encounters in the context of UK policies, where it was found that the identity of the health consumer, with its emphasis on choice, can prove problematic for individuals:

'We view individuals as negotiating identities in the context of conflicting ethical codes [which] deny legitimacy to certain behaviours and promote others. In relation to the health consumer identity ... the good citizen is one who demonstrates competency to make the right choices' (McDonald et al., 2007: 448).

Similarly, Nordgren (2010) argues that discourses of choice are at odds with other health policy discourses such as prioritisation and rationing which will have the consequence of weakening the position of the patient rather than empowering them.

This limited knowledge on the part of the patient also makes it difficult to simultaneously compare different forms of medical care in the same way as consumer goods. For example in the UK, where just over a tenth of the population are covered by private health insurance (the majority of which are in schemes financed by employers rather than the individual), those who wish to use this provision tend to ask their general practitioners about how best to use the associated services (Calnan, Cant and Gabe, 1993). This suggests a more collaborative and co-produced approach to choice (as opposed to a consumerist model) which, as was suggested earlier, was prevalent in UK health service policy in the earlier years of the NHS (Greener, 2009). Marketing by private health insurers in both Australia and the UK appear to recognise this, with their websites offering seemingly contradictory discourses of choice and individual responsibility and of partnership (Harley et al., 2011).

There is also evidence in England that the recent emphasis in health service policy on choice has had more influence on the behaviour of providers than patients (Peckham et al., 2012). Certainly, evidence from a literature review and analysis of the intended and unintended impact of choice-related policies in health care in the UK, European Union and USA by Fotaki et al. (2008) showed that choosing between hospitals or primary care providers is not currently a high priority for the public, except where local services are poor (for example where there are long waiting times) and where individual patients' circumstances do not limit their ability to travel (Exworthy and Peckham, 2006). When patients become ill, they are increasingly likely to want to

rely on a trusted health practitioner to choose their treatment, which once again illustrates the co-production model of choice (Nordgren, 2010). Fotaki et al. (2008) found that the better educated patients tended to make greater use of information and were more likely to exercise choice in health care in relation to treatments than providers (see also Fotaki, 2013). These authors suggest that there was little evidence in the literature that providing greater choice will in itself improve efficiency or quality of care. They concluded that although patients may themselves make limited use of choice, they do, however, want to be more involved in individual decisions about their own treatment than is currently the case (Fotaki et al., 2008).

Following on from this, Fotaki (2013) suggests that the impact of choice policies is unpredictable and very limited in terms of efficiency and quality. At the same time these policies have a significantly negative impact on equity, highlighting the influence of pre-existing inequalities of income and education on patients' ability to choose. This is salient as in the early part of this century it was argued that English health service policies aimed at enhancing choice were compatible with those aimed at reducing social inequalities in health (Mays et al., 2011). Fotaki (2010) examines such policies, for example those designed to promote equity of access in the English NHS by giving patients the power of exit over unresponsive providers. She concludes that there is a potential conflict between choice and equity in terms of both the values and the outcomes which each policy is likely to produce.

### **This special issue**

The evidence presented above about how so-called consumers perceive and use choice in relation to their take-up of health services is in short supply and limited to specific health care systems, primarily in the global north. The aim of this special edition is to fill this gap by exploring how choice is perceived and utilised in the context of different, more pluralistic systems of healthcare throughout the world, where choice, at least in policy and organisational terms, has been embedded in health systems for some time. The focus here is on health care, as opposed to public health where there has been a great emphasis on individual responsibility, informed choice and so-called healthy lifestyles. However, as several authors have pointed out (e.g. Greener, 2008), it might be best to understand patient choice policy within this more

general trend in health policy which emphasises greater personal responsibility for making healthy choices. This in turn could be linked with a rationing strategy as a means of controlling demand for health care.

