

The rationality of rationing: a rhetorical policy analysis of deliberations about resource allocation in the NHS

Jill Russell

A thesis submitted for the degree of Doctor of Philosophy in
Evidence-Based Health Care

Green Templeton College, University of Oxford

Trinity 2017

Abstract

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The rationing of health care is one of the most politically sensitive and challenging issues facing policymakers today. Despite long-standing debate about how we should or might make rationing decisions, we still know surprisingly little about how such decisions are accomplished in practice.

This thesis opens up the 'black box' of rationing practices. It explores theoretically and empirically what it means for rationing decisions to be made rationally. My work challenges dominant conceptualisations of rationality in health policy, suggesting that rationing is inevitably and inextricably as much a social practice of deliberation and judgement, involving experiential knowledge, emotional engagement, and what Aristotle called 'phronesis', as a technical process of applying research evidence and ethical principles, and following fair processes.

I locate my research in the emerging fields of interpretive policy analysis and linguistic ethnography, and draw on sensitising concepts from rhetorical theory and Bakhtinian scholars to develop a novel approach to rhetorical policy analysis. My study is based on ethnographic observation of the deliberations of one priorities forum and three individual funding request panels of local NHS commissioning organisations. I explore close up the role of language and meaning making in these rationing groups, and demonstrate the ways in which they create their own 'interpretive communities' within which rationality is locally constructed.

My findings focus on four aspects of practice I identify as dilemmatic: the legitimacy of affordability as a guiding value of NHS health care, the emotionality of decision-making, the construction of some treatments as 'low priority', and the role of lay people and ordinary knowledge in deliberations. My analysis exposes the ideological work of rationing discourse in defining the boundaries of what the NHS will fund, and shifting notions of entitlement to health care.

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Acknowledgements

I would like to thank my primary supervisor, Trish Greenhalgh. Her persistent and enthusiastic reminders that my research interests could and should become the focus of a doctorate gave me the encouragement I needed to embark on an endeavour I had been putting off for over 30 years. Trish and Sara Shaw (my second supervisor) have been outstanding supervisors, guiding me with just the right balance between a 'hands on' and 'hands off' approach, always responding to drafts with impressive speed, challenging my thinking with their insightful comments and sage advice, and helping me maintain a steady momentum of writing, whilst never showing (to me at least) any supervisory anxiety over the relaxed pace I have adopted at times.

The participants in this study were generous with their time and embraced with goodwill my requests for access to observe their work practices and talk with me. I hope I have sensitively reported the stories of patients, whose cases illuminate the human impact of the rationing of health care. I would also like to thank the many practitioners and policymakers beyond my case-study sites who invited me to participate in training days, workshops, and other networking events, facilitated the 'action' aspect of my research, and encouraged me to feel part of their community of practice.

I am grateful to a number of other colleagues who helped me develop the ideas in this thesis, including advisory group members, co-authors of published papers, and those who acted as assessors for my upgrade examinations at Queen Mary University of London and my transfer and confirmation of status at the University of Oxford. In particular, I would like to thank Andrew Burnett, Emma Byrne, Ros Levenson, Janet McDonnell, Jonathan Montgomery, Clive Seale and Deborah Swinglehurst.

Finally, heartfelt thanks to my husband Charles Sweeney and daughter Josephine Sweeney. It has been a great pleasure to discuss my work with Josephine, a fine artist, and to explore theoretical ideas through our different disciplinary lenses. Charles has not read a single word of this thesis, and he probably never will. Nevertheless I could not have completed it without his unstinting support in so many other ways, and his unfailing good humour.

Glossary

AMD	Age related macular degeneration
BMI	Body Mass Index
BMJ	British Medical Journal
CCG	Clinical Commissioning Group
CSU	Commissioning Support Unit
ESCR	Economic and Social Research Council
GP	General Practitioner
IPC	Individual patient commissioning
IVF	In-vitro fertilisation
MRI	Magnetic resonance imaging
MP	Member of Parliament
MCDA	Multi-criteria decision analysis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence (prior to 2013 the National Institute for Health and Clinical Excellence)
NIHR	National Institute for Health Research
NPC	National Prescribing Centre
PbR	Payment by Results
PEG	Percutaneous endoscopic gastrostomy
PIP	Poly Implant Prothese
PCT	Primary Care Trust
PoLCE	Procedures of Limited Clinical Effectiveness
PBMA	Programme budgeting and marginal analysis
QALY	Quality Adjusted Life Years
QMUL	Queen Mary University of London
RfPB	Research for Patient Benefit programme
SS	Sara Shaw
TG	Trish Greenhalgh
UCL	University College London

1 Introduction

“We understand that Mrs M has wet age-related macular degeneration with a visual acuity of 6/12 in her right eye and 6/60 in her left eye. You propose to treat her right eye.

You have told us that Mrs M lives with her older husband and that they both live independently and care for each other. Apparently he has osteoarthritis and is due to have a hip replacement. You have said that were she to lose her sight then they would lose their independence. We do not consider that Mrs M’s circumstances could be considered to be ‘far beyond what is usual’ and would expect Mr M’s hip replacement to enable him to become more mobile than he is now. Whilst we recognise that were Mrs M to lose her sight this would be very significant to her and would make her dependent on her husband, we do not consider that this makes her exceptional when compared with others with age-related macular degeneration.

In the absence of evidence of exceptional circumstances in Mrs M’s case we consider that it would be inappropriate for us to fund the proposed treatment.” [Extract from decision letter from local funding panel to referring clinician]

The rationing of health care is arguably one of the most politically sensitive and challenging issues facing policymakers today. In a decade in which the NHS is experiencing unprecedented spending constraints, rationing has become an ever more pressing concern (Iacobucci, 2017a; Maybin & Klein, 2012; Edwards et al, 2015). An overriding requirement of those responsible for the rationing of health care resources is that their decision-making is considered ‘rational’ (National Prescribing Centre, 2009a); indeed, the word ‘rationing’ is a cognate of ‘rationality’ (Klein et al, 1996). A much-quoted phrase from the English NHS Constitution is that patients have the right to decisions about access to medicines and treatments to be made ‘rationally’, and the right to challenge those decisions in the courts if they consider them ‘irrational’ (Department of Health, 2015).

This thesis explores the rationality of rationing. Its starting point is that looked at from both a theoretical and practical perspective, rationality means different things to different people (Townley, 2008). My research examines these different meanings empirically, through an exploration of the deliberations of local NHS rationing groups in England. The excerpt at the beginning of this chapter, discussed further in Chapter 6, is illustrative of the data I collected concerning the dilemmas faced by those involved in the rationing of health care, and conveys that the rationality of rationing, far from being a given, has to be argued for.

My research question is: How is rationality constructed and accomplished in local NHS rationing practices? The aim is to offer a rich account of how rational judgements are produced in particular, situated contexts. I am not so interested in the question of how rationing might become more 'rational' in the normative evidence-based sense (a question that has tended to dominate policy research in this field; see for example, Hunter (1997), Ham and Robert (2003), and Robinson (2011b)), but rather in gaining an understanding of rationing practice 'as is'.

A review of health policy debate suggests that the predominant discourses of rationality in rationing decisions are so strongly indexed to the paradigm of evidence-based medicine, with a concomitant concern for institutional processes, that a more embedded and embodied perspective on rationality is largely occluded (Greenhalgh & Russell, 2009; Ham & Robert, 2003; Klein & Williams, 2000; Klein, 2005). The result, I suggest, is a distorted view of

practice. My aim is to illuminate a broader, and I shall argue, more appropriate, conception of the rationality of rationing; one that can support and strengthen practitioners' capacity to act when faced with difficult rationing decisions.

The so called 'postcode lottery' of health care, and restrictions on access to some NHS treatments, have received considerable attention in academic literature and the media in recent times (Ashcroft, 2006; Charles, 2017; Iacobucci, 2017a; Maybin & Klein, 2012). And beyond current concerns, lie long-standing and seemingly unresolvable debates about reasonable approaches to the allocation of health care resources, and the 'tragic choices' facing decision-makers (Bobbitt & Calabresi, 1978). However, despite this attention, we still know surprisingly little about how rationing decisions are accomplished in *practice*. Researchers have called for more research that opens up the 'black box' of rationing practices; in other words, the day-to-day micro-level practices of deliberation and decision-making (Davies et al, 2006; Light & Hughes, 2001). This is the focus of my thesis. I suggest a framework of ideas and methods that draw on the emerging fields of interpretive policy analysis and linguistic ethnography, sensitised by concepts from rhetorical theory, to explore close up the role of language, deliberation, and meaning making in the enactment of rationing. At the same time, I explore how micro-level practices are shaped by and feed into broader historical, social and institutional practices.

My research is firmly based within an interpretivist research tradition. This means that I am interested in understanding people's interpretations of the world and how social meaning is constructed through language and discourse (Green & Thorogood, 2004). Underlying an interpretivist approach are ontological assumptions about the nature of reality; namely, that the social world is not a pre-existing given, 'out there' to be studied, as with positivist research, but rather is socially constructed through language and the actions and interactions of people. From this perspective, "*words are about the world but they also form the world as they represent it*" (Wetherell et al, 2001: p16). There are also underlying epistemological assumptions about the nature and scope of knowledge; a belief that naturally occurring data such as situated talk allows researchers to explore and come to understand the world "*from the point of view of participants in it, rather than offering an explanation of the world*" (Green & Thorogood, 2004: p13).

My DPhil journey has had a somewhat unusual trajectory. I decided to register as a part-time doctoral student towards the end of my academic career as a researcher, coinciding with my decision to take early retirement. I initially enrolled (in May 2011) at Queen Mary University of London and transferred to the University of Oxford in January 2015 when my supervisors moved there. A key reason for undertaking a doctorate at this stage of my life was to do with having discovered new methodological approaches to qualitative research that I was enthusiastic to explore in more depth. Additionally, leading up to my registration, I had undertaken two funded research projects on different aspects of rationing practices, which I

considered to offer rich data sets for further analysis and exploration. The funded projects had specific research questions concerned with the use of evidence in priority setting and how decisions were taken about requests for treatments not normally funded by the NHS. I was keen to re-frame the data from these studies to address a broader research question about conceptualisations of rationality in rationing practices. From a personal perspective, the decision to undertake a doctorate provided me with a stimulating intellectual challenge as I made the transition from full-time work to retirement. In Chapters 4 and 10 I describe and reflect upon these aspects of my doctoral journey in more detail.

1.1 A brief outline of my thesis

Following this introduction, in Chapter 2 I locate the focus of my research within the context of wider debate about the rationing of health care. I begin by exploring representations of rationing. I outline the ways in which rationing takes place in the NHS, and summarise the longstanding debate about explicit versus implicit approaches to rationing. I map the various levels at which rationing occurs, and introduce the particular focus of my empirical work: priorities forums and individual funding request panels. I also explore the broader policy, regulatory and legal context within which local decision-making takes place, and the role of the media in reporting and shaping debate.

The chapter highlights the competing demands and tensions inherent in rationing work: making decisions that are transparent and accountable

whilst recognising the inevitable role of nuanced judgement in decision-making; addressing the health care needs of individual patients *and* the interests of population groups; and upholding the values of comprehensiveness and universality to which the NHS remains publicly committed (through the NHS Constitution (Department of Health, 2015)), whilst discharging duties to manage local budgets. Throughout the chapter I signpost changes in the landscape of the NHS that have occurred over the period of my research. I argue that, notwithstanding these important changes, the issues explored in subsequent chapters continue to be as, if not more, germane today as when my research began in 2005.

In Chapter 3 I review theoretical approaches to conceptualising rationality. Specifically, I explore three fundamental approaches identified by scholars within the health care rationing debate: instrumental, institutional and practical rationality. I outline how common ‘tools’ of resource allocation – QALYs (Quality Adjusted Life Years), ethical frameworks, and the ‘accountability for reasonableness’ framework – fit with these conceptualisations of rationality.

In the second part of Chapter 3 I review empirical studies of local rationing panels to explore how these different conceptualisations of rationality play out in practice. Studies highlight the enduring appeal and influence of instrumental rationality, but at the same time, the divergence between the theory of rationalist imperatives and what happens in practice. Similarly, studies have highlighted the complexities and uncertainties surrounding the

processes and procedures embodied in an institutional perspective on rationality. I review the small number of studies that have explored the situated, contingent nature of rationality from a practice-oriented perspective, and I position my work as building on these studies.

In Chapter 4 I introduce my study design. I begin by documenting my methodological journey and orientation as an interpretivist researcher, introducing the emerging fields of interpretive policy analysis and linguistic ethnography that have been key to the development of my research thinking. I then provide a reflective account of my methods of data collection and analysis. Throughout the chapter I attempt to balance a sense of the emergent, iterative and sometimes untidy reality of research practice with a clear account of the work undertaken.

Having outlined broad ideas from interpretive policy analysis and linguistic ethnography, in Chapter 5 I sharpen the focus on to specific theoretical, or 'sensitising', concepts that I found especially useful in my analysis. The concepts I explore derive from rhetorical theory and the work of the Bakhtin Circle of scholars. In subsequent chapters I draw eclectically on these concepts to develop my own particular approach to rhetorical policy analysis. Whereas rhetoric is commonly positioned as a distorting and manipulative force, I follow scholars who suggest that rhetoric also has an affirmative role, and through my data I explore the ways in which rhetoric opens up as well as closes down debate, and has the potential to both enrich and compromise democratic deliberation.

In Chapters 6, 7, 8 and 9 I present my findings and develop my analytic arguments. Each chapter addresses one of four focal themes I identified through a recursive process of immersion in data and theory and 'progressive focusing' (the process of simultaneously exploring meaning and redirecting research efforts to refine and substantiate those meanings (Stake, 1995)). In Chapter 6 I explore how rationing panels negotiate the issue of affordability of health care. The NHS was founded on three core principles: universality, comprehensiveness, and provision free at the point of delivery, and these principles continue to be upheld through the NHS Constitution. Yet patients are increasingly hearing that some treatments are unavailable on the NHS. Through an analysis of discursive practices, I demonstrate how the question of the affordability of health care to individuals has gained legitimacy. I explore how rationing panels construct certain truths about eligibility to health care, and the ways in which particular representations of what the NHS can and cannot afford are explicitly and implicitly constructed and negotiated.

In Chapter 7, sensitised by the Aristotelian concept of 'phronesis', I explore the role of emotions in the rationing panels I studied, and the enactment of practical reasoning. My analysis illustrates the ways in which intuition, practical knowledge and emotional engagement form an integral part of and facilitate the processes of decision-making. I argue that these aspects of 'being human' are inextricably linked to the ethicality of decision-making, and I conclude by drawing attention to the value of a narrative ethics in theorising my observations of panel deliberations.

Chapter 8 focuses on an increasingly significant aspect of rationing practice: the categorisation of some treatments as 'low priority' for NHS funding (sometimes referred to as 'procedures of limited clinical effectiveness' (PoLCE)). I take the example of breast surgery to explore how, through the discursive practices and rhetorical work of rationing panels, some individuals' treatments come to be deemed low priority and thus not eligible for NHS funding. I demonstrate how each decision-making group creates its own 'interpretive community' within which, through the subtleties of social interaction, a particular decision comes to be justified. I argue that, in this sense, despite an intuitive appeal, the search for uniformity of decision-making is likely to remain an illusory policy goal.

In Chapter 9 I turn my attention to the issue of public involvement in health care rationing decisions and the concept of lay knowledge. I argue that the Bakhtinian notion of the multi-vocality or 'discursive heteroglossia' of language (Maybin, 2001) opens up new ways of looking at the issue of public involvement in rationing deliberations. I present data suggesting that when deliberation is looked at close-up, the commonly assumed categories of 'lay' and 'professional', 'ordinary' and 'expert', and 'objective' and 'subjective' knowledge, dissipate. A Bakhtinian perspective facilitates an exploration of the continual tension between discourses that restrict and those that open up debate. Rather than the public necessarily having a differentiated role in rationing deliberations, I suggest that the challenge is for *all* panel members, lay and professional, to deliberate in ways that

facilitate the multi-vocality of meaning, and thus encourage a reflexive and democratic mode of policy discourse.

In the final chapter (Chapter 10) I begin, somewhat unconventionally, by exploring another data extract: a recent judicial review case of an individual funding request decision. My analysis of this legal judgement serves to highlight the tensions in rationing work exposed in previous chapters, and to demonstrate the applicability of my findings to new rationing dilemmas. In subsequent sections, I summarise the overall arguments of my thesis, reflect on my methodology of rhetorical policy analysis, identify implications of my research for policy and practice, and end with critical reflections on my personal journey as a doctoral student.

2 Setting the scene: NHS rationing in context

2.1 Introduction

In this chapter I locate the focus of my research - the deliberations of local NHS rationing groups - within the context of wider debate about the rationing of health care. I begin by exploring the contested meanings of the terms 'rationing' and 'priority setting', and introduce the notion of 'linguistic work' (Wetherell et al, 2001) discernible within resource allocation debates. I draw on Maybin and Klein's conceptual model of rationing strategies to outline the different ways in which rationing takes place within the NHS (Maybin & Klein, 2012), and summarise the longstanding debate about explicit versus implicit approaches to rationing. I then map the various levels (national, local and 'bedside') at which rationing occurs, identify key components of the policy context within which rationing decisions take place, and consider the role of the courts and media in shaping debate. The chapter sets the scene for an in-depth review of literature in Chapter 3 on theoretical approaches to conceptualising rationality, and what we know about rationing practices from previous research work.

Over the period of my research (2005 – 2017) there were significant changes to the terrain in which my work is located. In April 2013, as part of a package of reforms to the way the NHS in England is organised, primary care trusts (PCTs) were abolished and replaced with general practitioner-led clinical commissioning groups (CCGs) (Department of Health, 2012). The research I report on in this thesis focused on the rationing groups of primary

care trusts; however, comparable rationing groups have been established by clinical commissioning groups. I suggest that the issues I explore, concerning for example how local rationing groups negotiate the tensions and paradoxes of their role, how judgements come to be made about who is deserving of NHS funding and who is not, and the question of public participation in rationing decisions, continue to be as relevant today as when my research began.