Choice, at least as presented in policy discourse (Peckham and Sanderson, 2012), might manifest itself in a number of different ways through the use of: public, private or third sector facilities; practitioners (which type and which one - biomedicine, generalist or specialist, allied health, complementary therapists); multiple treatment options (including natural versus surgical birth, over-the-counter, prescribed and unlicensed medications, complementary and alternative therapies); and timing, setting and location of treatments and care (e.g. inpatient or outpatient, the operation of different commercial surrogacy practices, organ donation for transplants, end-of-life care). Some of these different fields of choice will be explored in the papers included in the special edition. The emphasis here, however, is on not assuming that these choices are perceived to be available to potential users of service. Such users may not be aware of these choices and even if they are may not have the resources in terms of finance, time, networks and capital to utilise them. So there are questions which relate to perception of choice and the enactment of choice which need to be explored. Moreover, decision-making about this enactment may be shaped by different influences compared with the perception of choice. There is also the related issue of the salience of choice and whether patients/users want choice or put a priority on it and whether they find it a burden rather than an asset. Some critics have talked about the "tyranny of choice" which damages both individual well-being and social relations (Bauman, 2011; Salecl 2011; Schwartz 2005). Certainly, it should not be taken for granted that users readily accept or are duped into accepting policy and associated neoliberal discourses about choice. Finally there is the question of decision-making in relation to the assessment and use of health care and how choice manifests itself. For example, it might be that the decision-making is routinised rather than calculative, based on assessments grounded in past experiences and stocks of knowledge. This special issue aims to throw light on such questions.

### **Sociological themes in the context of choice**

Sociological studies and theorising of health care choice in practice, including those contained in this special issue, commonly use concepts that reveal complexities not always apprehended in policy discourse. The concepts which were evident in the different articles might be divided into those that emphasise the body and the meaning of choice; the social processes associated with choice; the uncertainties, risks and trust involved in making choices and the issues of access and inequality associated with enacting choices. While we have used these concepts to group the articles below, it is worth noting that many of the articles have more than one of these concepts running through them, again testifying to the complexities of choice in health care.

### Embodiment

First, health care decisions are made by embodied selves, both in the sense that matters of health and illness are matters of the body, and in the sense that choices are made with reference to our bodies. Thus Clark's (2001) interviews with Scottish patients following admission to hospital after myocardial infarction (heart attack) found that their changing experiences of their bodies during the attack and subsequent decision-making shaped their pathway to seeking medical treatment. In Crompton's (2003) case study account of a failed bilateral breast reconstruction following mastectomy, she shows how health care choice can be entangled with the lived body and with notions of an appropriately feminine, sexual and 'normal' body.

The entanglement between the lived body and choice is also illustrated in Malacrida's paper (this volume) on women's prenatal knowledge and choice in two Canadian contexts. She shows how childbirth choices occur within contested discourses about medical, natural and woman-centered births. All three perspectives, to slightly differing degrees, presume that informed choice will facilitate women's birthing decisions. She employs a critical feminist analysis to examine how women learn about childbirth and choice long before the moment of informed choice so often noted as crucial in medical, feminist and natural childbirth discourse. Interviews with 40



pregnant and recently birthing women in two cities in Alberta, Canada illustrate how media, family and friends, and prenatal courses comprised core pre-birth knowledge systems informing women's choices about how to manage their bodies during childbirth. The interviews exposed how medicalization is naturalized in these knowledge systems, so that women approached their actual births with an already-medicalized set of perceptions. This already-medicalized knowledge foreclosed women's choices, a finding that complicates arguments over improving informed choice during childbirth as a means of reducing childbirth medicalization.

Embodiment and choice also feature in Kirby et al.'s paper on suffering, recognition and reframing in the plural care pathways of women with chronic back pain. Chronic back pain is a major health and social problem in Australia, often concealed and given limited credibility vis-à-vis other health conditions. Care practices are diversified with allied health, biomedical and complementary and alternative medicine (CAM) practitioners regularly being consulted for help and care, often concurrently. While this differentiated 'healthcare market' may on one level be viewed as positive in terms of diverse therapeutic choices, there is also potential for difficulties in regards to care practices and negotiating competing therapeutic modalities. Drawing on qualitative interviews with fifty women aged 60-65 from the Australian Longitudinal Study on Women's Health living with chronic back pain, they explore these women's accounts of suffering and the experiences of engaging in pluralistic healthcare choices, with a particular focus on CAM. Our findings reveal the ways by which healthcare pluralism is connected to the dynamics of suffering and relations of recognition.

The third paper to consider embodiment and choice is Freidin and Ballesteros' paper on choosing Ayurveda as an embodied health care practice in Argentina. They analyze the process of adoption of Ayurveda as a healthcare practice in Buenos Aires, focusing on sociocultural dimensions and material aspects which either facilitate or discourage the following of this foreign medical tradition. Ayurveda is an ancient Indian medicine whose popularity has been on the rise among the Argentinean middle and upper classes.

Introduced as a "lifestyle" medicine, it resonates with the new health consciousness of individual responsibility in health maintenance and bodily improvement. Based on in-depth interviews conducted with 20 followers of Ayurveda in Buenos Aires, they show that it attracts New Agers, adherents to food-driven subcultures, and patients dissatisfied with the limitations of biomedicine. Followers develop new skills for self-understanding, self-healing, and bodily wellbeing. As adherents to a foreign medical approach, however, these followers adopt Ayurvedic practices in flexible ways, and some even hold critical views on the elitist market niches of Ayurvedic specialists and products.

### Social processes

Rapley's (2008) focus on distributed decision-making across a range of doctor-patient encounters draws attention to the ways in which health care choices are not made solely by autonomous rational individuals but constitute pluralistic, relational, negotiated social processes. Patients not only frequently interact with more than one health care practitioner (e.g. GP, specialists, hospital physicians, radiologists) but also partner with and draw on knowledge from non-medical people from their social networks in making decisions about health care.

Similarly Mol (2008) draws on theory outside of economics and the potentially flawed notion of the rational actor to analyse the case of the lived experiences of a diabetic and the care received in the Netherlands. This research adopts a critical approach to the notion of choice and the portrayal of patients as consumers, customers and citizens and shows how the idea of the patient choosing for themselves can lead to poor quality of care and the logic of patient choice may be at odds with good quality care. Mol does not contest the idea of an active patient but argues that care is best seen as a practice that involves shared work between patients, professionals and the technologies involved in the care process. She states that "care activities move

between doctors and nurses, machines, drugs, needles and so on (and that) patients have to do a lot as well" (Mol, 2008: 32).

In this special issue, the paper by Collyer et al. explores the potential of Bourdieu's three interlinked concepts of capital, habitus and field to challenge rational choice theory and provide theoretical insights into this social dimension of healthcare choice. They emphasise how the intersection of different forms and amounts of capital, embodied in the habitus, unequally position individuals to have more or less choice, and to make different choices, in navigating the multiple potential pathways of the healthcare "maze", a point also touched on in the paper by Brown and Meyer, discussed below. Importantly, and evidenced in the Australian context with its complex mix of publicly and privately funded and provided care, they argue that sociological analyses of healthcare choice must take greater account of the 'field' in which choices are made in order to better explain the structuring of choice.

Lee and Sheon's (2008) analysis of recordings of HIV test counselling sessions in Northern California demonstrates how this social process of healthcare choice can also involve negotiation of identities with social others. Clients used different techniques to present themselves as responsible and in control of their HIV status, deflecting counsellors' attempts to focus on risk-taking behaviours. Biddle et al. (2007) also explore this negotiated, and importantly temporal, aspect of healthcare choice, evident in their analysis of non-help seeking (arguably itself a choice) amongst young adults experiencing mental distress. They develop a circular 'cycle of avoidance model' to capture the dynamic and changing nature of this form of health care choice.