Since 2005 there have also been substantial changes in NHS funding. When I began my research the NHS was experiencing average annual real growth in spending of 6.4% (Crawford & Emmerson, 2012). The economic crisis of 2008 and government imposed reductions in public sector spending resulted in the NHS entering a 'fiscal ice age' of austerity (Klein, 2010), with funding essentially frozen in real terms since 2011 (Crawford & Emmerson, 2012; Roberts et al, 2012). Whilst rationing has been present in the NHS since its inception in 1948 (Maybin & Klein, 2012), the severity of the current funding crisis arguably brings the issues of rationing discussed in this thesis into sharper relief (Iacobucci, 2017b). As Maybin and Klein suggested in 2012 (a comment even more pertinent in 2017): *"[a] changing and financially meaner environment will also give new urgency to issues that have long been debated but not resolved"* (Maybin & Klein, 2012: p2).

2.2 Representations of rationing

The conventional view is that the rationing of health care is an unavoidable 'fact of life' (Edwards et al, 2015; Maybin & Klein, 2012) in the NHS and health systems worldwide (Ham & Robert, 2003). According to this viewpoint, following mainstream economic theory, health care resources are finite and demand potentially infinite, and thus decisions about the allocation of resources inevitable (Syrett, 2007). The specific argument in relation to the NHS is that the imbalance between demand and supply will continue to increase with the ageing of the population, more and more costly innovations in treatment, and rising public expectations, set against tight government funding restrictions and imposed efficiency savings as a result of national economic policy (Edwards et al, 2015; Iacobucci, 2017b).

However, some critical commentators challenge this orthodoxy of rationing as an "*invariant economic fact*" (Light & Hughes, 2001: p552), arguing that [a] national health service expenditure is a matter of political choice not unaffordability, [b] the assumed imbalance between demand and supply is unsupported by evidence, and [c] the pessimistic combination of population ageing, costly innovations and rising public expectations is overstated (Appleby, 2011; Frankel et al, 2000; Higgs & Jones, 2001; Light & Hughes, 2001). This alternative position suggests that the concept of rationing can in part be seen as a rhetorical construction, in other words, a particular way of framing reality, and prompts us to explore the role of language in constructing the rationality of rationing.

A simple illustration of the significance of language in the rationing debate is the different understandings and uses of the terms 'rationing' and 'priority setting'. Although the terms are often conflated and used interchangeably, some commentators highlight important distinctions. Maybin and Klein distinguish between *priority setting* decisions, which focus on the allocation of resources between the competing claims of different services, patient groups and elements of care (which can occur at the national 'macro' and local 'meso' levels), and *rationing* as describing the effect of those decisions on individual patients (at the 'micro' level of health care) (Maybin & Klein, 2012: p5). However, Syrett argues that the distinction between these two terms extends beyond simply the level at which decisions are made, and can be seen more in terms of a 'politics of representation' (see Chapter 5):

"Rather, the choice of one over the other amounts to a political strategy. Put simply, in adopting the language of 'priority-setting', politicians and others who are responsible for making resource allocation decisions seek to avoid the negative connotations attached to the 'rationing' of healthcare resources and the consequent electoral unpopularity which will ensue from being seen to deny treatment to individuals". (Syrett, 2007:p23)

In a similar vein, Loughlin highlights the ideological role played by language, suggesting that the term 'priority setting' encourages us to think about which services to provide and thus what has been achieved, rather than focusing on the 'failure' of what health care will *not* be provided (Loughlin, 2002). Thus there is linguistic work in marking out priority setting as something distinct from rationing.

The language I use in this thesis is also, inevitably, a rhetorical choice (Golden-Biddle & Locke, 1993). I primarily use the term 'rationing', although

I sometimes vary the language by substituting the term ‘resource allocation’, and use the term ‘priority setting’ when referring to the specific work of the priorities forum I studied. In part, I favour the term ‘rationing’ as a convenient umbrella term to cover the work of the different types of resource allocation panels I observed. Additionally, I use the term to emphasise the potential impact of panels’ work – a restriction on the supply of health care and the deprivation of possible benefit (Maybin & Klein, 2012).

2.3 Approaches to rationing

The rationing of health care takes many forms. Maybin and Klein identify five rationing strategies discernible within the NHS: denial, selection, delay, deterrence, and deflection (Maybin & Klein, 2012). Examples of rationing by denial (that is, refusal to fund) are the increasingly common lists produced by local clinical commissioners of treatments that will not normally be funded as part of the NHS ‘package’ of care (for example, varicose vein removal and other cosmetic surgery) (Audit Commission, 2011; Royal College of Surgeons of England, 2014; Gray et al, 2012; Robertson, 2016), and at a national level drugs that the National Institute for Health and Care Excellence (NICE) have deemed not to be cost effective to provide on the NHS (for example certain expensive cancer drugs) (Mayor, 2009).

The eligibility or ‘threshold’ criteria for certain treatments, for example bariatric surgery (Owen-Smith et al, 2013), hip replacement, cataract surgery, and hearing aids exemplify rationing by selection (see Section 2.6 and Chapter 8) (Royal College of Surgeons of England, 2014). Waiting lists

are the classic example of rationing by delay and have long been a widespread form of rationing in the NHS (Klein et al, 1995). There is evidence that waiting times in accident and emergency departments, from GP referral to hospital appointment, including for urgent cancer referrals, and for elective surgery such as cataract surgery, have all increased in recent years (Campbell, 2016; Robertson, 2016).

Under the category of rationing by deterrence, Maybin and Klein include charges that patients must pay for treatment (for example, eye examinations and dental care, which have long been subject to charges (House of Commons Health Committee, 2006)) and other barriers (lack of information, difficulty accessing GP surgeries, hospital car park and bedside telecommunication charges, for example) (Maybin & Klein, 2012; Robertson, 2016). The NHS also rations by deflection, redirecting patients to social care or the private sector, and by dilution, through reduction in the quality of service. Interpreting data about dilution in care quality is complex, however data from the King's Fund indicate that reductions in district nursing and mental health services in recent years have led to dilution in care quality (Robertson, 2016).

This thesis addresses the first two approaches to rationing – rationing by denial and selection – as these are the forms of rationing undertaken by priorities forums and IFR panels, the focus of my empirical work.

2.4 Implicit versus explicit rationing

Another way of categorising rationing is according to whether it is implicit or explicit. Historically, rationing processes have been largely *implicit*, “*camouflaged under clinical judgement*” (Doyal, 1997: p1115), and integrated into routine decision-making through mechanisms such as waiting lists (Coast, 1997). However, the development of the purchaser/provider split in health care in the 1980s, which required purchasers to be explicit about what services to commission, together with the trend towards more open and accountable forms of government, prompted more explicit systems of rationing (Joyce, 2001; Light & Hughes, 2001), exemplified by the formation of NICE in 1999, the setting up of ‘priorities forums’ at a local level (Hope et al, 1998), and the deployment of economic methodologies such as QALYs as the basis for resource allocation decisions (see Section 3.2.1).

There has been longstanding debate over the advantages and disadvantages of these different approaches to rationing (Coast, 1997; Doyal, 1997; Hunter, 1997; Klein, 1993; Locock, 1998; Mechanic, 1997; Bobbitt & Calabresi, 1978). In summary, the arguments in favour of explicit rationing appeal to ideological and ethical concerns: the democratising and accountability of decision-making, the moral imperative of honesty and transparency, the dangers of paternalism and the bias of discretionary decisions in implicit rationing. According to Doyal, there is “*too much secrecy in British public life*” and, however difficult the task may be, we

should have the moral courage to clarify and develop the principles on which rationing decisions are made (Doyal, 1997: p1118).

Other commentators have put forward a number of counter arguments, lending support to the benefits of implicit rationing. The overall strengths of implicit rationing are seen as its “*discretion, flexibility and ability to take account of emotions, aspirations, and preferences*” (Mechanic, 1997: p90). One strand of argument is that explicit rationing is impractical – given the diversity of objectives that health care is required to pursue simultaneously, we are unlikely ever to be able to agree on a set of principles or criteria for rationing (Coast, 1997). Klein, for example, has suggested that the search for a set of ethical principles or technical methodologies by which to make explicit decisions is likely to remain elusive, and argues that ultimately rationing decisions must be a process of debate involving political, moral and clinical judgements (Klein, 1993). His argument highlights the oversimplification of a strict explicit/implicit dichotomy. For example, are we to categorise deliberative judgements as explicit or implicit? Even Hunter’s much quoted phrase (adopted by Mechanic) in favour of implicit rationing – that the best we can hope for is “*muddling through elegantly*” (where ‘muddling through’ is considered a virtue rather than a negative (Ham & Coulter, 2001)) – can arguably be considered a form of explicit rationing, in terms of its call for honesty and transparency (Hunter, 1995; Mechanic, 1997).

Other arguments against the practicality of explicit rationing concern the inherent uncertainty and contingent nature of much decision-making about medical treatments, making it difficult if not impossible to apply explicit, standardised criteria (Mechanic, 1997). Some proponents of implicit rationing have focused on the disutility (adverse effect) of explicit rationing. Coast, for example, has argued both from a theoretical and empirical perspective that rationing health care may cause disutility to those making the decisions ('disutility associated with denial') and to patients denied treatments ('disutility associated with deprivation') (Coast, 1997). Researchers have found that those involved in specific priority setting exercises have often been reluctant to specify services to be denied (Coast, 1997; Coast et al, 2002; Lomas, 1997), and have reported that patients on the receiving end of explicit rationing decisions (unsurprisingly) found denial of treatment difficult and hurtful (Owen-Smith et al, 2009).

2.5 Levels of rationing

Any discussion of explicit versus implicit rationing approaches needs to be located within a framework of the different *levels* at which the rationing of health care can occur. At a national level central government decides the level of resources allocated to the health care budget, which, as described in Section 2.1, had steadily grown in real terms from 1948 until 2010. In 2010 the prolonged budget freeze announced as part of the government's austerity plans included the expectation that the NHS make up to £20 billion of efficiency savings by 2015, and continued savings in the period up to 2021/22 (Roberts, 2012). The term 'efficiency savings' is another example of

the role of language in the rationing debate. In theory efficiency savings are distinct from cuts to services; the former meaning delivering the same service at less cost without any loss in quality, but as has been noted, *“the boundary between efficiency savings and service cuts is porous and blurred”* (Maybin & Klein, 2012: p1).

A key mechanism of rationing at a national level in the UK is NICE. A central role of NICE is to evaluate health technologies (drugs and medical treatments) and make recommendations based on clinical and economic evidence as to whether the NHS should fund a particular technology. A popular perception is that NICE is the main rationing arm of the NHS, arguably however it is local commissioning groups, in their role as NHS budget-holders, that are the principal site of rationing decisions in the NHS (McMillan et al, 2006). When NICE recommend the adoption of a new technology (with which local commissioners are statutorily obliged to comply) this is rarely accompanied by extra funding, and it is thus at a local level that rationing decisions have to be made to release extra funds for the new technology (Barrett et al, 2006; Cookson et al, 2001). Ham and Coulter see this devolving of responsibility as an attempt by national policymakers to avoid direct blame for rationing (Ham & Coulter, 2001).

The monies that central government allocate to the NHS are distributed through an agreed formula to local commissioners of health care – now CCGs (previously PCTs). The role of local commissioners is to purchase health care for their local population, involving ‘meso-level’ resource

allocation decision-making based on factors such as local needs assessment, national guidelines (from NICE and professional bodies), and invariably the legacy of previous spending decisions (Edwards et al, 2015). Rationing at this level occurs through various mechanisms, structures and strategies as indicated by Maybin and Klein's model outlined above (see Section 2.3), a significant one being sub-committees of commissioning groups referred to generically in this thesis as 'priorities forums' (but in practice variously named priorities panels, groups, committees, and so on).

A survey undertaken by the Nuffield Trust in 2011 indicated that the majority (86%) of local NHS commissioning organisations had a formal priority setting structure in place for making resource allocation decisions, the remit of which includes making decisions on new developments, prioritising between service areas (such as cancer or mental illness), patient groups (children or the elderly, for example) and interventions, and deciding about substitution of, and disinvestment in, interventions and services (Robinson et al, 2011b)¹. The empirical work for this thesis explores the work practices of one such priorities forum.

Whereas most priorities forum decision-making is prioritising at a population level, another significant rationing mechanism at the local level of the NHS concerns the funding of treatments to individual patients. Local committees known as 'individual funding request' (IFR) panels are statutorily required to

¹ As part of the reforms of the NHS in England following the Health and Social Care Act 2012 (Department of Health, 2012), commissioning support units (CSUs) were established to support the work of local groups of CCGs, and some priorities committees are now located within CSUs.

consider requests from patients and their doctors to fund a particular treatment as a 'one-off', 'exceptional' case, even if it is a treatment that the NHS (at least in that locality) does not normally fund (either because it is a treatment that NICE has rejected or not yet appraised or because the local commissioning group has explicitly decided not to fund, or for which there is no policy about its funding) (Austin, 2009; National Prescribing Centre, 2009a). The data extract at the beginning of this thesis (see Chapter 1) is an example of an IFR request, in this case for ranibizumab (Lucentis) for wet age related macular degeneration.

At the time of my fieldwork, IFR panels were committees of primary care trusts; in 2013, as part of the reforms of the Health and Social Care Act 2012 (Department of Health, 2012), they were reconstituted as committees of clinical commissioning groups, or set up as part of commissioning support units operating on behalf of a number of neighbouring CCGs². Despite these organisational changes, the basic role and remit of IFR panels has been maintained.

Remarkably, there are no routinely published national data on IFRs, and the data that are available present an incomplete picture of IFR activity. An investigation by GP magazine based on information from 123 (of 152) PCTs

² Whilst most NHS commissioning continues to be managed locally, in 2013 the NHS Commissioning Board also established a national IFR process for services directly commissioned by NHS England (some aspects of specialised services, health services for the armed forces, and people in prison) (NHS Commissioning Board, 2013; NHS England, 2016). A recent BMJ investigation of trends in IFRs (Iacobucci, 2017a) indicated that compared with CCGs, NHS England only deal with a very small proportion of IFRs (personal communication, June 2017).

responding to a Freedom of Information request indicated that the number of IFRs rose from 53,300 in 2008/9 to 85,000 IFRs in 2011/12, a 60% increase. The investigation also reported a small drop in the proportion of requests approved over the same time period, and wide variation between PCTs in both the number of requests submitted (from one for every 200 patients in some areas to one for every 11,000 in others), and the proportion approved (from 7.5% in some areas to more than 84% in others) (Moberly, 2012b).

A more recent investigation of CCGs by the British Medical Journal (BMJ), based on data from 169 CCGs in England (of 207) from Freedom of Information requests, also reported an increase in the overall number of requests between 2013 and 2017, and substantial variation between CCGs in the number of requests received and approved (Iacobucci, 2017a). The BMJ investigation reported a slight increase in the proportion of IFRs approved (from 43% to 52%), although it is unclear whether these figures were based on the total number of requests received or the number considered by IFR panels (in other words, whether it included those ‘triaged out’ at a pre-panel screening stage – see Section 8.1). Nor did the BMJ investigation include data about those IFRs now dealt with by NHS England rather than CCGs (see footnote 2). Figures quoted in a recent judgement of an IFR case that came to judicial review (see Section 10.2) indicate that fewer than 15% of IFR applications to NHS England in 2015/16 were approved.

In numeric terms, IFRs comprise only a relatively small percentage of NHS activity. Indeed, some commentators question how much money this form of rationing saves the NHS, when the costs of administrative processes are taken into account (Edwards et al, 2015). However, IFRs are highly significant symbolically in defining the boundaries of NHS care and what it will and will not fund, particularly since decisions sometimes come to judicial review, hence legal scrutiny and public attention (see Section 2.7 below). Arguably, the work of these panels has become ever more significant, as pressures on NHS resources, and the list of 'low priority' treatments, or 'procedures of limited clinical effectiveness' (PoLCE), that local commissioning organisations will not normally fund, continues to increase (Audit Commission, 2011; Royal College of Surgeons of England, 2014; Iacobucci, 2017a) (see Chapter 8).

IFR panels have to consider the rights of an individual patient to treatment alongside population interests in the allocation of health care resources. They must also consider, within the context of the statutory duty of commissioning organisations not to exceed their allocated budget, the potential disruption of individual, one-off claims to the coherence of planned provision (Newdick, 2014). As such, IFR panels have become sites of contestation between competing patient, clinical, institutional and political perspectives, and represent a particularly fertile context for studying the rationality of decision-making in practice. In addition to the priorities forum referred to above, the empirical work for this thesis explores the work practices of three IFR panels.

The third level at which rationing takes place in the NHS is what is referred to as 'bedside rationing' by clinicians. It is likely that all consultations between health professionals and patients involve some sort of rationing decision – how much time to spend with a patient, whether a referral to specialist care is needed, whether it is high or low priority, and so on.

Considering the different levels of decision-making outlined here alongside the debate about explicit and implicit approaches to rationing, few would disagree with there being transparent, explicit decision-making at governmental level of resource allocation, nor with 'meso-level' priorities forums making decisions that are openly accountable to their local populations. However, the question of how explicit IFR panels should be about rationing decisions for individual patients is a trickier one. For example, given the recent emphasis in the NHS on shared decision-making (Foot et al, 2014), should patients whose cases are being considered be allowed to attend panel meetings? Or is this taking explicit decision-making one step too far? And are decisions about individual treatments best taken by public administrative panels, or as an integral part of the doctor-patient relationship? (Russell et al, 2011). The research reported in this thesis sought to explore (but not resolve) these difficult issues.

Furthermore, at the level of bedside rationing, how explicit or implicit should rationing decisions be? For example, should doctors discuss treatments with their patients that others may consider effective but they do not? Whilst this level of rationing and questions such as these go beyond the scope of my

research study (which is focused at the meso-level of priorities forums and IFR panels), the evidence relating to bedside rationing from other studies is noteworthy background (Danis et al 2014). A systematic review of qualitative studies of bedside rationing found a considerable gap between the abstract principle of explicitness and reported practice, and tension between the doctor's role as patient advocate and their wider responsibilities as public servants for budgets, populations, and society in general (Strech et al, 2008). And a survey of oncologists found that almost one third chose not to discuss unfunded drugs with their patients (Richards, 2008). In the context of rationing decisions, it is clear that beneath the surface of popular slogans such as 'no decisions about me without me' there lie complex ethical and political choices (Russell et al, 2011).