The paper in this volume by Borgstrom picks up on these themes, while also highlighting the mismatch between neoliberal notions of individual choice emphasised in end-of-life care policies and practical experience. Advance care planning, promoted as the instrument whereby individuals can make choices about their end-of-life care, necessitates a temporal shift forward to predict what kind of

death one's future self will want when the time comes. Interestingly in this case, enactment of choice that represents individual autonomy explicitly requires sociality: communication with both health professionals and loved ones. Data presented in the article illustrate some of the challenges entailed, and hence Borgstrom concludes that ' "although death is certain, the possibility of control alluded to by choice rhetoric is not realised in practice" .

### Risk, Trust and Uncertainty

The risks and uncertainty associated with health and health care - across diverse contexts including pregnancy and childbirth (e.g. Eckermann, 2006), different treatments (e.g. Clark, 2001; Tovey and Broom, 2008), whether or not to undertake testing or screening (e.g. Willis, 2004), and end of life care (Borgstrom, discussed above) - are not typically amenable to straightforward calculations. Thus, for instance, Tovey and Broom (2008: 389) found that cancer patients 'considered scientific evidence to be unnecessary for their own decision-making [about use of CAM therapies], but necessary to justify NHS funding'. Karen Willis's (2004) interviews with Australian women aged 40-49 about their choice to make use of the local mobile breast screening service (before age 50, when public health guidelines recommend mammography as a routine) showed that both those who considered themselves to be at high risk of breast cancer, and those who didn't, understood their decisions as a matter of both personal and social responsibility. Their choices were variously understood as linked to being responsibly well-informed and actively engaged in looking after one's health, taking care for family, and supporting this public service as responsible citizens. Different understandings or 'regimes' of risk were also revealed in Eckermann's study of pregnancy and childbirth in Laos, where:

'The palpable risks of death, sickness and disability associated with pregnancy and childbirth have been largely replaced with the unintended "risks" of both governmentality and unbridled choice which form part of a risk management cosmology' (Eckermann 2006: 375).

Besle and Schultz (this volume) explore similar issues in their paper, “Signing up for an early clinical trial in oncology”. Through observations and interviews with clinical researchers and trial participants at two French clinical trial centres and phone interviews with referring physicians, they identify three stages of signing up and their related uncertainties. The first, access, occurs where conventional treatments have failed and the treating oncologist entrusted with the patient's care hands them over to the unknown, different world of clinical research for the possibility via clinical trials of ongoing treatment, but using therapies whose unknown efficacy introduces inherent uncertainty. In the second, inclusion, there are uncertainties for both patients and researchers about the mutually desirable prospect of matching patient and trial, a process guided more by trial protocols than immediate therapeutic effect. Finally, participation becomes highly routinised (with, for instance, weekly hospitalisation) with uncertainties such as the potential for an 'adverse event' to end involvement. Besle and Schultz argue that notions of choice involving well-defined options are ill suited to such uncertainties, a point that might be seen to apply to health care more broadly.

Related to matters of risk and uncertainty is the related question about how notions of choice link with trust as people access and decide on health care, and whether active control over decision making is compatible or at odds with trusting relationships (Nordgren, 2010). Fotaki (2014) suggests that some groups may trade-off choice against trust, although this might be less prevalent amongst the relatively socio-economically disadvantaged who rely more on trust. This author also suggests that interpersonal and embodied forms of trust are still very salient in the doctor-patient relationship leading to patients, particularly in situations involving emotionally laden decisions, relying more on trust than on informed choice. Research on trust relations in general practice in England suggests that rather than enact exit or voice or even loyalty patients often simply choose to avoid the practitioners that they do not trust (Calnan and Rowe, 2008).

Trust is a theme in Morgan et al.'s paper in the volume on "'Nudging" registration as an organ donor: implications of socio-cultural variations in knowledge and attitudes'. In this paper they examine "nudge" as a policy response to the risky health problem of increasing registration rates for deceased organ donation. Nudge works via designing "choice architecture" so as to render "healthy" or otherwise desirable choices easier (specifically through opt-out or "forced choice" consent systems in the context of organ donation). Data from focus groups conducted with Black and South Asian ethnic minorities in London identified ways in which members' habitus, understood in terms of their past experience, culture and social structural position, shapes both knowledge and affective responses to deceased donation. For some groups, trust in the English health system, counterposed to that of their home countries, disposed individuals favourably towards organ donation (although this did not necessarily translate into practice); others' distrust, influenced by their feeling of social marginalisation, carried across into fears that registering for organ donation may lead to decreased efforts by doctors to keep them alive, and that existing unfairness would be compounded.

The final paper in this section, by Brown and Meyer, examines the interrelationships between choice and trust in secondary health care as an instance of the persistent sociological duality of structure and agency. The paper complements theoretical consideration of how aspects of illness vulnerability, temporality and understandings of health systems constrain choice and trust, with qualitative interview data from two studies, one of Australian cardiac care patients, the other of gyno-oncology patients in England. They argue that trust is 'usefully understood as an emergent enactment of structure from the (near or distant) past which in turn structures, but does not determine, "choice" in the present', preserving a role for agency. Distrust, more commonly described by the English oncology than Australian cardiac patients, was more likely to shape the healthcare experience as one of vulnerability and fear than to result in different choices, an option itself more available to those with greater financial and cultural resources and better health.

## Access/Equality

The final theme in the special edition focuses on access and equality which are major problems for patients from socio-economically disadvantaged backgrounds living in countries with health care systems which are predominantly privately financed and provided.

In the USA, however, characterised historically by (managed) competition among health care providers and, increasingly, consumer/patient "choice", those who can afford to buy themselves out of one or other source of insurance still face many of the constraints associated with unpredictability and uncertainty, such as asymmetrical knowledge and difficulties making informed comparisons between treatments (Calnan, 2010). In addition, the rapidly rising costs of healthcare appear to have led policymakers in the USA to limit individual patient choice in this highly marketised health care system and choice of provider and available forms of treatment are claimed to be restricted by the insurer and determined by how much the patient is able to pay (Fotaki, 2013).

The need to extend health insurance coverage was the driver of recent changes in policy in the United States and their implications for choice is the focus of the paper in this special edition by Doonan and Katz. This paper explores how so-called Obamacare or more specifically the implementation of the Affordable Care Act (ACA) in the United States changed the available options of healthcare coverage and providers. Through a case study methodology, the authors analysed variations and trends regarding choice of provider and/or health plan and implications for consumers. Choice is explored at the national and state level for public and private health insurance options. This includes employer-based insurance, marketplace options, and the public Medicare and Medicaid programs. Findings indicate that too much choice can create confusion and lead to economically inefficient plan selection. Employer structuring of choice retains a wide choice of providers, but passes more cost on to employees. ACA marketplaces come up short of structuring managed competition where choice drives efficiency. While the previously uninsured have far

better options under these reforms, the system wide range, degree, and complexity of choice tend to favour insurers over consumers

Globalisation and its inequitable impact on health care, including biomedical research, is exemplified in the final paper by Kingori which looks at policies developed in the global North in the area of biomedical research and their implementation in the global South. Economically, research conducted in accordance with market forces and neoliberal policies has led to a reduction in costs as institutions in the Global North search for institutions and governments in the Global South choosing to host biomedical research. Ethically, the key paradigm of biomedical research in the last 60 years has been the emphasis on individual choice as an ethical imperative. Ethical research is one where participants have entered into it voluntarily. Kingori explores the views of frontline research staff in different Sub-Saharan African contexts on notion of choice in biomedical research. She argues that the current emphasis on individual choice ignores significant structural and contextual factors in resource-limited settings. The author shows through her ethnographic data that it is not only important to provide potential research participants with a choice of whether or not they participate in research but that evaluating the quality of options in that choice is equally important. This paper introduces the concept of the "empty choice" as means of moving the discussion from making choice available to being concerned with the quality of the options within the decision-making context. The choice provided to prospective research participants in resource-limited sub Saharan Africa is described as being empty because structural factors and power relationships constrain viable options to healthcare to such an extent that choice becomes a perfunctory performance. Structural factors cannot, according to this author, be divorced from choice, they permeate through the options and decisions involved in research participation. Furthermore, possessing knowledge and agency do not mitigate the weight of these structural factors.