2.6 The policy context

Approaches to rationing in the NHS need to be located within the broader policy, regulatory and legal context within which those responsible for rationing are required to make decisions. The English NHS Constitution sets out the rights of patients and the principles that guide the NHS. The Constitution states that *"the NHS provides a comprehensive service, available to all"*, and *"access to NHS services is based on clinical need, not an individual's ability to pay"*. It tells patients:

"You have the right to access NHS services. You will not be refused access on unreasonable grounds..... You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you. You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your

doctor feel would be right for you, they will explain that decision to you.”
(Department of Health, 2015: p7)

These apparently straightforward pledges contain considerable ambiguity and room for interpretation. What does it mean in practice to state that patients will not be refused access to treatments “*on unreasonable grounds*”, and for funding decisions to be made “*rationally*”? Such questions point to the very core of this thesis, the starting position of which is that words such as ‘rationality’ and ‘reasonableness’ are contested terms, meaning different things to different people. My research is concerned with examining these different meanings empirically, through an exploration of the deliberations of local NHS rationing groups.

Furthermore, what does ‘comprehensive’ mean in the context of NHS care? The NHS was built on the founding principles of universality, comprehensiveness and provision free at the point of delivery (Bevan, 1948), and under the NHS Act 2006 and the Health and Social Care Act 2012 the Secretary of State continues to have a duty to promote a comprehensive service, delegated to local commissioners of health care (Maybin & Klein, 2012). The 2012 Act defines this duty in terms of CCGs being responsible for arranging the provision of health services “*to such extent that it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility*” (Department of Health, 2012), a definition that arguably falls short of any common understanding of the word ‘comprehensive’.

Maybin and Klein note that whilst the Secretary of State has a statutory obligation to promote a comprehensive service, the phrase has never been defined in terms of a list of treatments the NHS should provide (Maybin & Klein, 2012). In 2012 the Nuffield Trust raised the question of *“whether it is time to set out more clearly what is funded by the NHS”* and asked whether England should be following the example of other countries such as Germany, Chile and New Zealand, and introduce an NHS benefits package which would make explicit what the public could expect to be ‘in’ and ‘out’ of entitlement to state-funded health care (Rumbold et al, 2012: p5). Although no such package has been drawn up, there is increasing evidence that, to quote the Chair of the British Medical Association Council in 2012, there are now *“lots of areas where bits of the NHS have been taken out of the offer”* (Campbell, 2012). For example, the Royal College of Surgeons has reported evidence of CCGs imposing *“unproven and arbitrary”* thresholds for surgery for hip replacements, hernia repair, and a number of other surgical procedures (Royal College of Surgeons of England, 2014). A Freedom of Information investigation by GP magazine in 2012 showed that 91% of the 101 responding primary care trusts had imposed restrictions on some treatments, including cataract procedures (66% of PCTs) and bariatric surgery (59% of PCTs) (Moberly, 2012a). More recently, a survey of CCGs by the Health Services Journal in 2015 indicated that 39% of CCGs were considering imposing new limits on eligibility for some treatments such as in-vitro fertilisation (IVF), hip and knee replacements, and were looking at extending their lists of procedures of limited clinical effectiveness (Campbell, 2015b; West & Welikala, 2015).

In 2011 Sir Bruce Keogh, the then Medical Director of the NHS, sent a letter to all commissioners that highlighted the tension between an NHS publicly committed to the values of comprehensiveness and universality on the one hand, and the need to respond to financial pressures on the ground on the other. He stated that, in response to *“press and Parliamentary interest in PCTs looking to address their current financial challenges through restricting patients' ability to access or be referred to some services”*, there was a need to emphasise that local processes *“must not introduce outright blanket bans for interventions and treatments”* and *“must be sensitive to individual circumstances”* through exceptional case review (Keogh, 2011):

“As you are aware, the NHS is facing an unprecedented financial challenge, needing to achieve up to £20 billion of efficiency savings by 2014/15. In light of this it is to be expected that reasonable policies and procedures regarding referrals will be put in place, with a view to ensuring as full a range of services as possible can be provided for the whole population.

[...]

It is my expectation that you will be taking an active role in ensuring that PCT clusters are meeting their legal obligations and not unreasonably restricting access to treatment for their patients.” (Keogh, 2011)

A central focus of this thesis is an exploration of how local resource allocation groups negotiate these tensions and paradoxes of their role as rationers of health care within the wider context of an NHS still publicly committed to the values of comprehensiveness and universality.

2.7 The role of the courts

Since local commissioning organisations are national bodies, the legality and rationality of their decisions can be challenged through judicial review (Maybin & Klein, 2012), and over the past 20 years there have been a series of judicial review cases concerned with individual funding requests, resulting in the courts having played a significant role in shaping the context in which rationing decisions are made.

Notable and frequently quoted judicial review cases include those of Jaymee Bowen (Child B) (*R v Cambridge Health Authority, ex parte B* (1995)), seen by many as epitomising the dilemmas of rationing in the NHS (Ham, 1999), *R v North West Lancashire Health Authority* (2001), and *R v Bromley PCT* (2006). In the case of Jaymee Bowen, a 10 year-old girl with leukaemia, her father unsuccessfully applied to get the health authority to fund a second bone marrow transplant for his daughter. In the Court of Appeal, Sir Thomas Bingham made the following judgement:

“Difficult and agonising judgments have to be made as how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make. In my judgment it is not something that a health authority such as this authority can be fairly criticised for not advancing before the court”. (R v Cambridge Health Authority ex parte B, 1995: 906)

This judgement, as I will discuss in Chapter 6, has been widely quoted as providing justification for local rationing decisions, supporting the position that the NHS does not breach its duty of care by failing to fund that which it cannot afford (Lock, 2007), and some would argue, a utilitarian approach to

rationing, in which collective benefit for the majority takes a higher priority than individual need. Subsequent cases have reinforced that the courts are willing to consider it rational for health authorities to deny care to individuals on affordability grounds (*Rogers v Swindon NHS Primary Care Trust* (2006)) (*R on the application of Thomas Condliff v North Staffordshire PCT* (2011)).

The case of *R v North West Lancashire Health Authority* is commonly cited as defining the critical concept of exceptionality. In this case, concerning three people who were refused gender reassignment treatment by their PCT, the judge deemed that:

“The precise allocation and weighting of priorities is clearly a matter of judgment for each authority, keeping well in mind its statutory obligations to meet the reasonable requirements of all those within its area for which it is responsible. It makes sense to have a policy for the purpose - indeed it may well be irrational not to have one.... It is proper for an authority to adopt a general policy for the exercise of such an administrative discretion, to allow for exceptions from it in ‘exceptional circumstances’ and to leave those circumstances undefined...” (Auld LJ in *R v North West Lancashire Health Authority, ex parte A, D &G, n 12, 2001: 991*)

Translated into policy, this and subsequent judicial pronouncements have enabled the concept of exceptionality to become the ‘get-out clause’ to any suggestion of blanket bans in the NHS, and have provided the rationale for IFR panels to deliberate over exceptional cases. In this thesis I explore the meaning making practices in relation to exceptionality at the local level of NHS decision-making (see Chapters 6 and 8).

Syrett suggests that we can see “a gradual but perceptible trend in the English courts towards requiring decision-making on the allocation of scarce resources to be more transparent” (Syrett, 2007: p174). For example, in *R v*.

Bromley NHS Primary Care Trust in 2006 Linda Gordon submitted an IFR to her PCT to fund erlotinib (Tarceva) for lung cancer. This was refused. She applied for judicial review on the grounds that the refusal amounted to a blanket ban, which had ignored her particular circumstances and was therefore arbitrary and irrational. The court granted the application on the basis that the PCT's reasons for refusing treatment had not been made explicit (Newdick, 2007). Newdick suggests that this case demonstrates that commissioners must now be "*absolutely candid*" about the grounds on which they are making allocative choices (Newdick, 2006). Another example of the courts increasingly requiring explicitness and transparency comes from the recent case of *Rose v NHS Thanet CCG (2014)*, in which the judge ruled that CCGs must be clear in giving good reasons for departing from NICE guidance. Hitherto, CCGs have been under no statutory obligation to comply with NICE guidance, unlike NICE technology appraisal recommendations, which they are legally obliged to comply with (Williams, 2014).

It is noteworthy that whilst the judgements made in these individual cases have been highly significant in defining what is and what is not considered lawful practice for commissioning groups, the courts have on the whole restricted their role to a consideration of the rights and wrongs of the decision-making *process* rather than the *substance* of the decision (Newdick, 2014). Newdick argues that this restrictive role of the courts in health care decision-making is an entirely appropriate one: "*..hard choices between deserving patients... should be made by well equipped bodies applying*

consistent policies with proper regard to fairness and equality”, rather than by courts that only deal with isolated cases and, it is argued, have little understanding of the opportunity costs that commissioning groups have to grapple with in their funding decisions (Newdick, 2006: p208). Others, however, have argued that potentially the courts could and should play a greater role in opening up public deliberation about the allocation of health care resources by promoting a ‘culture of justification’, specifically by undertaking more intensive scrutiny and evaluation of the content of allocative decisions (Syrett, 2007; Syrett, 2011). A recent study of a lawsuit concerning health care rationing in the Netherlands concluded that legal scrutiny can be of value in encouraging institutional reflexivity (Moes et al, 2016).

2.8 The role of the media

In setting the scene for the research presented in this thesis it is relevant to consider the role of the media in reporting and shaping debate about the rationing of health care. As Wilson et al have noted, the media do not simply transmit information, but represent it in a particular way, influenced by others (such as drug companies, patient organisations, and government) with interests in shaping the news agenda and thus public perceptions, expectations and opinion (Wilson et al, 2008; Williams, 2015).

The so called ‘postcode lottery’ (geographical variation) of health care is a key theme in media coverage of NHS rationing (Charles, 2017). Headlines such as *“IVF ‘postcode lottery’ on NHS criticised by infertility campaigners”*

(BBC News, 2016), *“Postcode lottery for cancer drug as Nice rules Kadcylla too expensive”* (Boseley, 2015), and *“Patients wait up to 15 months for cataract ops in ‘devastating’ lottery”* (Donnelly, 2016) have become commonplace over the last decade. Back in November 2006 Channel Four screened ‘Britain’s healthcare lottery’, reporting on *“the scale of the NHS postcode lottery that is denying some patients vital drugs”*, and offering *“a user’s guide on how to fight the system to get the treatment you need”*. The following extract about the programme from the Channel Four website is typical of how the postcode lottery has been represented in media reporting:

“[Jon] Snow investigates why, despite pouring money into the NHS, the government has failed to tackle the lottery, and travels across the country to visit some of the people whose lives have been shattered by the rationing of certain treatments. He discovers decisions taken at local levels within the NHS that result in only one of two women, who are practically neighbours and have an identical condition, receiving the treatment they need.” (Channel 4, 2006)

Arguably, programmes such as this and similar ones aired by the BBC (Corden, 2008; Wishart, 2009), along with newspaper coverage of campaigns by cancer charities, played a significant role in prompting the government to set up the Cancer Drugs Fund in 2011. Some commentators went so far as to suggest that the Fund could be seen as *“a political sop to the high profile negative press cancer drugs not approved by the National Institute for Health and Clinical Excellence (NICE) have received”* (Thornton, 2011). The purpose of the Fund was to improve access to cancer drugs not routinely available on the NHS (National Audit Office, 2015). The Fund attracted considerable controversy for singling out cancer patients over and above other groups of patients, over-riding and undermining the established processes of NICE and local commissioning groups, and thus representing

a diversion from the fair allocation of NHS resources (Thornton, 2011; Duerden, 2010; The Lancet, 2010; Maynard, 2012). The Nuffield Trust described the Fund as “*a fudge with a weak intellectual foundation*”, with a lack of evidence to justify its existence (Edwards et al, 2015: p10), and the authors of a review of the Fund published in 2017 described it as “*policy on the hoof*” (Triggle, 2017; Aggarwal et al, 2017). In 2016, following an investigation by the National Audit Office (Morse, 2015), the Fund was disbanded in its original form and brought under the remit of NICE.

The media has played an active role in publicising judicial review cases, such as those outlined above, as well as local rationing decisions taken by IFR panels. Headlines such as “*Life or death High Court verdict is a ‘death sentence’ for former PC*” (This is Staffordshire, 2011), “*Man who inspired Government cancer pledge is refused treatment*” (Donnelly, 2011), and “*Father continues the fight after NHS refuses vital operation for his daughter suffering with gastroparesis*” (Gillespie, 2014), convey a strong narrative of individuals unfairly denied NHS care, and the ‘life and death’ decisions undertaken by local decision-makers and the courts. Some argue that the media’s tendency to focus on the emotive human interest story crowds out a more balanced account of the complexity of allocative decision-making and the competing demands on resources between individual and population needs (Entwistle et al, 1996). Furthermore, Wilson et al pose the question of whether the media’s focus on denial and the rationing of certain treatments is in part prompted by the interests of pharmaceutical companies, and suggest evidence of pharmaceutical companies targeting journalists as part

of a marketing strategy to raise public awareness of and stimulate demand for their products (Wilson et al, 2008).

A parallel narrative in media reporting is that of wastage of NHS resources, conveyed in headlines such as: *“NHS blows millions on boob jobs and facelifts and taxpayers foot the bill”* (Martin, 2014). In Chapter 8 I explore how the media’s representation of breast surgery cases provides a backdrop against which deliberations about the funding of ‘low priority’ procedures come to be framed.

2.9 Summary and conclusion

The key conclusion from this overview of the NHS rationing debate is that the rationing of health care is a complex and contested process that takes many forms, and is undertaken at a number of different levels in the health care system. It is inescapably a political process involving competing demands and containing unresolvable tensions: tensions between national and local decision-making, the health care needs of individual patients and population groups, and the interests and responsibilities of policymakers, health professionals, the courts, pharmaceutical companies, the media, and patient groups. As Light and Hughes argue, considered as a social practice, the topic of rationing offers much scope for *“exploring power relations in health care systems, particularly the linkage between resource allocation, rhetoric and the interests of different parties”* (Light & Hughes, 2001: p551). This linkage is a central focus of my thesis.

Many aspects of the rationing debate touched upon in this scene-setting chapter could have provided the focus of an entire thesis. Indeed, in-depth work has been undertaken by other researchers exploring, for example, the role and workings of NICE (Crinson, 2004; Davies et al, 2006; Milewa, 2008; Moreira, 2011; Calnan et al, 2017), the role of law and specific judicial review cases in the rationing debate (Ford, 2012; Newdick, 2007; Newdick, 2009; Syrett, 2004; Syrett, 2007; Harrington, 2016), and rationing practices of clinicians at the micro-level of the bedside (Carlsen & Norheim, 2005; Hedgecoe, 2006; Danis et al 2014). My research zooms in on one small piece of the rationing puzzle, but aims to consider this aspect of rationing within the broader picture presented in this chapter, and, following case study tradition, to draw insights into the general through a study of the particular (see Chapter 4).

3 A review of the literature

3.1 Introduction

As indicated in the previous chapter, an overriding requirement of those responsible for the rationing of health care resources is that their decision-making is considered rational. The NHS Constitution enshrines the rationality of rationing within a rights-based discourse, informing patients that they have the right to rational decision-making about access to NHS treatments, and the right to legal challenge through judicial review if they consider access has been refused on unreasonable grounds (Department of Health, 2015). But what does it mean for rationing decisions to be made 'rationally'?

In this chapter I begin to address this question by reviewing theoretical approaches to conceptualising rationality. Specifically, I explore three fundamental approaches to conceptualising rationality identified by scholars within the health care rationing debate: instrumental, institutional and practical (Gkeredakis et al, 2011; Ham & Robert, 2003; Holm, 1998). Taken together these approaches reflect long-standing and wide-reaching debates across disciplines concerning the nature of rationality (Habermas, 1987; Simon, 1978; Townley, 2008; Weber, 1978). I begin by outlining both the appeal and limitations of instrumental and institutional rationalities from theoretical perspectives, and argue for the value of a practical orientation to rationality (Flyvbjerg, 2001; Miller, 1990; Parsons, 2002; Sayer, 2011). However, I suggest that the hegemony of instrumental and institutional

views of rationality have largely occluded practical ways of seeing in health care rationing discourse. I consider why a practical conceptualisation of rationality, despite its strengths as an embedded and embodied form of rationality, has a problematic status in formal accounts of decision-making, and may even be deemed outside the realms of reason. I then summarise what we have learned about the rationality of rationing from existing research studies, highlighting what a practice-oriented research approach can add to our understandings of rationing.

3.2 Instrumental rationality

Based on Weberian notions of rational action as technical calculation (Weber, 1978), 'instrumental' or 'technocratic' rationality focuses on apolitical, scientised approaches to resource allocation (Sanderson, 2004; Tenbenschel, 2000; Dryzek, 1987) :

“The ‘rational method’ is a precisely ordered way of reasoning, abstract theorizing from disengaged principles, focusing on logical rules, principles of consistency, coherence, and non-contradiction, specifying rules of inference, and appropriate means of reaching conclusions.”
(Townley, 2008: p23)

Lefstein summarises the basic logic model of instrumental rationality in terms of certainty (knowledge should be based on secure foundations); objectivity (as opposed to personal subjectivity); method (as the primary means by which objectivity is secured); measurement and calculability, efficiency, and control (the ability to isolate and control objects of inquiry and manipulation (Lefstein, 2005).

Manifestations of instrumental rationality can be seen in the view that resource allocation is essentially an exercise in what Miller has termed 'decision science' (Miller, 1990); a case of gathering the 'objective facts' about the efficacy and cost-effectiveness of options from knowledge sources such as randomised controlled trials, evidence reviews, health technology assessments, and cost utility analyses (Tenbensen, 2000). Decision science positions decision-making as a technical, logical process, comprising the selection, synthesis and evaluation of evidence, from which the preferred answer to a particular policy problem will emerge (Miller, 1990). Holm, writing in 1998, suggested a first phase of rationing activity characterised by:

“a search for priority setting systems which, through a complete and non-contradictory set of rational decision rules, could tell the decision maker precisely how a given service should be prioritised in relation to other services.” (Holm, 1998: p1000)

Although, as outlined in Section 3.3 below, a second phase of rationing activity has focused more on the *institutional processes* of resource allocation, with recognition that the search for a 'technological fix' for determining priorities is likely to remain an illusory one (Klein, 1993), in this thesis I demonstrate the enduring appeal and influence of an instrumental rationality, exemplified through the hegemony of evidence-based policy discourse (Greenhalgh & Russell, 2009; Parsons, 2002; Russell et al, 2008; Sanderson, 2003).

Critiques of instrumental rationality by political scientists have been substantial and sustained (Bacchi, 2000; Dryzek, 1987; Fischer, 2003; Lindblom, 1959; Parsons, 1995). Early critiques questioned the feasibility of

this model, arguing that rationality is unavoidably 'bounded' by factors such as the time available for making decisions, the complexity of decision problems, and the cognitive limits of human beings' powers for processing information (Simon, 1991). More fundamentally, many have questioned the *desirability* of the instrumental model. In relation to rationing activity, commentators argue that the ethical and political issues faced by resource allocators cannot and should not be reduced to questions of 'best evidence'; that what matters is not simply 'what works' (Bullock et al, 2001), but what is considered appropriate in the circumstances and what is agreed to be the desired goal (Sanderson, 2003). The question of 'what should we do?', as opposed to 'what do we know?', involves social values and cannot be answered by science alone (Greenhalgh & Russell, 2009). The danger of an instrumental rationality, according to Fischer, is that it sees "*politics as the problem rather than a solution*" (Fischer, 1990: p21).

While evidence from randomised controlled trials and health technology assessments has an important role to play in informing rationing policies, it is suggested that the body of evidence is often incomplete, ambiguous and conflicting (Black, 2001; Dopson & Fitzgerald, 2005), and that evidence may not be considered generalisable or applicable to a given local context by those wanting to use it (Williams et al, 2011). Moreover, evidence is never simply abstract, neutral knowledge but always 'embodied' (Townley, 2008) by those constructing, collating, synthesising and assessing it; it cannot 'speak for itself', but must be spoken for to establish its relevance and credibility (Green, 2000).

Furthermore, some argue that too great an emphasis on instrumental rationality 'dehumanises' health care rationing by shifting power away from the clinical judgement of doctors towards the tools of a 'scientific-bureaucratic medicine' (Harrison, 2002). It is argued that neoliberal policies (increased competition through a regulated market, greater attention to performance measures and cost effectiveness analyses, for example) have squeezed out the role of experiential knowledge and professional judgement in health care decision-making, in favour of evidence from external bodies of knowledge such as systematic reviews, and the use of algorithmic tools, such as treatment thresholds and eligibility criteria (Harrison & Smith, 2003; Smith et al, 2014).

3.2.1 The QALY and decision tools

In health care a key tool in the technocratic rationer's toolkit is the QALY (Quality Adjusted Life Years), the cornerstone of much of NICE's work, and epitomising both the workings and limitations of an instrumental rationality *par excellence* (Tenbensen, 2000). The QALY is a combined measure of survival and quality of life resulting from a given treatment, offering a common currency for assessing health gain from medical interventions. When combined with the costs associated with an intervention, the QALY enables cost utility ratios to be calculated, and thus the value of any given intervention to be quantified (Williams et al, 2011). NICE currently uses a threshold for recommending treatments costing £20,000 - £30,000 per QALY (Dillon, 2015); more expensive interventions are generally considered

to be not a cost effective use of NHS resources, with some exceptions made for end of life treatments (Maybin & Klein, 2012).

Criticisms of this approach focus on the implied judgement of what a life is worth to a person, and assumptions about the value of different health states. For example, it has been argued that the way in which QALYs are calculated means they discriminate against disabled and elderly people (although modifications to the basic QALY approach can include some adjustments for age and disability) (Maybin & Klein, 2012).

Other criticisms focus on the philosophical principle on which the QALY is based. The QALY assumes that the goal of health care is maximising the benefits to society from health care spending, in other words the utilitarian principle of collective benefit for the majority having a higher priority than individual need or entitlement, or the goal of addressing inequalities among specific population groups (Harrison & Dowsell, 2001). Thus, it is argued that important questions about 'ends' are eclipsed by the focus on technical method (Locock, 1998; Saarni & Gylling, 2004). It is suggested that technocratic approaches to rationing such as QALYs generate a 'pseudoscientific aura' and offer an illusion of objectivity by implying that it is possible to identify valid and reliable utility values, and funnel a complexity of health outcomes into a single measure (Coast, 2004; Harris, 1987; Loughlin, 1996). Furthermore, the apparent precision of the QALY calculation contrasts with the defined thresholds of what NICE considers the

NHS can and cannot afford, which Maybin and Klein suggest are “*arbitrary, based on neither theory nor evidence*” (Maybin & Klein, 2012: p11).

At a local level, QALYs represent an important component of rationing decisions, in so far as they form one currency on which NICE guidance is based and must be interpreted locally. Local commissioners also have a range of decision tools at their disposal (for example programme budgeting and marginal analysis (PBMA), multi-criteria decision analysis (MCDA), and the Portsmouth scorecard), which to varying degrees move beyond straightforward economic evaluation of costs and benefits, but still numerically weight and/or rank various criteria, and in this sense form part of the technocratic rationer’s toolkit (Maybin & Klein, 2012; Robinson et al, 2011b). The problem with all such tools, according to Smith and colleagues, is their reductive nature; their use means that other forms of talk and sense-making in rationing deliberations, such as storytelling, and emotional and figurative speech (see Chapter 5) are lost or shut out by the privileging of scoring and abstracted forms of argument (Smith et al, 2014).

3.2.2 Ethical frameworks

Another example of instrumental rationality in resource allocation is the belief in the possibility of applying a set of ethical principles that will give decision-makers the ‘rules’ by which decisions about priorities can be made. The introduction of ethical principles can be seen as addressing some of the limitations of the ‘value-blind’ use of evidence discussed above. However, the idea that a predefined set of principles can be applied instrumentally to

reach the 'right' decision still fits broadly within Holm's description of the first phase of rationing activity as the search for a "*complete and non-contradictory set of rational decision rules*" (Holm, 1998: p1000).

Ethical frameworks and lists of principles are widely used by local NHS rationing bodies (Newdick, 2009); indeed they are recommended as part of good practice in priority setting and resource allocation (NHS Commissioning Board, 2013; Austin, 2007; Austin, 2008; National Prescribing Centre, 2009b). The principles and values included in these frameworks are diverse and vary from locality to locality (see Section 7.4.2), including, for example, principles of clinical effectiveness, cost effectiveness, affordability, equity, ethical consideration of respect for personal autonomy, beneficence, non-maleficence, distributive justice, and the goal of transparency (Robinson et al, 2011b). These frameworks and lists encompass a mixed bag of guiding principles, ethical values, intentions and goals. What they have in common is an underpinning in the concept of principlism - the idea that a set of principles can be applied universally and in a logico-deductive way to reach a 'rational' decision (Persad et al, 2009; Evans, 2000).

Such frameworks of principles can undoubtedly play a constructive role in decision-making (for example by providing convenient reference, helping to keep ethical values to the fore, and offering structure) (Giacomini et al, 2001). However, principlism has been extensively criticised by moral philosophers and political scientists, who highlight its limitations as an

approach for supporting decision-making. For instance, Murray (1987) argues that in real life people do not proceed deductively from moral principles to judgement, but rather immerse themselves in the particularities of a case, and then justify their moral judgements in the opposite direction. Similarly, Miller (1990) argues that the notion that a group's values can be thought of as pre-determined entities rather than an emergent and immanent part of decision-making is a scientific illusion. Moreover, there is the problem that various ethical principles lack any systematic relationship to each other, and may conflict with each other (Maybin & Klein, 2012). Some have suggested that ethical frameworks serve more as 'litanies' (Marinker, 2006), to be "*recited dutifully*" (Giacomini et al, 2004: p20), "*simply named but not well elaborated, deliberated or acted upon*" (Giacomini et al, 2001: p6).

The attraction of sets of ethical principles for decision-makers, according to Evans, is that, like cost-utility analysis, they offer the false allure of commensuration. Commensuration, Evans suggests, is "*essentially a method for discarding information in order to make decision-making easier by ignoring aspects of the problem that cannot be translated to the common metric*" (Evans, 2000: p32). Evans draws on the work of the historian Theodore Porter to explain the popularity of commensurable devices – they give the appearance that decision-makers are not so much exercising judgement but following transparent, calculable and predictable rules (Porter 1995, cited in Evans, 2000: p35). And, as critical commentators have noted, and I argue in Chapter 5, in modern life there appears to have been a

turning away from the art of judgement, and the *“transformation of judgement from a moral to a scientific accomplishment”* (Furedi, 2014). In a similar vein, Loughlin suggests that principle-based approaches to ethics in health care management have become a substitute for *“sincere critical thinking about right and wrong... as if the very fact that an ‘ethical code’ exists can settle a substantial question about how we ought to behave....”* (Loughlin, 2002: p28). In Section 7.4.2 I give an example from my empirical data of how ethical deliberation appears to be suppressed rather than invoked by reference to the ‘rules’ and principles in ethical frameworks.

In summary, despite significant critical analyses from social and political scientists over the past three decades, many rationing practices remain rooted in an instrumental rationality, sometimes referred to as ‘naïve rationalism’ (Russell et al, 2008). The continuing appeal of this conceptualisation of rationality can be seen as part of the hegemony of positivism, with its emphasis on objectivity and the logic of rules, as a mode of thinking about and method for exploring the social world (Greenhalgh & Russell, 2009). Some argue that it can also be seen as part of a neoliberal agenda that has shifted power away from medical expertise and clinical judgement towards the apparatus of managers and administrators (Smith et al, 2014).

3.3 Institutional rationality

Acknowledging the limitations of an instrumental rationality, Klein and Williams argue:

“Given conflicting values, the process of setting priorities for health care must inevitably be a process of debate. It is a debate, moreover, which cannot be resolved by an appeal to science and where the search from some formula or set of principles designed to provide decision-making rules will always prove elusive. Hence the crucial importance of getting the institutional setting of the debate right ... the right process will produce socially acceptable answers - and this is the best we can hope for.” (emphasis added) (Klein & Williams, 2000: pp20-21)

Thus the second phase in the development of approaches to rationing activity focuses less on techniques and more on decision-making processes (Ham & Robert, 2003). Within an institutional rationality the emphasis is on the *processes and procedures* through which decisions are made (Holm, 1998; Maybin & Klein, 2012; Townley, 2008). In line with this ‘procedural turn’ in health care rationing debates (Syrett, 2007), decisions become rational if they are taken in accordance with certain procedural requirements such as transparency, public involvement in decision-making, and a formal appeals process.

3.3.1 *Accountability for reasonableness*

An influential manifestation of this conceptualisation of rationality is Daniels and Sabin’s ‘accountability for reasonableness’ framework (Daniels & Sabin, 1997). This framework posits four conditions that, its originators argue, will assure the legitimacy and fairness of resource allocation decisions. The emphasis is on ensuring [1] public accessibility of rationing decisions and their rationales (the publicity condition), [2] that the rationales for decisions

should be based on evidence, reasons and principles *“that all fair-minded parties (managers, clinicians, patients and consumers in general) can agree are relevant to deciding how to meet the diverse needs of a covered population under necessary resource constraints”* (Daniels & Sabin, 1998: p57) (the relevance condition), [3] appeal mechanisms for challenge (the revision and appeals condition), and [4] voluntary or public regulation of the process to ensure that all conditions are met (the enforcement condition).

The value of the framework is that it brings to the fore the role of deliberation and democratic debate in rationing decisions, and emphasises the importance of transparency and accountability in decision-making. The framework is closely connected to Habermas’ notion of the communicative ideal (Habermas, 1987), which suggests that deliberative democracy can be achieved by adhering to certain procedural rules of communication (see Chapter 9).

The English courts have endorsed and emphasised this view of rationality, through legal judgements in which decisions that deny access to health care have been deemed rational by virtue of their procedural soundness (Syrett, 2011). Specifically, judicial reviews of IFR decisions have ruled that decision-makers must be transparent about the reasoning and criteria behind decisions (Newdick, 2007) (see Section 2.7). The accountability for reasonableness framework has shaped the work of NICE, through the setting up of its Citizens’ Council to incorporate social value judgements into its recommendations (although some argue that NICE used the Council *“to*

do precisely what Daniels and Sabin think we cannot do - generate unproblematic principles that will automatically produce a just prioritisation") (McMillan et al, 2006: p128). The framework has also been widely adopted by local commissioning groups to guide and demonstrate the rationality of their decision-making (Williams et al, 2011). Friedman suggests that Daniels and Sabin's framework *"has been rapidly gaining worldwide acceptance, arguably to the point of becoming the dominant paradigm in the field of health policy"* (Friedman, 2008: p101).

This form of institutional rationality is not without its problems. Some commentators express concern that the conditions as defined fail to encourage sufficient public involvement to support claims of democratic legitimacy (Friedman, 2008). Most criticism, however, is focused on the relevance condition. Critics argue that we cannot assume that 'fair-minded people' (defined as people who are *"trying to find ways of cooperating with each other on mutually acceptable terms"* (Daniels, 2007: p124)) will necessarily agree on what are considered relevant reasons for decision-making; rather, the issue of relevance is likely to be *"heavily value laden and controversial"* (Friedman, 2008: p107). For example, Hasman and Holm argue that it is by no means obvious whether or not solidarity based reasons are reasonable (and therefore relevant) or unreasonable in the context of discussions about rationing (Hasman & Holm, 2005). Friedman concludes that:

"... we should give up on the idea that we can simplify the task of democratic deliberation by disallowing particular kinds of reasons and types of reasoning. Reasons of all kinds should be on the table..." (Friedman, 2008: p101)

Other criticisms focus on the feasibility and desirability of separating process from the substance of deliberation (Waymack, 2001), arguing the two are inextricably linked, with the process of deliberation both requiring and creating substance (i.e. systems of meaning) (Miller, 1990). For example, in her exploration of the 'relevance' of the concept of exceptionality in IFR decisions, Ford suggests that the relevance condition is ultimately redundant: it cannot on its own determine whether a reason is a legitimate or illegitimate basis for decision-making; rather relevance must emerge through deliberation about the substance of a case (Ford, 2015).

These criticisms of the accountability for reasonableness framework relate to broader arguments by deliberative theorists about the nature of deliberation (Barnes, 2008; Dryzek, 1987; Gutmann & Thompson, 2002), forms of public involvement in decision-making, and the distinction between deliberation as a process underpinned by some common understanding of public reason (Habermas' notion of the communicative ideal) and rhetorical deliberation, which assumes no shared point of agreement (Garsten, 2006). I explore these arguments in Chapters 5 and 9 of this thesis.

3.4 Practical rationality

The notion of practical rationality depicts rationality not as produced by the application of a formal knowledge base (instrumental rationality), nor as invested in processes and procedures (institutional rationality), but as an interpretive, practical activity about 'complex particulars' (Sanderson, 2006;

Townley, 2008). This conceptualisation of rationality is sometimes distinguished from other forms by representing it as practical reason, establishing a distinction between rationality and reason (Myerson, 1994). Sayer (drawing on various scholars including Aristotle) argues that whereas rationality implies logical, rule-following action, based on formal, abstracted knowledge, and a focus on means rather than ends, practical reason, what Aristotle called 'phronesis', is distinguishable by its concern with concrete particulars, its embodied, tacit and intuitive character, its link with emotional engagement and ethical judgement, and a focus on ends rather than means (Sayer, 2011). In this thesis I tend to favour the term practical reason when referring to the activity in which panel members are engaged; however, I also use the term practical rationality as way of contrasting with other conceptualisations of rationality.

The embodied, tacit and intuitive character of practical rationality is an acknowledgment that, in the words of Polanyi, "*we know more than we can tell*" (Polanyi, 1983: p4). Far from being 'irrational', acting intuitively has been identified by scholars as a characteristic of expert judgement. Dreyfus and Dreyfus argue that what distinguishes experts from novices is the ability to move beyond rule-based knowledge to intuitive understanding gained from extensive experience and context-dependent knowledge (Dreyfus & Dreyfus, 1986). In practical rationality:

"There is an emphasis on the concrete details of practical experience and practical wisdom built up through reflection on experience. It does not 'devolve' from abstract knowledge; it does not argue from foundationalist assumptions. ... It is the active, hard, work that is involved before 'decisions' are made, attentive listening, paying attention,

teasing out issues, awareness, and engagement, not the following of rules or formula.” (Townley, 2008: p215)

Aristotle distinguished between three types of knowledge: analytical scientific knowledge (episteme), technical knowledge (techne) and practical, experiential knowledge (phronesis), and argued that wise judgements come from an ability to combine these different forms of knowledge (Flyvbjerg, 2001). Thus phronesis is based neither on ‘objective’ nor ‘subjective’ judgement, but rather is demonstrated by the person who “*creatively combines knowledge of universals with experience-based rules of thumb*”, and has “*the ability to judge what will be good for another person in a given situation and to act accordingly*” (Schei, 2006: p403). Schwandt provides us with the following description of phronesis:

“This kind of practical-moral knowledge is acquired and deployed in one’s actions with one’s fellow human beings. ... Associated cognitive virtues are understanding, judgement and interpretation. Phronesis is intimately concerned with the timely, the local, the particular and the contingent (e.g. what should I do now, in this situation, given these circumstances, facing this particular person, at this time).” (Schwandt, 2001: p229)

Whereas instrumental and institutional framings of rationality emphasise the *irrationality* of emotions, depicting them as the “*murky contaminants to reason*” (White, 2011: p179) and the “*dysfunctional antithesis of rationality*” (Ashforth & Humphrey, 1995: p120), practical reason recognises the role and value of emotions in coming to understand what is rational. Emotions are seen as doing moral work and provide a crucial stimulus for, and component of, ethical action (Nussbaum, 2001). As Garsten says of the role of emotions:

“[they] lead us to identify certain moments as presenting a choice and also to identify which material is relevant to making that choice. Many deliberations include a moral component, and emotions help to define which considerations seem morally relevant.” (Garsten, 2006)

Barbalet (2001) suggests that emotionality and rationality can be conceptualised as continuous, in the sense that [a] rationality itself can be a feeling (a “*sentiment of rationality*”) (James, cited in Barbalet, 2001: p45); [b] emotional responses to situations can be appropriate and ‘rational’ (for example, not to feel outrage at a gross injustice would be considered ‘irrational’), and [c] emotions are “*woven into the very fabric of our reasoning*”, helping to give it “*salience, direction and purpose*” (Williams, 2000 cited in Townley, 2008: p178).