## **Conclusions**

Policy discourse heavily influenced by neoliberal ideology and its emphasis on marketisation and competition has highlighted the importance of choice in the context of healthcare and health systems globally. This special issue has attempted to show



how sociological studies and theorising of health care choice in practice can reveal complexities not always captured in policy discourse. The authors of papers published here have clearly shown that the adoption of notions of choice in the context of healthcare is not straightforward and is sometimes problematic both in relation to its meaning and enactment.

Some sociological commentators argue that there is a need to see the world through the lens of globalisation rather than the bounded nation state (Burawoy, 2005). The spread of neoliberal policies has more generally been associated with the process of globalisation which in turn has implications for choice. For example, in the health arena not only is illness increasingly travelling across the world through epidemics such as Asian flu but so are patients or potential patients. The latter group has been described as medical tourists: that is those who travel outside their national jurisdiction for the enhancement or restoration of their health or well-being through medical interventions (Pocock and Phua, 2011; Connell, 2013). Medical tourism has been seen to exemplify the commodification of health care as it is generally assumed that such medical tourists make rational decisions to travel on the basis of available information and self-interest. However, evidence suggests that these behaviours are more often the result of the actions of intermediaries who arrange services or as a result of networks (demand side networks of family and friends or treatment based groups, or professional networks of clinicians) (Lunt et al., 2014). According to Lunt et al. these networks moderate or mediate consumer choice which is understandable given the inherent difficulties involved in establishing quality and the salience of trust in decision-making. Hence, globalisation and its implications for increased choice for those funding and providing healthcare as well as those who need and use it might be the focus of further analysis of healthcare choices.

## References

- Bauman Z (2011) *Collateral Damage: Social Inequalities in a Global Age*. Cambridge: Policy Press.
- Biddle L, Donovan J, Sharp D et al. (2007) Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behavior, *Sociology of Health and Illness* 29(7): 983-1002.
- Buroway M (2005) For Public Sociology. *American Sociological Review* 70(4): 4-28.
- Calnan M (2010) Consumerism and the provision of health care. *British Journal of Health Care Management* 16(1): 609-610.
- Calnan MR, Cant S and Gabe J (1993) *Going Private: Why People Pay for their Health Care*. Buckingham: Open University Press.
- Calnan M and Rowe R (2008) *Trust Matters in Health Care*. Maidenhead: Open University Press.
- Clark AM (2001) Treatment decision-making during the early stages of heart attack: A case for the role of the body and self in influencing delays. *Sociology of Health and Illness* 23(4): 425-446.
- Clarke J, Smith N and Vidler E (2006) The indeterminacy of choice: political, policy and organisational implications. *Social Policy and Society* 5(3): 327-336.
- Connell J (2013) Contemporary medical tourism: conceptualisation, culture and commodification. *Tourism Management* 34(1): 1-13.
- Cromptoets,S (2003) Reconstructing the self: breast cancer and the post-surgical body. *Health Sociology Review* 12(2): 137-145.
- Eckermann L (2006) Finding a 'safe' place on the risk continuum: A case study of pregnancy and birthing in Lao PDR. *Health Sociology Review* 15(4): 374-386.
- Exworthy M. and Peckham S (2006) Access, choice and travel. *Social Policy and Administration* 40(3): 267-287.
- Fotaki M (2007) Patient choice in healthcare in the UK and Sweden: From quasi-market and back to market? A comparative analysis of failure in unlearning. *Public Administration* 85(4): 1059–1075.
- Fotaki M (2010) Patient choice and equity in the British National Health Service: towards developing an alternative framework. *Sociology of Health and Illness* 32(6): 898-913.
- Fotaki M (2013) Is patient choice the future of health care systems? *International Journal of Health Policy and Management* 1(2): 121-123.
- Fotaki M (2014) Can consumer choice replace trust in the National Health Service in England? Towards developing an affective psychosocial conception of trust in health care. *Sociology of Health and Illness* 36(8):1276-1294.