Above all, practical reason is narrative based (Townley, 2008). It is through the construction and interpretation of stories of human experience that individuals and cultures come to “*make sense of their circumstances and work out [...] what is, on the whole, the better thing to do*” (Hunter, 1996: p308). This emphasis on teasing out the uniqueness of each moral situation through a focus on the concrete particulars of individual cases contrasts sharply with the instrumental view that principles can be applied universally and in a logico-deductive way to reach a rational decision about what is right. Key elements of ‘sense-making’, according to Gkeredakis and colleagues (drawing on Weick (2005)) are:

“... language mediation, identity, plausibility of meaning, embodied mental structures, coordination, and enactments in situations, which are ‘talked about’ rather than analysed rationally. From a sense making perspective, story making and telling become more important than logical analysis. Narratives become the basis for any meaningful action....

Rationalisation (albeit of a different kind) is about the enacted narrativisation of 'what is going on'. (Gkeredakis et al, 2011: p5)

The problem with modern life, according to Sayer, is that *“reasonableness or practical reason have tended to become undervalued, indeed to be seen as beyond or antithetical to rationality...”* (Sayer, 2011: p66). In other words, instrumental and institutional views of rationality have become so pervasive and dominant that other conceptualisations have become marginalised and deemed outside the realms of reason (King, 2000). This viewpoint, concerning the dominance of certain ways of seeing rationality to the exclusion of others, is fundamental to the argument I develop in this thesis.

The merits of practical rationality identified by its advocates, can equally be seen as limitations. Its embodied, tacit and intuitive nature means that it is not readily apparent (Sayer, 2011). Unlike other forms of rationality discussed in this chapter, it is not easy to identify explicit, universal examples, in the way that QALYs exemplify an instrumental rationality, and the accountability for reasonableness framework an institutional rationality. The paradox of practical rationality is that while it is ever present, something we all engage in as sentient beings, (Sayer (2011: p86) suggests that *“practical reason or phronesis is indispensable; we cannot be competent actors, interacting successfully with our social, material world without it”*), it is hard to capture and label as such. The examples of practical reasoning I explore in later chapters of this thesis (Chapters 6, 7, 8 and 9) are often subtle instances that emerged through slow, in-depth analysis of concrete particulars. Practical rationality emerges as a messy, intuitive, emotional,

and indeterminate process (Wood et al, 1998), attributes at odds with the dominant conceptualisations of rationality so deeply rooted in Western ways of thought (Flyvbjerg, 2001).

3.5 What we know about the rationality of rationing practices

Having reviewed theoretical approaches to conceptualising rationality, I now examine relevant empirical literature. What can we learn from empirical studies of priority setting and rationing about how these different conceptualisations of rationality play out in practice? Compared with the extensive body of literature discussing how rationing *should* or *might* take place (Ashcroft, 2006; Austin, 2007; Austin, 2008; Callahan, 2011; Clark & Weale, 2012; Coast, 1997; Daniels & Sabin, 1997; Doyal, 1997; Foster, 2007; Ham & Coulter, 2001; Holm, 1998; Hunter, 1997; Klein, 2010; Maynard, 1996; Mechanic, 1997; Mitton et al, 2009; Oswald & Cox, 2011; Rumbold et al, 2012; Williams, 2015), the empirical research literature exploring what happens in practice is significantly smaller (Williams et al, 2011). In this section I summarise key findings from studies of local decision-making panels under three interrelated themes: [1] the enduring appeal and influence of an instrumental rationality, and the divergence between the theory of rationalist imperatives and what happens in practice; [2] stakeholder views about the accountability for reasonableness conditions; and [3] the situated, contingent nature of rationality when explored through a practice-oriented lens. The findings are drawn primarily from studies concerned with the work of rationing panels at the local level in

the NHS in England and Wales, and also from Canada and Australia, where comparable rationing structures exist.

3.5.1 Studies highlighting the enduring appeal of instrumental rationality and the theory-practice gap

Robinson et al undertook a national survey of the priority setting activities of PCTs in England in 2011 together with an in-depth case study of priority setting in four PCTs (Robinson et al, 2011b). The national picture obtained from the survey of local commissioners was of widespread use of scientific and economic evidence and decision tools to aid decision-making, such as epidemiological needs assessment data, predictive modelling, multi-criteria scorecards, cost-effectiveness and cost-benefit analyses, and programme budgeting and marginal analysis (PBMA). However, observational and interview data from their case study revealed *“tensions between what ought to be done according to the rationalist imperative and what could be done in practice”* (Robinson et al, 2012: p9). In one case study area, panel members were attempting to use a new decision tool comprising 16 questions relating to factors such as evidence of clinical and cost effectiveness, numbers of patients who would benefit, evidence of clinical engagement, and associated risks of not funding an intervention. In practice, panel members *“demonstrated dissonance with the rationalism of the decision tool”*, with some suggesting it was unfit for purpose, and indicating that they used ‘gut instinct’ or their own experience to help them form a decision. In the same study Robinson and colleagues found that although the panel’s policy was to use an agreed ethical framework to support decision-making, it was little

used in practice in meetings, although the researchers reported some limited use of the framework *“to legitimize particularly contentious decisions”* (Robinson et al, 2011b: p82).

Other researchers have similarly observed how the use of decision tools may serve a legitimising function. For example, in a 2003 survey of how NHS health authorities approach priority setting and resource allocation, Greener and Powell found that their respondents frequently described their activity in technical terms. However, the researchers noted how *“every time [their respondents] utilized the discourse of economics and finance, they felt the need to put the relevant terms in quotation marks, as if to distance themselves from the terms”* (Greener & Powell, 2003: p42). Thus, Greener and Powell suggest, decision-makers are:

“[using] the language of management, finance and economics to present a rational picture of their decision-making processes, making sure that they correspond with national agendas in health care. They are trying to demonstrate they are ‘talking the talk’ or using the prevailing acceptable discourse.” (Greener & Powell, 2003: p43)

The apparent disjuncture between what policies and stakeholders say and how rationing unfolds in practice and the dissonance between different rationalities is a theme I explore in later chapters of this thesis.

A number of studies have highlighted the limitations of instrumental approaches to decision-making, leading some researchers to conclude that *“simple solutions, such as cost-effectiveness analysis, are theoretically flawed and impossible to implement in practice”* (Martin et al, 2001: p1680).

Williams and Bryan found that it was rare for cost-effectiveness analyses to

inform technology coverage decisions of NHS local formulary committees (Williams & Bryan, 2007), and Jenkins and Barber similarly report from an ethnographic study of decision-making in a drugs and therapeutics committee that cost-effectiveness data were either inadequate or insufficient for a locally implementable decision (Jenkins & Barber, 2004). A systematic review of the use of economic evaluation in local decision-making found that decision-makers made limited use of technical data on cost-effectiveness in practice, identifying a number of institutional, political, cultural and methodological barriers to use (Eddama & Coast, 2008).

Smith and colleagues (2014) note that many studies of priority setting focus on identifying obstacles or barriers to use of the particular model or approach under scrutiny, with suggestions for overcoming these barriers (Eddama & Coast, 2008; Merlo et al, 2015; Peacock et al, 2009; Snape et al, 2014). Yet, as they argue, the concept of barriers is not a neutral one; rather:

“Its normative appeal directs us to think of potentially valid oppositional claims as blockages that must be overcome, rather than as situationally appropriate strategies deployed by actors concerned with conserving existing organizational forms that they deeply value.” (Smith et al, 2014: p336)

This observation points to yet another lesson that can be drawn from studies of rationing panels’ practices: in the process of reporting on how decision-makers use evidence and other tools in practice, researchers also convey their own normative assumptions about the rationality of rationing practices. So for example, when Robinson and colleagues report that factors such as political processes and the exigencies of the NHS financial planning context

come into the decision-making process, these are presented as “*dimensions which might be seen to dilute the degree of rationality*” (Robinson et al, 2011b: p45), rather than indicative of a different conceptualisation of rationality. In other words, it appears that frequently in researchers’ reporting of their findings, their own benchmark of rationality is an instrumental one.

A few researchers adopt a noticeably different stance, interpreting their findings not within a deficit framework, but as illustrative of the contingent and situated nature of practice. Jenkins and Barber, for example, describe how in practice decision-makers do not adhere to the hierarchy of evidence promoted by the evidence-based medicine movement, rather they draw pragmatically on multiple sources or a ‘mixed economy’ of evidence, including ‘softer’ forms of evidence, and take account of a range of local knowledge or ‘colloquial evidence’. In their study of NHS drug and therapeutic committees, they identify factors such as the decisions of other committees, patient demand, clinician excitement, and personality of the applicant, all as relevant factors for consideration, alongside other types of evidence. They conclude that:

“Together as a committee [members] succeed, often in the face of very limited scientific evidence, in making rational decisions on whether to accept or reject drug application in a way that is accountable to both ‘good’ EBM and the local contingencies that are the everyday reality of practical healthcare. This is a highly skilled and sensitive practice with various negotiated agreements to be achieved. In doing so they are sensitive to both the scientific rationality and the local rationality of the workplace.” (Jenkins & Barber, 2004: p1765)

3.5.2 Studies of stakeholder views about accountability for reasonableness conditions

A number of studies have explored stakeholder views about what constitutes fair and legitimate processes of rationing panels. In a qualitative study of priority setting committees in Ontario, Singer and colleagues report strong support for Daniels and Sabin's accountability for reasonableness model of fair processes. Decision-makers identified factors such as representation of multiple perspectives, opportunities for everyone to express views, transparency, and an explicit appeals process as key elements of fair decision-making (Singer et al, 2000). Sibbald and colleagues synthesised findings from three separate qualitative studies (interview and focus group studies in Canada and a Delphi study including scholars and decision-makers from five countries) of stakeholder views about the conditions that make for successful priority setting (Sibbald et al, 2009). From their findings they propose a conceptual framework for successful priority setting, comprising five 'process' elements (stakeholder engagement, including members of the public and patients; transparency of process; good information management; consideration of values and context so that priority setting decisions are based on reasons that are grounded in clear value choices; a robust revision or appeal mechanism), and five 'outcome' elements (improved stakeholder understanding; shifted priorities and/or reallocated resources; improved decision-making quality defined as: *"appropriate use of available evidence, consistency of reasoning, institutionalization of the priority setting process, alignment with the goals of*

the process and compliance with the prescribed process"; stakeholder acceptance and satisfaction, and positive externalities such as media coverage, peer emulation or changes in policy or practice) (Sibbald et al, 2009: p7). Many of the elements identified in this study echo the accountability for reasonableness model, but the researchers suggest their framework is distinguishable by its focus on outcomes as well as process (although arguably some of what they define as outcome elements are more akin to process).

Hasman and colleagues have attempted to test empirically the relevance condition of Daniels and Sabin's accountability for reasonableness framework, undertaking interviews with experienced local decision-makers to explore the reasons they identify as relevant in making allocation decisions (Hasman et al, 2008). On several of the 14 main reasons identified as relevant to drug priority setting there was general agreement (in particular cost effectiveness, clinical effectiveness, equality and gross cost), but with other identified reasons there was substantial disagreement about whether and why a particular reason was relevant. For example, some respondents thought the absence of alternative treatment for a condition meant an innovative drug treatment should be given priority, whereas others considered this to be an irrational position. This research, whilst helpful in providing an empirical perspective on the relevance condition of the accountability for reasonableness framework, can be criticised for the way in which it assumes that, in the context of committee decision-making, reasons are static, 'pre-packaged' individual positions, rather than contingent,

situated ideas that develop dynamically through deliberation with others (Davies et al, 2006).

As Daniels and Sabin's framework has suggested, an important way of making decisions more accountable and transparent is the inclusion of lay people in the decision-making process. A number of studies have focused on eliciting views about public involvement in the rationing decisions of local panels. Interview and focus group research with members of the public (Coast et al, 2002; Litva et al, 2002) and with professionals and other staff who sit on health committees (Chisholm, A et al, 2009; Nathan et al, 2011) have found that whilst there is widespread support for the *theory* of lay involvement, there is a striking lack of clarity about the detail of the lay role on committees. For example, Nathan et al (2011) found considerable support among staff members of health committees for the idea of the public having an important role to play, but this was not matched by the reality they observed, with little consensus about what the role of community representatives should be. Litva et al (2002) found that citizens sought to be involved in resource allocation decisions at a system level, setting priorities between population groups, but were reluctant to be involved in rationing decisions about individual patients. Even at the system level, respondents wanted 'accountable consultation' (defined as "*contribution to decisions by expressing views, a guarantee that this contribution will be heard, no responsibility for the decision but an explanation of the rationale for the decision ultimately made*" (Litva et al, 2002: p1834)) rather than sharing responsibility for specific decisions. Whilst these studies give some

indication of stakeholders' views about public involvement, there exists a notable lack of evidence about what lay people contribute in practice: a scoping review of public participation in health care priority setting reported no observational studies of practice (Mitton et al, 2009). In Chapter 9 I explore what my data revealed about lay involvement in rationing deliberations.

3.5.3 *Studies of the situated, contingent nature of rationality*

The final theme to emerge from this review of empirical literature, and of particular pertinence to the findings from my research, is the situated, contingent nature of rationality when explored through a practice-oriented lens. Gkeredakis and colleagues reject the notion of rationality as a normative principle and argue instead that rationality is a "*practical matter*" that emerges "*through a repertoire of socio-material performances*" (Gkeredakis et al, 2011: p7). From their in-depth observational study of three individual funding request panels they demonstrate how rationality is achieved by panel members collectively performing certain procedural requirements (such as documenting communication, circulating evidence, formally reporting reasons for a decision), sense-making activities such as categorising, authenticating and narrativising, and deliberating the merits of funding through articulating, sharing and debating arguments. Gkeredakis and colleagues argue that the pursuit of rationality is "*inherently connected to a quest for public legitimacy of decisions*" (Gkeredakis et al, 2011: p24), and suggest that actors mobilise universal, 'higher-order' NHS principles, such as comprehensiveness, and equity, to craft rational decisions to a

public audience. Their conclusion that our understanding of rationality “*may be significantly improved if we address and examine the pursuit and performance of rational judgement as a situated empirical phenomenon rather than as a normative ideal*” (Gkeredakis et al, 2011: p16) has been an important influence on my work.

Hughes and Doheny’s in-depth observational and interview study of IFR panels in Wales (where they are called individual patient commissioning (IPC) panels) also explored how rationality is discursively constructed in practice. Theirs is one of the few studies that has employed linguistic analytic methods to understand the work of rationing panels, in order to ground interactional study “*more firmly in detailed sequences of spoken interaction*” (Hughes & Doheny, 2011: p1462). As with Jenkins and Barber’s work quoted above, Hughes and Doheny observed divergent modes of reasoning within panel discussions. They contrast a “*technical, statistics-based mode of reasoning*” with a “*case and judgement-based approach*”, arguing that a productive tension is discernible between the two approaches:

“... variations in IPC funding decisions arise in large part because panels employ case-based forms of reasoning that stand in tension with the standardised recommendations that are built into NICE cost-benefit calculations. IPC panel discussions are affected by the cultures and discourses of health care work, and are discursively organised to leave a space for case-based deliberations, while also recognizing an institutional framework which encompasses NICE and national guidance.” (Hughes & Doheny, 2011: p1468)

These practice-oriented studies demonstrate the value of close-up, detailed empirical examination of the social construction and enactment of the rationality of rationing.

3.6 Summary and conclusion

In this chapter I have argued that there is no straightforward agreement on what it means for rationing decisions to be made rationally. Rationality is a contested term, meaning different things to different people. For some, the benchmark of rationality is scientific evidence and method, with clear-cut rules and principles for decision-making. For others, decisions become rational if they are taken in accordance with procedural requirements. And for others, rationality is something akin to practical reason, a moral-interpretive activity that facilitates wise judgement. This latter view is both an embedded and embodied conceptualisation of rationality (Townley, 2008), in which different types of knowledge, including tacit knowledge, emotion and values, enable people to act reasonably. It is a view that I shall argue in subsequent chapters has considerable potential for helping us to understand and rationalise the work of rationing panels 'as is', rather than as instrumental and institutional rationalists believe it should be. However, my findings will also demonstrate an ever-present tension between the observed practical reasoning of rationing panels and the hegemony of conventional rationalism in health care.

4 Methodology and methods

4.1 Introduction

The empirical studies reviewed in the previous chapter highlight the significant amount we now know about the work of local rationing panels. Nevertheless, a paradox of existing research is that while it describes the wide range of influences on decision-making, and the dynamic and complex nature of rationing health care, in the main, apart from the notable exceptions identified in Section 3.4.3 (Gkeredakis et al, 2011; Hughes & Doheny, 2011), the methodologies drawn upon fail to provide analytic frameworks to get inside what Light and Hughes have called “*the black box*” of rationing practices (Light & Hughes, 2001: p559), in other words, the day-to-day micro-level practices of deliberation and decision-making. In this chapter I suggest a framework of ideas and research methods that draw on the emerging fields of interpretive policy analysis and linguistic ethnography. This framework has allowed me to explore close up the role of language, deliberation, and meaning making in the enactment of rationing, and how micro-level practices are shaped by and feed into broader historical, social and institutional practices. Through my engagement with these ideas and methods I have developed my own particular approach to rhetorical policy analysis, which I demonstrate in subsequent chapters of this thesis.

I begin by documenting my methodological journey and orientation as an interpretivist researcher. I then present a reflective account of the methods of data collection and analysis I used in my research. A challenge of any

interpretive account of methodology and methods is the inescapable tension between presenting a convincing report of the research process, grounded in the normal conventions of scientific reporting (an unambiguous and neatly linear account), and conveying the emergent, iterative and not so tidy reality of research practice (Golden-Biddle & Locke, 1993). In this chapter I aim to give a clear, well-structured account without over-sanitising a research process that has involved considerable back and forth between different approaches and analytic lenses, some faltering about how best to make sense of at times seemingly un-organisable data, a blurring between conventional notions of method and analysis, and periods of considerable uncertainty about the direction and coherence of emerging arguments.

4.2 My methodological journey

When I began my research into the rationing of health care I had been working as a qualitative health policy researcher for over 25 years. I had gained considerable experience of undertaking research and evaluation projects about various aspects of health policy and practice, utilising interviews, focus groups and occasionally some observation. However, as is the norm in the medical school environment in which I have predominantly worked, these qualitative methods were usually underpinned by implicitly neo-positivist methodological presuppositions. By this I mean that the research I was involved in assumed the existence of a stable reality 'out there' to be studied (Green & Thorogood, 2004), and that language could be treated as a transparent medium, a lens through which I could simply examine and understand the real nature of events and people's views and

experiences, and extract 'themes' from my data (Wetherell et al, 2001). Moreover, my exploration of meaning was limited to identifying and documenting respondents' intentional, stated meanings (Wagenaar, 2011).

Likewise, my disciplinary background in social administration and policy, an applied academic field rooted in a predominantly positivist and rationalist paradigm of policy analysis, had given me little exposure to the interpretative tradition in the social sciences. However, the beginning of the period of research on which this thesis is based marked a significant turn in my methodological thinking. In collaboration with my colleague (and second supervisor) Sara Shaw, I came across the work of scholars such as Frank Fischer and John Forester (1993), Carol Bacchi (2009), Dvora Yanow (1996; 2000), Deborah Stone (1997), Maarten Hajer and Henk Wagenaar (2003), writers who opened my eyes to the field of interpretive policy analysis. Stone's study of narrative stories, metaphors, and ambiguity in policy analysis, Hajer and Wagenaar's conceptualisation of policy analysis as deliberative, and Fischer and Forester's focus on argumentation, for example, offered exciting new ways of thinking about the policy issues I was exploring and beginning to collect data on.

4.2.1 Interpretive policy analysis

Interpretive policy analysis is a broad field encompassing many different approaches (e.g. analysis of discourse coalitions, policy frames, rhetoric and narrative storytelling), with various theoretical underpinnings (e.g. hermeneutics, phenomenology, critical theory), and dispersed among many

disciplinary areas (e.g. public policy and political science, social policy, sociology) (Glynos et al, 2009; Wagenaar, 2011). Notwithstanding the diversity of the field, it is possible to identify key ideas common across these different approaches, which have informed my research.

The hallmark of interpretive policy analysis is its analytic focus on meaning-making. As Yanow suggests, interpretive policy analysis “asks not only *what* a policy means – a context-specific question about a specific policy – but also *how* policies mean – questions about the processes by which meanings are communicated” (Yanow, 2015: p417). Thus interpretive policy analysts are interested in exploring ‘architectures of meaning’ – how multiplicities of meanings are conveyed through language and other human artefacts, such as objects (e.g. policy documents, styles of dress) and acts (e.g. regularly repeated patterns of activity, commonly referred to as ‘rituals’, such as categorising) (Yanow, 2000). In Chapter 8, for example, I explore the way in which meaning is created dialogically in rationing deliberations about breast surgery through the particular ‘evaluative accent’ (Maybin, 2001) we give to certain words such as ‘cosmetic’.

From this perspective, a study of rationing demands attention to argumentation, since policy deliberations become fundamentally a struggle over ideas, expressed through arguments about different ways of seeing the social world (Stone, 1997). Fischer and Forester convey this viewpoint in describing how:

“policy-making is a constant discursive struggle over the criteria of social classification, the boundaries of problem categories, the intersubjective

interpretation of common experiences, the conceptual framing of problems, and the definitions of ideas that guide the ways people create the shared meanings which motivate them to act” (Forester & Fischer, 1993: p2).

Thus a significant strand of the interpretive turn in policy analysis has been the ‘argumentative turn’ (Fischer & Gottweis, 2012; Forester & Fischer, 1993). A conceptualisation of policymaking as argument brought important insights to my research thinking. First, it encouraged me to consider the policy process as a discursive, deliberative process, prompting forays into the related field of deliberative theory (Barnes et al, 2004; Gutmann & Thompson, 2002; Hajer & Wagenaar, 2003; Dryzek, 2000). I came to consider the priorities forum and individual funding request panels I studied (see Section 2.5) not simply as committees engaged in what might be called technocratic speech events (working through a formal agenda with interaction through a chair) (Cameron, 2001), but equally as deliberative spaces in which judgements and decisions are constructed through collective, interactive discourse.

Second, an argumentative approach to policy analysis shifted my analytic gaze from thinking about rationing in terms of finding solutions to problems (how to make rationing more evidence-based, for example) to a focus on problem *construction* (Edelman, 1985; Stone, 1997). Within an argumentative frame, decision-makers are not simply responding to the problem of resource scarcity that exists ‘out there’, but are discursively constructing and actively framing problems and thereby shaping what can be thought about and acted on (Light & Hughes, 2001). For example, in later

chapters of this thesis I explore the linguistic work that constructs the (un)affordability of health care as rational (Chapter 6), and illustrate how individual funding requests for breast surgery are problematised in a way that shapes decisions about who is deserving of NHS funding and who is not (Chapter 8). Alongside the work of those who define themselves as argumentative policy analysts, related work by Carol Bacchi (2000), considering ‘policy-as-discourse’, and scholars in the Bahktinian tradition such as Hugh Mehan (1996), writing about ‘the politics of representation’ (see Chapter 5), constitute a family of ideas concerned with the discursive construction of social problems, and in particular ideological struggles over different ways of representing the world.

Third, an argumentative approach has prompted me to consider the centrality of an audience. Arguments are constructed for particular audiences and argumentative policy analysis involves studying how and why particular arguments are framed for particular audiences and the meanings an argument holds for its audience (Billig, 1987). As I suggest in Chapter 5, this focus has encouraged me to explore both the micro-level interactions between speaker(s) and listener(s) within the immediate context of the policymaking table, and at the same time, the wider ‘argumentative context’ (see Section 5.2) (Billig, 2001; Perelman & Olbrechts-Tyteca, 1971).

Fourth, an argumentative view is “*a deeply practical one*” (Forester & Fischer, 1993: p6), recognising that policy and decision making is “*realised in the daily work practices of communities of individuals*” (Maybin, 2013: p3).

A focus on practice orientated my research gaze on to what practitioners actually do (Freeman et al, 2011). In this sense it provided an antidote to the emphasis of much mainstream policy research, with its concern for policymaking as 'ought to be', for example, addressing questions such as 'what are the barriers to getting policymakers to behave more evidentially'?

Freeman et al describe how a practical perspective:

"... counters top-down, macro explanations of policy, which typically appeal to grand narratives of change, locking policy makers into predictable path dependencies or overarching economic, political and social constraints. It renews a focus on the bottom-up translations of policy initiatives by local actors, providing alternative ways of explaining local diversity or differential outcomes." (Freeman et al, 2011: p130)

Policy arguments can thus be considered "*practical productions*" (Fischer & Gottweis, 2012: p3) produced at the micro-level of collective interaction. But, importantly, micro-level practices are shaped by and feed into broader historical, social and institutional practices. These ideas link philosophically with those of practice theorists (Feldman & Orlikowski, 2011; Nicolini, 2012), as Davies et al explain:

"Authors in this tradition define social practices as coordinated activities and performances which bring new situations into being but are constrained by, in interaction with, and sometimes in tension with, surrounding practices and with what has gone before" (Davies et al, 2006: p55).

This methodological frame encouraged me to engage in a recursive movement of 'zooming in' and 'zooming out' on my data, and between data and theory (Nicolini, 2009). For example, in studying how the affordability of individual health care treatments was accomplished in practice by local commissioning groups I both 'zoomed in' on the micro-detail of interactional

talk and ‘zoomed out’ to consider this talk within the policy and legal contexts that both shaped and were shaped by local situated practices (see Chapter 6).

An important criticism of argumentative policy analysis is its predominant focus on the *analytic*, or ‘logos’, element of communicative practices, and consequent neglect of other elements of persuasive discourse. Gottweis, for example, notes that:

“neither ‘rationalistic’ nor ‘post-rationalistic’ approaches in policy studies have paid much attention to a number of phenomena that, no doubt, play crucial roles in many policy-making processes: phenomena such as trust, credibility, virtue, emotions, feelings, and passions” (Gottweis, 2007: p237).

Gottweis notes the substantial influence of Habermas’ work on the field of argumentative policy analysis. For Habermas, rational deliberation, or what he referred to as the ‘ideal speech situation’, is characterised by sincerity, respect and the absence of coercive power (Habermas, 1987). It is a consensual form of talk and interaction, oriented to understanding and agreement. From this position, deliberative democracy requires that debate in participatory forums such as rationing panels be free from strategising and manipulation so that *“the only power remaining is that of the better argument”* (Dryzek, 1993: p228). There are clear parallels here between Habermas’ ideal form of communication and Daniels and Sabin’s ‘accountability for reasonableness’ conditions that I discussed in Chapter 3. In Chapter 9 I critically explore Habermas’ ideas in further detail.

A number of critical deliberative theorists argue that this privileging of reasoned argument is too narrow and restrictive a view of deliberation, and too constraining on what constitutes appropriate conduct and ways of speaking in policy debates. Young suggests that the privileging of “*neutral, universal and dispassionate expression*” has “*exclusionary implications*” (Young, 2000: p63), and argues for recognising and valuing other styles of speech in deliberation such as greeting, rhetoric and storytelling, and the role of emotional expression (see Chapter 5). Like Nussbaum and other scholars referred to in Chapter 3, Young argues that emotional engagement is a critical component of human interaction which cannot and should not be written out of conceptualisations of rational debate (Nussbaum, 2001; Young, 2000). Deborah Stone, in a keynote address to an International Interpretive Policy Analysis conference in 2013, argued that, despite paying lip service to the relevance of emotions, interpretive policy analysts have yet to take them seriously in their work. The challenge, she suggests, is for researchers to “*push beyond interpreting emotions as something purely personal and psychological to something policy relevant*” (Stone, 2013: p12).

The critiques by these scholars, together with my fieldwork observations of the messiness of real life argumentation, led me (with the help of colleagues from the Department of Computer Science at UCL who introduced me to work by Majone (1989) and Perelman and Olbrechts-Tyteca (1971)) to explore the application of rhetorical theory to the policy field. The value of rhetorical analysis is that it takes us beyond the “*coolly and purely argumentative*” aspects of deliberation (Young, 2000: p64), providing a lens

through which it becomes possible to explore practical reasoning, including emotional engagement, in deliberations about the rationing of health care. In Chapter 5 I expand upon these ideas, exploring key sensitising concepts from rhetorical theory and the work of Bakhtinian scholars, setting the scene for the development of my rhetorical policy analysis in subsequent chapters.

4.2.2 *Linguistic ethnography*

When I began the research for this thesis I had reached a point in my thinking where I was convinced of the critical role of language in shaping the social worlds I was studying, yet I had few skills or experience in linguistic analysis. Whilst an interpretive approach to policy analysis situates language at its core, I found texts in this tradition often frustratingly thin on the detail of *how* to analyse language close up. Reading accounts of interpretive policy analysis studies I was frequently surprised by the limited focus on what constitutes data and a lack of attention to making analytic claims accountable to evidence (see for example (Hawkins & Holden, 2013)).

In 2005 I undertook an Open University postgraduate course on discourse analysis, and in 2007 an intensive course in linguistic ethnography (Key Concepts and Methods in Ethnography, Language and Communication, organised through an ESRC funded Researcher Development Initiative). Both courses were helpful in introducing me to theoretical, philosophical and methodological debates around discourse analysis. However, the latter in particular turned out to be another important turning point for me as a

researcher, providing immersion in micro data analysis sessions, and allowing me to learn, through practical engagement, what it means to undertake an analysis based on the study of language in use.

As a methodology, linguistic ethnography shares many of the characteristics of interpretive policy analysis. Both are emerging fields, and as with interpretive policy analysis, linguistic ethnography is an umbrella term rather than a clearly defined approach, encompassing a broad range of disciplinary perspectives and backgrounds (for example, interactional sociolinguistics, anthropology, law, education, health). The emphasis of both is on combining analysis of the detail of situated interactions with the wider social, political and historical context within which interactions occur, and on seeing social and linguistic features as being in a dynamic, co-constructive relationship to each other (Blommaert, 2007; Copland et al, 2015; Rampton et al, 2004; Snell et al 2015).

The additional insights that linguistic ethnography has brought to my work are to do with its strong focus on anchoring analysis in the detail of the data, and thus its commitment to making analytic claims accountable to evidence (Rampton et al, 2015). For a linguistic ethnographer, a typical data analysis session begins by studying a transcript of an extract of interactional data and asking relatively broad brush questions to get an initial orientation of what is going on: what kinds of event/activity type participants are engaged in, what roles are being activated, and so on. The next stage involves the linguistic ethnographer working slowly through an extract, exploring turn-by-

turn, moment-by-moment, what ‘work’ particular words and language are doing, and following the slow, unfolding of communication. As Shaw et al note:

“The slow and intensive analysis of language and communication sheds light on small (but consequential) aspects of social practice, taking the ethnography into smaller and more focused spaces and drawing analytic attention to fine detail” (Shaw et al, 2015: p8).

It is in this sense that linguistic ethnographers describe how linguistic analysis is able to ‘tie down’ ethnographic insights, resulting in the exploration of *“big social issues through careful examination of small communicative behaviours on the micro-level”* (LeBaron, 2008: p763). Equally, it is suggested that ethnography ‘opens up’ linguistic analysis (Snell et al 2015).

The methodology of linguistic ethnography, and most importantly becoming part of an emerging community of linguistic ethnographic researchers, was enormously helpful in developing my analytic skills as an interpretivist researcher. As Rampton suggests, my general sense of *“what communication involves [has been] irreversibly changed”*, with *“no going back to the shallow interpretation of flat transcripts that our normal reading habits lull us into”* (Rampton, 2007). In the findings chapters of this thesis (see Chapters 6, 7, 8 and 9) I present in-depth analyses of data extracts that illustrate how a linguistic ethnographic perspective has encouraged me to persistently question what is going on in any interactional encounter, and to surface the moment-by-moment struggles over meaning within discourse.

However, bringing linguistic ethnography to interpretive policy analysis has also exposed a number of tensions and challenges. In a chapter exploring the influence of linguistic ethnography on our work as health policy analysts, Sara Shaw and I note how many linguistic ethnography studies are able to demonstrate the key analytic point in a small strip of talk or a few exchanges (for example between a classroom teacher and pupil or doctor and patient), but how analysis of health policy arguments and narratives often stretches over multiple and extended exchanges and/or documents (transcripts of several hours of deliberation, policy documents, emails, and so on) and cannot easily be captured in a specific segment of data (Shaw & Russell, 2015). Whilst this does not militate against close analysis, it makes it difficult sometimes to present evidence of analytic claims in the conventional way. Nevertheless, the dialogue between linguistic ethnography and interpretive policy analysis has been helpful in simultaneously encouraging me to undertake close analysis of policy practices (a less usual context for linguistic ethnography) and pushing me to evidence my analysis (in ways not traditionally undertaken within interpretive policy analysis).

4.3 Methods

My DPhil grew out of two interlinked studies of local rationing practices, conducted between 2005 and 2012. I undertook the first study between 2005 and 2008 as part of a large three year interdisciplinary programme of research at UCL on 'Evidence, Inference and Enquiry: Towards an Integrated Science of Evidence', funded by the Leverhulme Trust and the Economics and Social Research Council (ESRC) (Dawid et al 2011). The

Programme incorporated and coordinated a collection of research projects from a number of disciplines, including education, economics, forensic science, history, law, statistics, and philosophy of science. Trish Greenhalgh (my primary supervisor) and I submitted a successful application to this Programme and received a grant to undertake a small-scale qualitative study of the introduction, interpretation, negotiation and application of research evidence in health care policy decisions, focused on a case study of one local priorities forum (Russell & Greenhalgh, 2009; Russell & Greenhalgh, 2010). Over the period of this study I became increasingly interested in the work of individual funding request panels, and in 2008 successfully applied for a three year grant from the National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) to study this particular aspect of local rationing practices.

An important question for me to address is the relationship between the work produced by these research projects and the work presented in this thesis. I did not start the projects with the intention of developing the research I was undertaking into a DPhil. However, towards the end of the study period a number of factors converged that resulted in me deciding to register as a doctoral student. The factors influencing my decision were firstly a keen sense that this was an area of research that fascinated me and was worthy of more in-depth study than the constraints of short-term contract research allowed. As the projects progressed I became increasingly aware of the potential for further analysis of the data I had collected beyond the specific foci of the funded research protocols. I also became increasingly

interested in theoretical ideas about rationality and wanted an opportunity to explore this rich field of inquiry. Secondly, as indicated in Section 4.2 above, over the period of the funded studies I discovered new methodological approaches to qualitative research, and was keen to find an intellectual space that would enable me to learn more and reflect upon these approaches. Thirdly, in 2012 I took the decision to take early retirement from full-time academic work and saw a doctorate as a stimulating new project for me to embark upon during a period of significant transition in my life. Lastly, I was fortunate to have the full support of colleagues who I have worked with for many years, who helped me develop many of the intellectual ideas in this thesis, and who agreed to be my supervisors.

To give some detail of the division of labour on the projects from which this DPhil has emerged: I led on developing the ideas for both projects, supported by Trish Greenhalgh (TG) as the principal investigator; as the lead researcher I undertook most of the fieldwork (TG accompanied me on some initial 'access' visits to sites and we jointly engaged in some observational visits to enrich our ethnographic data), and I took the lead on data analysis. Most publications were jointly authored by TG and me (Russell & Greenhalgh, 2009; Russell & Greenhalgh, 2010; Russell & Greenhalgh, 2011; Russell & Greenhalgh, 2012; Russell & Greenhalgh, 2013), one publication included two members of one of the project advisory groups as co-authors (Russell et al, 2011), another included members of a NICE steering group we participated in (Russell et al, 2013), and two included academic colleagues with whom we had engaged in collaborative

data analysis sessions (Russell et al, 2008; Russell et al, 2014). I was the lead and corresponding author on all these publications. In this chapter I mostly use the singular pronoun when describing the research activity I engaged in; however, where TG was also involved as principal investigator I indicate this by use of the term 'we' rather than 'I'. Appendix 1 contains a contribution statement from TG as my primary supervisor.

The above description serves to highlight that the trajectory of my DPhil journey was not of the typical 'register for DPhil - define topic of interest – identify research question – undertake fieldwork – analyse – write-up' type. Rather, I chose to prepare a thesis that attempts to develop an original contribution to rhetorical policy analysis by revisiting and developing the analysis of data I collected for two completed research projects, and expand upon findings and arguments from a number of published journal papers, chapters and project reports (see Appendix 2). The rigour of the analysis presented in this thesis has undoubtedly benefited from the peer review of these publications.