- Fotaki M, Roland M, Boyd, A et al (2008) What benefits will choice bring to patients? Literature review and assessment of implications. *Journal of Health Policy and Services Research* 13(3): 178-184.
- Gabe J (2013) Consumerism. In Gabe J and Monaghan L (eds) *Key Concepts in Medical Sociology*. London: Sage, pp. 203-206.
- Greener I (2009) Towards a history of choice in UK health policy. *Sociology of Health and Illness* 31(3): 309-324.
- Ham C, Baird B, Gregory S et al. (2015) *The NHS under the Coalition Government*. London: Kings Fund.
- Harley K, Willis K, Gabe J et al. (2011) Constructing health consumers: private health insurance discourses in Australia and the United Kingdom. *Health Sociology Review* 20(3): 306-320.
- Lee S-H and Sheon N (2008) Responsibility and risk: Accounts of reasons for seeking an HIV Test. *Sociology of Health and Illness* 30(2): 167-181.
- Legrand J (2007) *The Other Invisible Hand: Delivering Public Services through Choice and Competition*. Princeton NJ: Princeton University Press.
- Lunt N, Horsfall D, Smith R, et al. (2014) Market size, market share and market strategy: Three myths of medical tourism. *Policy and Politics* 42(4): 597-614.
- Mays N, Dixon A and Jones L (2011) *Understanding New Labour's Market Reforms of the English NHS*. London: Kings Fund.
- McDonald R, Mead N, Cheraghi-Sohi S et al. (2007) Governing the ethical consumer: Identity, choice and the primary care medical encounter. *Sociology of Health and Illness* 29(3): 430-456.
- Milewa T (2009) Health care, consumerism and the politics of identity. In Gabe J and Calnan M (eds) *The New Sociology of the Health Service*. London: Routledge, pp.161-176.
- Mol A (2008) *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge.
- Newman J and Clarke J (2009) *Public, Politics and Power*. London: Sage.
- Nordgren L (2010) Mostly empty words-what the discourse of 'choice' in health care does. *Journal of Health Organization and Management* 24(2): 109-126.
- Peckham S and Sanderson M (2012) Patient choice: a contemporary policy story. In Exworthy M et al. (eds) *Shaping Health Policy*. Bristol: Policy Press, pp. 219-232.

Peckham S, Mays N! Hughes D et al (2012) Devolution and patient choice: policy rhetoric versus experience in practice. *Social Policy and Administration* 46(2): 199-218.

Pocock N and Phua KH (2011) Medical tourism and policy implications for health systems: a conceptual framework from a comparative study of Thailand, Singapore and Malaysia. *Globalization and Health* 7, 12.

Rapley T (2008) Distributed decision making: The autonomy of decisions-in-action. *Sociology of Health and Illness* 30(3): 429-444.

Salecl R (2011) *The Tyranny of Choice*. London: Profile Books.

Schwartz B (2005) *The Paradox of Choice: Why More is Less*. New York: Harper Collins.

Smart B (2010) *Consumer Society. Critical Issues, Environmental Consequences*. London: Sage.

Titmuss R (2004) Choice and the welfare state. In Oakley A and Barker J (eds) *Private Complaints and Public Health, Richard Titmuss on the NHS*. Bristol: Policy Press, pp. 167-174.

Tovey P and Broom A (2008) The problematic nature of conflating use and advocacy in CAM integration: Complexity and differentiation in UK cancer patients' views. *Health Sociology Review* 17(4): 384-395.

Willis K (2004) Personal choice/social responsibility: Women aged 40-49 years and mammography screening. *Journal of Sociology* 40(2): 121-13