4.3.1 Site selection

The aim of the first study, as part of the UCL Evidence Programme (introduced above), was to explore how policymakers talk about and reason with evidence by studying the micro-processes of deliberation, and specifically the meaning-making practices, of a group of people charged with prioritising health care within a local NHS commissioning organisation (Dawid et al 2011). We approached the local primary care trust (PCT) (Site

A) with which TG had an established academic link as honorary consultant in primary care to discuss our research ideas and identify opportunities for ethnographic study. One objective of the research, as conceptualised in the funded proposal, was to work with those we were researching to engage in 'joint problematisation' of emerging issues (Roberts & Sarangi, 2004), and explore how research findings might engender what Rein and Schon refer to as 'frame-reflective awareness' (Rein & Schon, 1993). In other words, we hoped that through on-going dialogue and specific feedback and training workshops we might make visible the role of language, argument and discourse in policy discussions, give policymakers new insights into their work, and increase awareness of the conditions shaping their actions and choices. This dimension of our research guided us to select a site in which we already had an established working relationship, and the keen support of senior managers to engage with research as an opportunity for organisational learning (although initially at least they saw the learning opportunity more in terms of 'how can we make our decisions more evidence-based' than concerned with frame-reflective awareness). Thus from the outset my study design incorporated aspects of an action research approach, with its focus on reflexivity and professional development (Taylor & White, 2000).

To a researcher steeped in the conventions of a positivist research paradigm, in which the tenets of representativeness and generalisability are paramount, a research design focused on a single site for data collection might be considered far from ideal. However, from an interpretivist case

study perspective the aim of research is not to produce generalisable findings or 'typical' accounts, but rather to explore the 'particularities' of social practices (Green & Thorogood, 2004; Stake, 1995). That said, the epistemological position of the interpretive researcher is that it *is* possible to gain a general understanding from studying the complexities and nuances of the particular. Erickson, for example, suggests that: "*One discovers universals as manifested concretely and specifically, not in abstraction and generality*" (Erickson, 1990: p130). For me, this point is perhaps best illustrated by a description from May of the impact on his perception of trees in general from viewing a particular painting of trees by the artist Cezanne:

"Primarily it is a vision that is now not tree, but Tree; the concrete tree Cezanne looked at is formed into the essence of tree... I can say without exaggeration that I never really saw a tree until I had seen and absorbed Cezanne's paintings of them". (May, 1994: pp77-8)

Simons argues that, as with artists, interpretivist researchers can potentially discover something of universal significance by capturing the essence of a single case through intensive exploration (Simons, 2015). In line with this thinking, my approach was to study in-depth the micro-processes of deliberation of a particular rationing panel to better understand and theorise the rationality of rationing practices.

After preliminary meetings with members of the PCT Health Improvement team it was agreed in principle for me to attend regular meetings of the Priorities Forum and access to Site A was secured.

As described above, the IFR study developed directly out of the emerging findings of the first study. In Site A it was apparent that an increasing amount of time was devoted to discussing IFRs, and we observed how this aspect of rationing was identified as particularly troublesome. In collaboration with senior managers and patient representatives from Site A, we submitted a proposal to the NIHR RfPB programme to explore the PCT's IFR deliberations. With this study, aware that the methodological orientation of NIHR would likely favour breadth over depth, we proposed to study IFR deliberations in a sample of six PCTs. Segar et al note that it is not uncommon for case study researchers, faced with an audience of funders and reviewers unfamiliar with 'the science of the singular', to design their studies defensively in this way (Segar et al, 2015). In the event, once our study was funded and underway we raised our concerns with the project advisory group that breadth may be achieved at the expense of depth; accordingly, that group endorsed a change in the study design to enable us to concentrate on fewer sites for in-depth exploration.

We selected two PCT sites (Site B and Site C) in which to study IFR deliberations in addition to Site A. The sites were located in London and the south east of England. Our selection was guided partly by a purposive sampling approach (where 'information rich' cases are selected on the basis of criteria of particular interest to the study (Green & Thorogood, 2004)) and partly by pragmatic considerations. At Site A the majority of IFR deliberations took place by email so we were keen to select a site where we could observe face-to-face interaction. And we were aware from our reading

of policy literature that the issue of patient and public involvement/representation in the IFR deliberative process was a contentious one and so were keen to study a site with an explicit policy of patient and public involvement. Pragmatically, we drew on local contacts (our own and those of advisory group members) to identify PCT sites that showed interest in the research and a willingness to participate, and were feasible in terms of travel time for fieldwork. We held preliminary meetings with senior managers and negotiated access.

As with the Priorities Forum study, the IFR study incorporated an action research orientation. At the outset there was an expectation that the research would contribute to organisational learning and reflective practice across the three sites, and those with whom we negotiated access were particularly enthusiastic about this aspect of the research. However, as a result of the changes to local NHS organisational structures brought about by the Health and Social Care Act 2012 (including the abolition of PCTs and the establishment of CCGs, see Section 2.1), Site A and B IFR panels were reconfigured during the period of our study (merging with other local panels), and the complexities of renegotiating access and working relationships meant that we chose to concentrate the local 'action' element of the research for this study primarily in Site C. Furthermore, as described in Section 4.3.5, our focus increasingly shifted towards opportunities we were able to exploit to explore the implications of our research with practitioners and policy makers at a national level.

Table 1 summarises the range of data collected across the three sites; the details of these data are described in Sections 4.3.2 and 4.3.3.

Table 1: Summary of data collected across the study sites

	Site A	Site B	Site C
No. of Priorities Forum meetings observed	8 meetings	-	-
No. of IFR meetings observed	Meetings conducted by email. 6,500 emails collected, discussing 1,000+ cases	1 meeting at which 7 IFR cases discussed	5 meetings at which 15 IFR cases discussed
Data collected	<p>Transcripts from audio recording of Priorities Forum meetings (25 hours of discussion)</p> <p>Emails of IFR discussions and associated documentation</p> <p>10 interviews with Priorities Forum and IFR panel members</p> <p>1 focus group discussion of panel members</p>	<p>Ethnographic field notes and transcript from audio-recording of IFR panel meeting</p> <p>Agenda papers and minutes</p> <p>4 interviews with IFR panel members</p>	<p>Ethnographic field notes</p> <p>Agenda papers and minutes</p> <p>7 interviews with IFR panel members</p>

4.3.2 Ethnographic observation

For the Priorities Forum study I observed eight meetings of the Site A Priorities Forum over a two and half year period (June 2005 – November 2007). Meetings were generally held bi-monthly and were typically two to three hours in length, with about 10 participants. Membership of the Forum

comprised a consultant in public health medicine (the Chair), other executive and non-executive directors of the PCT, two 'patient representatives' (appointed through local patient networks), and two local general practitioners. Prior to my attendance at the first meeting all members were circulated with details of the research study and asked to complete a consent form. At each subsequent meeting I checked collective consent for me to attend and audio record the meeting, and any new members were asked to complete a consent form. All members consented. In total I observed and audio-recorded approximately 25 hours of discussion. I also took ethnographic field notes at each of the meetings attended.

The stated role of the Forum was to provide "*a mechanism to ensure a robust ethical and evidence-based process for identifying treatment priorities in [the Primary Care Trust]*" (Priorities Forum policy document, Site A). The focus of its work was to deliberate about population-level resource allocation, addressing questions such as should the PCT invest less or more money in a particular service or population group? (e.g. assisted conception services), should it shift funding from one form of service provision to another? (e.g. from secondary to primary care for dermatology services), or should it prioritise funding for a new service? (e.g. a fracture liaison service for elderly people at risk of osteoporotic fracture). A number of agenda items were directed at discussing the PCT's prioritisation processes, for example, should the Priorities Forum introduce an additional principle of affordability into its framework of principles? How should the PCT make funding decisions on IFRs? These discussions constituted rich data to explore my

research question of how rationality is constructed and accomplished in local NHS rationing practices.

Prior to each meeting of the Priorities Forum background papers were prepared by members of the PCT Health Improvement team and circulated to all members. We were included in this circulation and the background papers formed part of my data set. We were also included in email discussions of the Forum and over the study period an email sub-group was established to discuss IFRs (with a fluctuating membership but typically comprising the director of public health as Chair, director of finance, director of commissioning, commissioning manager, general practitioner, pharmacist and public health specialist). When our interlinked IFR study began we negotiated continued access to this email group and 'observed' their IFR discussions over a three-year period. This amounted to a data set of over 6,500 emails discussing more than a thousand IFR cases. The advantage of virtual ethnographic observation was that it allowed us to collect a large amount of interactional data relatively easily. However, it was sometimes difficult to follow the thread of discussion and it became apparent that some communication had occurred 'offline' or in email discussions we had not been copied in to. Whilst the choice of this PCT to conduct IFR discussions by email provided me with an extensive and fertile data set, in my analysis I had to remain mindful of the different culture of virtual communication from face-to-face interaction (Elwyn et al, 2001).

In the IFR study I observed face-to-face meetings of IFR panels in sites B and C. In Site B the IFR panel (known locally as the complex decisions panel) met weekly, and comprised a director of contracting, director of public health, pharmacist responsible for medicines management, the PCT's medical director (Chair), and administrative coordinator. I followed similar consent procedures with the IFR study in sites B and C as with the Priorities Forum study, gaining individual written consent from each member of the panel prior to attending my first meeting, and subsequently reaffirming consent verbally at the start of each meeting. In negotiating access to Site B it was agreed that I could audio-record discussions and this provided me with an excellent opportunity to collect interactional data. I observed and recorded one meeting at which seven IFR cases were discussed; unfortunately the panel was disbanded soon after this as part of the transitional arrangements to clinical commissioning groups (see previous section), and my involvement with this site ceased.

In Site C the IFR panel met monthly and typically comprised a director of nursing (the Chair), a consultant in public health, a public health registrar, a general practitioner, a director of commissioning, a lay representative (appointed through a locally advertised recruitment process), a pharmacist, and the IFR manager. In this PCT patients whose cases were considered were routinely invited to attend part of the panel meeting. This produced an extra layer of complexity to the consent procedure. The normal practice was for the patient to be greeted by the PCT patient and public involvement liaison officer and I arranged for this person to go through the research

information sheet with the patient and seek consent. Seven patients attended the meetings I observed and all consented to my observation.

In Site C it was agreed that initially I would attend IFR panel meetings and take notes rather than audio record, with the understanding that this access would be reviewed as the project progressed. As I built trust and rapport with members of the panel I felt that I could perhaps have negotiated access to audio record, but sensed that the Chair's preference was for me to continue to take notes, and I made a decision to stay with this. I discovered some benefits of relying solely on written notes: knowing that there was no transcript to wait for or rely upon, the process of converting my 'observational notes' into typed up, more reflective and analytically engaged 'field notes' (Copland et al, 2015) became a more urgent and methodical one. At each meeting I observed, sensitised by a recent linguistic ethnography workshop I had attended on field notes as data, I strove to develop my skills in writing notes that were as much an 'act of inscription' (i.e. an authored account from a particular perspective) as description (Copland et al, 2015). I found that I was also able to utilise my skills in speedwriting acquired from learning shorthand to record some short interactions verbatim. Over a period of eight months, I attended five panel meetings at which 15 IFR cases were discussed.

As an ethnographic researcher I had to carefully manage a variety of roles and identities. On the one hand I remained an outsider, allowing me to observe from a position of making 'the familiar strange' (Hammersley, 2013).

At the same time, the more meetings I attended, the more knowledge I acquired and the more familiar I became with research participants, the more I came to be seen as a regular participant in the group, and the more I unavoidably adopted an 'insider' perspective (my field notes of one of the last panel meetings I attended noted the following: "*I'm now greeted very much as one of 'them'; all the members said it was nice to see me again and asked about the research as they drifted into the room before the meeting*") (Site C field notes, February 2012).

A related tension concerned my position as both participant and non-participant. On the whole in attending meetings I adopted the role of non-participant observer; in other words I did not participate in the discussion of cases I observed. However, at the end of meetings it was not uncommon for the Chair to invite me to give some feedback on my observations. Responding to these requests meant finding a balance between saying something and engaging meaningfully in any subsequent discussion, whilst holding back from giving undeveloped and unanalysed impressions. The strategy I developed to manage this tension was, instead of giving immediate feedback, to simply flag up issues that I wanted to go away and consider further, and offer a brief presentation of my emerging findings at a subsequent meeting.

In the three IFR sites, I was given access to associated documentation relating to the IFR cases under discussion, such as evidence reviews and

correspondence with referring clinicians and patients, and these textual data comprised part of my data set.

4.3.3 Interviews

Alongside ethnographic observation I undertook semi-structured interviews with most (21 out of approximately 28) panel members across the three study sites (the total number of panel members was approximate because of some fluctuation in membership over the study period). Some staff had left by the time of my interviews and I was unable to make contact. In the Priorities Forum study I undertook five context-setting interviews to introduce myself to the PCT members of the Forum and gain an understanding of the role of the Forum within the organisational context of the PCT. In the IFR study I conducted five interviews with key members of the IFR panel in Site A, four in Site B, and seven in Site C. The purpose of these interviews was to gain an additional perspective (the participant's 'emic' perspective) on the work practices of the IFR panel to that obtained from observation. The checklists of interview questions are reproduced in Appendix 3. We also undertook one focus group in Site A; this was arranged opportunistically, and took place at a special meeting of the Priorities Forum to discuss the PCT process for dealing with IFRs.

In Site C an opportunity arose for me to undertake interviews with patients who had attended the panel meeting at which their individual funding request was discussed. The panel Chair was keen to obtain patient feedback on their innovative policy of patient involvement and asked for my

help with this small evaluation of practice. Seventeen patients who had attended panel meetings were approached by the PCT and five responded to the invitation; all agreed to be interviewed. I was unable to make contact with one of the five and undertook telephone interviews with four patients (all of whom had had their request for funding approved by the panel).

The PCT's specific interest was in eliciting patients' views about attending panel meetings: what was their experience of attending, what were the positive and negative aspects, and did they have any suggestions of how the PCT could improve the process? In practice, however, respondents found it hard to separate their feedback on the specifics of attending the panel from their views about the IFR system more broadly, and the findings highlighted the difficulties of evaluations that attempt to ring-fence feedback on one particular aspect of policy and practice. Whilst these interviews were of interest to me as someone researching the work practices of IFR panels, and undoubtedly sensitised me to the patient perspective, their small number and selective nature meant that I treated them largely as data collected for PCT purposes rather than as part of the research study, and data from these interviews are not included in my findings chapters.

4.3.4 *Action interventions*

In keeping with the action research framing of the studies, we organised and participated in a number of events and processes that drew upon emerging findings to facilitate organisational learning and reflective practice. We considered the sharing and discussing of research findings to be an integral

part of the research process rather than, as is more conventional, something that happens at a dissemination end phase. These action-oriented activities served to bring me into contact with a wide group of practitioners and policymakers beyond the case study sites, facilitating my immersion in and knowledge of the field. Whilst not formally counting as 'data collection', this aspect of research activity generated rich insights that fed into my emerging data analysis.

During the Priorities Forum study we organised a training workshop for PCTs in the same geographical sector as Site A, in which we explored the complexity of rationing judgements. I also participated in a priorities committee development day for a number of PCTs in another NHS region. In the IFR study I was invited (through one of the members of the project advisory group) to participate in a series of regional 'learning and sharing' events for IFR managers and panel members organised by NICE and the National Prescribing Centre (NPC). I participated in four such events, running sessions on patient and public involvement in IFR decisions. Over 200 participants from 80 PCTs in England attended the events, giving me insight into variation in local rationing practices. We were also invited to join (and TG to chair) a NICE/NPC steering group to guide the development of a competency framework on local decision-making for newly emerging clinical commissioning groups, a process which we published as a paper with other members of the steering group (Russell et al, 2013). In Site C I was invited to join a panel debate to discuss the pros and cons of patient involvement in IFR deliberations at an IFR policy development event for PCTs in the region.

Whilst we considered our involvement in these activities to be an indication of the success of the action research methodology, it also exposed a number of inherent tensions – what Elliott refers to as ‘discordant discourses’ in action research (Elliott, 2000: p16): between our role as ‘outside’ academic researchers and ‘inside’ change agents in the policy process, between a focus on sharing abstract, theoretical knowledge and practical messages from our research findings, and between offering helpful recommendations for policy and practice and our sense that there are no easy answers, no self-evidently right course of action in the rationing debate.

4.3.5 Data analysis

I begin my description of the analytic process with three qualifications. First, the interpretivist research paradigm acknowledges that analysis cannot be considered a distinct phase, but rather an activity that occurs throughout the formally delineated processes of data collection, analysis and writing up. Furthermore, within an action research framework, dissemination of findings feeds into the analytic process, as participants and researchers engage in joint problematisation of emerging issues.

Second, although I am the single author of this thesis, the analysis of my data was far from a solitary activity. In addition to the insights I gained from discussing findings with research participants, my supervisors and academic colleagues with whom I published papers brought significant insights to the analytic process. Supervision meetings were often structured as data

analysis sessions focused on one or more data extracts, and on a number of occasions I shared data extracts with academic colleagues at linguistic ethnography micro-analysis sessions, at which a small group (typically 10 or so researchers) would collectively engage in fine grained analysis and sense-making. I presented my work at conferences and dissemination events and discussions with the audience commonly prompted significant shifts in my analytic thinking.

A third caveat I wish to make concerning the analysis presented in this thesis relates to its eclectic nature. Unlike some doctoral theses that are firmly embedded within a particular methodological approach or specific school of thought, I have drawn on a mix of methodological approaches. Maclure describes her *“intentionally impure”* approach of drawing on different methodological traditions to make best sense of her research data, and this description applies well to my approach (MacLure, 2003). Similarly, Denzin and Lincoln describe the ‘researcher-as-bricoleur’ who *“deploys whatever strategies, methods or empirical materials are at hand”* in a pragmatic and self-reflexive manner in order to secure an in depth understanding of the phenomenon in question from as many angles as possible (Denzin & Lincoln, 2011: p4). As well as locating my work within the ‘umbrella’ methodologies of interpretive policy analysis and linguistic ethnography, there is an orientation towards action research and case study in my work.

For an initial interrogation of my data set I found Gee's conceptualisation of discourse analysis helpful. Gee reminds us that, as with interpretivist approaches in general, his 'method' for doing discourse analysis is not intended to provide a step-by-step set of 'rules' to follow, but rather a set of 'thinking devices' (Gee, 1999). He identifies seven broad building tasks of language and uses these to suggest generic questions an analyst might address in any discourse-oriented research study. I used these questions as exploratory devices to orientate and familiarise myself with my observational and interview data:

- Building significance – how is language used to make certain things significant or not and in what ways? How is language used to give things particular meaning or value?
- Building activities – what activity or set of activities is language being used to enact?
- Building identities – what identities and roles/positions is language being used to enact?
- Building relationships – what sort of relationships is language seeking to enact with others?
- Building politics – what perspective on social goods is language communicating (i.e. what is being communicated about what is taken to be 'normal', 'right', 'good' etc.)
- Building connections – How does language connect or disconnect things; how does it make one thing relevant or irrelevant to another?
- Building knowledge – How does language privilege or disprivilege different ways of knowing and believing or claims to knowledge and belief?

Gee stresses that these questions can help to expose not only how language is used 'on-site' at the micro-level of social interaction ('little d' discourses), but also broader societal discourses ('big D' discourses), and the ways in which these discourses co-construct one another. Thus in my initial readings of my data I was particularly interested in exploring how 'big D' discourses in UK health policy such as evidence-based policy and the affordability of health care were represented, reinterpreted, shaped and constituted at the micro-level of the policymaking table. I listened back to my audio-recordings of meetings and read and re-read transcripts, field notes and other documentation and regularly discussed my emerging 'sense-making' with academic colleagues in both formal (supervision and seminar sessions) and informal settings.

A challenge, as already indicated in Section 4.2.2, was finding a manageable and coherent way of engaging in close analysis of my data, whilst also taking a broader 'helicopter' view that allowed me to get a sense of the overall paths of argumentation and storylines in lengthy discussions of agenda items, and across different types of data (background documentation, emails, field notes, legal judgements, policy guidance, and so on), all interpreted through an ethnographic understanding of context. I found it helpful to produce narrative summaries of specific agenda items and cases under discussion as part of my sense-making process. I also developed extracts of transcripts (which in the main had been transcribed by another person at a basic level of detail rather than for fine-grained linguistic

analysis) into more detailed transcripts to allow closer analysis (Bailey, 2008). I found transcribing to be an interpretive as well as a technical process, helping me to adopt a more enquiring attitude to the communication by drawing attention to the particular characteristics of language in use (Cameron, 2001).

The switching between 'zooming in' and 'zooming out' of my data, and adopting different degrees of granularity in my analytic gaze, sometimes resulted in feelings of uncertainty about how best to make sense of seemingly unorganisable data. However, slowly, as other aspects of the analytic process facilitated a focus on particular themes in my data (see below), I found this varying of the scope and delicacy of my analysis and moving back and forth between different types of data to be a fruitful one. I also found Yanow's broad categorisation of human artefacts into language, objects and acts a useful heuristic device for structuring my analysis (Yanow, 2000), and I demonstrate use of this framework in chapter 8.

Alongside this practical process of immersion in my data set, ran a parallel process of immersion in theoretical ideas that came to constitute the key sensitising concepts of this thesis, explored in detail in Chapter 5. As my analysis progressed, ideas from rhetorical theory and Bakhtinian ideas about the ideological role of language became central to my sense-making, enabling me to identify new features in the data, and facilitated a sharpening of my analysis. For example, the exploratory questions identified by Gee above were supplemented with questions specifically focused on

illuminating aspects of rhetorical deliberation such as: How do committee members direct attention to what they see as the morally relevant features of a case through particular rhetorical moves? How is authority and legitimacy established? What seems to be taken for granted as 'common sense' appeals to a universal audience? Are expressions of and appeals to emotion discernable?

Slowly, through this back and forth process between immersion in theory and data, I came to 'progressively focus' on certain recurring and 'troublesome' themes (Stake, 1995). I honed and narrowed my analytic gaze to address the following key questions:

1. How do resource allocation groups negotiate the tensions and paradoxes of their role – to ration health care within an NHS publicly committed to the values of comprehensiveness and universality?
2. What is the role of emotions in rationing deliberations and how do resource allocators manage the tension between being 'rational' and being 'human' in their decision-making?
3. How do some treatments come to be deemed low priority and therefore not eligible for NHS funding, and thus how are decisions about who is deserving of NHS funding and who is not accomplished?
4. What in practice do lay people bring to deliberations about the rationing of health care?

Each of these questions was informed both by 'focal' themes that resonated with current policy and public debate (such as the affordability of health care,

the 'postcode lottery' in local decision making, patient and public involvement) and 'analytic' themes from linguistic ethnography and interpretive policy analysis (such as the politics of representation, categorisation, and the recontextualisation of language) (Roberts & Sarangi, 2004). And behind each question lay the fundamental question I address in this thesis of how rationality is constructed and accomplished in local NHS rationing practices.

The four findings chapters of this thesis address these questions in turn. Each chapter started life as a journal paper and this has resulted in each chapter having to a certain extent its own particular analytic lens and theoretical perspective. In the final chapter I draw out the commonalities in my analysis across the four chapters, identifying the essential features of my approach to rhetorical policy analysis.

4.3.6 *Ethical issues and governance*

In this section I discuss the procedural ethical issues involved in my research, focussing primarily on managing consent, confidentiality and anonymity. In the concluding chapter of this thesis (Section 10.6.1) I reflect further on the 'micro-ethical' issues of everyday research practice (Guillemin & Gillam, 2004).

Members of the Priorities Forum and IFR panels participated in the research both as individuals and as members of a group and our consent procedures (as described in Section 4.3.2 above) accommodated this dual basis of

participation. As part of the process of negotiating access and consent I drafted an ethical code of practice and data management policy, which TG provided feedback on, and which we then shared and discussed in a revised draft form with key contacts at each site (Appendix 4 contains a copy of the ethical code of practice for the IFR project; a similar code was used in the Priorities Forum project). In the IFR project, interviews with patients were not part of the formal research plan, however when invited to undertake these as part of a PCT policy evaluation in Site C, I established additional consent procedures for this purpose, as described in Section 4.3.3, and informed the QMUL REC of these additional evaluation interviews. As described in Section 4.3.2, I agreed additional procedures with the Chair of the IFR panel for gaining consent from patients who attended IFR panels in Site C.

All research data were stored with regard to confidentiality. Password protection was used on all audio recordings and transcriptions of audio recordings stored on computer to ensure that access was restricted to the research team.

In terms of anonymity, case study designs present particular challenges (Greenhalgh et al 2015). Not only may cases (i.e. local commissioning organisations) be recognisable, even if not explicitly named, but individuals may be identifiable too – there may only be one director of finance or commissioning in the PCT studied, for example. This places an additional responsibility on the researcher to ensure that written accounts, and

especially verbatim quotes, are considered for their sensitivity, appropriateness and fairness. We sent draft reports and journal papers to respondents (or the Chair of the Forum/panel if a respondent had left the organisation) for them to check and agree prior to publication. We received no requests for amendments. In some instances (for example at training and other dissemination events) sites chose to be identified, and in any case it was unrealistic and impractical for them to remain anonymous.

Whilst the focus of the deliberations I observed included requests to fund treatments for individual patients, all information relating to individuals was anonymised by the PCT, both in documentation and panel meetings. Thus there was no risk of us being exposed to identifiable patient data. The exception to this were the seven cases where the patient attended the IFR panel I observed; in these cases the Chair asked the patient how they would like to be addressed and in all cases first names were used. These patients' names were immediately anonymised in my field notes.

As part of research governance procedures, we reviewed ethical issues at each meeting of the project advisory group. We were mindful of possible adverse effects of the research process on respondents, such as feeling watched and even scrutinised by people outside the organisation, and the research processes making respondents more aware of tensions inherent in individual and group practices. However, in practice we received very positive feedback on our research presence, due in large part we suspected

to the sense engendered by the reciprocal nature of an action research methodology.

We were also mindful of the very difficult nature of the rationing decisions faced by those we observed, in some cases amounting to arguably life and death decisions for patients whose cases were considered. We became aware of how the enormity of decision-making could place strain on individuals, who talked of “*sleepless nights wondering if you are doing the right thing*” [Interview with Priorities Forum panel member, Site A]. As researchers hearing accounts of human suffering of patients we too experienced emotional engagement with the tough decisions, albeit as observers. Stone has cogently argued that as interpretive researchers we need to consider how emotions are not simply something to be coped with, but rather a significant source of knowledge and insight (Stone, 2013). I explore this important role of emotions further in Chapter 7, and reflect on my emotional engagement with my data and respondents in Section 10.6.1.

Ethical approval for the Priorities Forum study was obtained from the local NHS Research Ethics Committee (REC) (ref: 04/Q0509/39, September 2004). For the IFR study we initially sought advice from the NHS REC. The committee deemed our project to be outwith their definition of research (primarily on the basis of the action research framing) and therefore that it did not require ethical review by an NHS REC. We received approval for the IFR study from UCL Ethics Committee (ref: 0363/004, May 2009), and

QMUL REC subsequently endorsed the approval when the research grant moved from UCL to QMUL in September 2010.

As the Priorities Forum study was part of the large-scale Evidence Programme at UCL (see Section 4.3), it was governed by the Programme's own governance structures. This comprised regular monitoring and reporting of progress, both to academic colleagues who were part of the interdisciplinary programme and to funders. For the IFR study we established a project advisory group, comprising a chair with a strong background in patient and public engagement, a number of academic colleagues and practitioners in the field, and two lay members appointed through INVOLVE. The advisory group met six times over the duration of the study, and in addition to general monitoring of progress and financial issues, provided an important forum for discussing a range of practical, methodological, policy-oriented and ethical issues arising from the project. As part of the conditions of RfPB funding, we also provided interim and final reports to NIHR.

4.4 Summary and conclusion

In this chapter I began by documenting my methodological journey and orientation as an interpretivist researcher, exploring how both interpretive policy analysis and linguistic ethnography have shaped and informed my work. I then presented a reflective account of my methods of data collection and analytic process. I hope to have conveyed a sense of the emergent,

iterative and sometimes untidy reality of research practice, alongside a clear account of the work undertaken.

In the next chapter I explore key sensitising concepts from rhetorical theory and the work of Bakhtinian scholars, to set the scene for the development of my rhetorical policy analysis in subsequent chapters.

5 Sensitising concepts

5.1 Introduction

In the previous chapter I outlined how key ideas from the fields of interpretive policy analysis and linguistic ethnography about the role of language in constructing, shaping and representing the social world have informed my thinking. I described how I came to discover and engage with these fields as emerging, informative academic communities of practice. In this chapter I 'drill down' in setting the scene for subsequent findings chapters, by exploring in-depth a set of theoretical ideas, or 'sensitising concepts', that I have brought to my data analysis.

Sensitising concepts, according to Blumer "*suggest directions along which to look*", as opposed to more definitive concepts, which "*provide prescriptions of what to see*" (Blumer, 1969: p148). Thus, I see the concepts I explore in this chapter not so much as offering a pre-specified, all-encompassing framework of analysis, but more as helpful interpretive devices that I have drawn upon eclectically in my analysis as and when I have found them illuminating. The specific concepts I explore derive from rhetorical theory and the work of the Bakhtin Circle of scholars.

5.2 Rhetorical theory

In everyday language and much academic debate, rhetoric is commonly considered undesirable; at best superficial and meaningless, and at worse a

manipulative, disruptive force (Garsten, 2006; Young, 2000; Winton, 2013).

Typically, a distinction is drawn between rational speech and rhetoric:

“Rational speech, on this view, the speech to which deliberative democracy should be confined, consists of universalistic, dispassionate, culturally and stylistically neutral arguments that focus the mind on their evidence and logical connections, rather than move the heart or engage the imagination..... Rhetorical speech, on the other hand, aims not to reach understanding with others, but only to manipulate their thought and feeling in directions that serve the speaker’s own ends.” (Young, 2000: p63)

From this perspective, rhetoric is seen as a threat to democratic deliberation (Jones & Exworthy, 2015). However, there is an alternative, affirmative conceptualisation of rhetoric, which has its roots in classical scholarship. Aristotle identified three dimensions of scholarship – analytic (logical argument using premises based on certain knowledge), dialectic (debating moves to argue for and against a standpoint), and rhetoric (the art of persuasion to influence the thought and behaviour of one’s audience) (Aristotle, 2004). To Aristotle, the art of persuading an audience comprised three elements: *logos* (the argument itself, including the clarity of the argument and the logic of its reasons); *pathos* (appeals to emotions, including beliefs, values, experience, and imagination); and *ethos* (the credibility, legitimacy and authority that a speaker develops over the course of the argument). To persuade an audience these three elements must come together in such a way that people are engaged and won over to the proposition (Aristotle, 2004; Chambers, 2009; Van de Ven & Schomaker, 2002).

For rhetorical theorists, rhetoric is not something that can be bracketed out or expunged from speech, but an inherent and inevitable part of all discourse. They dismiss the idea that speech acts can be divided into the rhetorical and non-rhetorical. Young points out that even speech that social convention labels as coolly rational and dispassionate carries with it an emotional tone of neutrality and distance (Young, 2000). And Potter has argued that a claim of factual status is itself a powerful rhetorical device (Potter, 1996). For example, as discussed in Chapter 2, the claim by many politicians and other commentators that rationing is an ‘invariant economic fact’ can be seen as a rhetorical construction, depicting a particular linkage between allocative decisions and resources (Light & Hughes, 2001). Similarly, Harrington points out that *“any bid to claim the mantle of ‘reason’ by condemning an opposing view as ‘mere rhetoric’, is itself a thoroughly strategic, or rhetorical, move”* (Harrington, 2016: p14).

Lingard suggests that rhetorical analysis draws attention to the social relations embodied in *all* language acts (Lingard, 2007). It allows us to explore *how* discourse is persuasive, and ultimately suggests *“the power of language and discourse to fundamentally structure our thinking, our systems of representation”* (Leach, 2000: p208).

An affirmative view of rhetoric positions it as inherently deliberative – it is the back and forth of arguing, listening, and thinking collectively. Booth’s definition of rhetoric highlights this aspect: *“the art of discovering warrantable beliefs and improving those beliefs in shared discourse”* (Booth,

1974: pxiii). And Majone suggests that persuasion is “*a method of mutual learning through discourse*” (Majone, 1989: p8).

Rhetorical theory has provided me with a lens and vocabulary through which to study aspects of the deliberative process that are often occluded when deliberation is studied through the lens of instrumental or institutional rationality (see Sections 3.3 and 3.4). For example, the predominant focus of many of the research studies of rationing deliberations reported in Chapter 3, and indeed of my own research gaze early on in my study of priority setting, was the use of evidence in decision-making. But to focus only on the evidence (the *‘logos’*) that participants bring to the policymaking table, is to ignore other critical components of the deliberative process. As Judith Green demonstrates in her informative study of the use of evidence by multi-professional accident alliance groups, evidence “*does not speak for itself, but must be spoken for*” (Green, 2000: p473). She describes how, in the deliberations of the groups she studied, more important than citations of published research evidence about ‘what works’ was the use of ‘ethos’ and ‘pathos’ by participants:

“...it was apparent that establishing credibility for a proposed course of action within [the] disparate field [of accident prevention] requires considerable rhetorical skill on the part of the advocate. To achieve this, professionals appeal to a variety of sources, including professional expertise, common sense, local knowledge and personal anecdote.”
(Green, 2000: p466)

In a similar vein, in his rhetorical analysis of medical law, Harrington illustrates how the different elements of language interact, with reference to Lord Bingham’s judgement in the case of Child B (see Section 2.7). He

demonstrates how the judge in this case drew on logos (in the form of specific arguments), pathos (through creating a sense of fatalism and tragedy in the depiction of the scarce resources of the NHS), and ethos (through emphasis on the authority of the court, the health authority and medical experts) to establish a “*rhetorical climate*’ sufficient to justify the very difficult decision to deny life-saving treatment to B” (Harrington, 2016: p22).

The value of a rhetorical perspective is that it illuminates how in real life people ‘talk beyond the rational’ (King, 2000). It alerts us to the specific ways in which language is drawn upon and used persuasively (Malkowski et al, 2016). In subsequent chapters of this thesis I explore how participants of the priorities forum and IFR panels I studied directed attention to what they saw as the relevant features of a situation or argument through the use of particular figures of speech and rhetorical moves (for example the use of numbers to authenticate a particular argument (Stone, 1997)); the ‘character work’ of language in establishing authority and legitimacy (Hall et al, 2006); the detailed stories and overall ‘framings’ constructed in unfolding narratives of agenda items under discussion (Gibson, 2003), and the emotional tone that speakers evoked, and their expressions of and appeals to beliefs, values, feelings, and personal experience.

Rhetorical theory has also helped to open up the somewhat elusive notion of practical reason. In Chapter 3 I discussed how practical reason (what Aristotle called practical wisdom or ‘phronesis’) is a form of situated

knowledge distinct from analytical or technical knowledge, acquired through deliberating with others. The critical link between deliberation and practical reason is that of active persuasion and judgement. Young maintains that, through the disclosure of ideas, careful listening, reflecting upon values, questioning, and thinking things through, rhetorical deliberation functions to motivate the move from reason to judgement:

“The good rhetorician is one who attempts to persuade listeners by orienting proposals and arguments towards their collective and plural interests and desires, inviting them to transform these in the service of making a judgement together, but also acceding to them as the judges, rather than claiming himself or herself to ‘know’”. (Young, 2000: p69)

Garsten draws an important distinction between justification, the favoured mode of discourse in much liberal political theory (for example, in Habermasian ideas of deliberative democracy), and persuasion. The problem with justification, Garsten suggests, is that it assumes a universal standard of public reason:

“When we justify a course of action, we argue that it is just, legitimate, or reasonable. We ask for our listeners’ consent insofar as they take on the role of impartial or reasonable judges and adopt the shared public perspective that John Rawls and others have called the standpoint of ‘public reason’, but we do not ask for more than that. We stop short of what persuasion might require. We show why any reasonable person should accept our view but not necessarily why these particular people listening here and now should do so”. (Garsten, 2006: p5)

By contrast, persuasion does not rest upon a commitment to any underlying agreement. Rather, to persuade someone is to induce them to change their own beliefs in light of what has been said. It is an appeal to their capacity for judgement, *“the mental activity of responding to particular situations in a way that draws upon our sensations, beliefs, and emotions without being dictated by them in any way reducible to a simple rule”* (Garsten, 2006: p7).

Thus, the role of deliberation from a rhetorical perspective is one of drawing out good judgement. Rationality is redefined in terms of what a group engaged in deliberation come to agree as 'reasonable' (Perelman & Olbrechts-Tyteca, 1971). Ethical decisions are those that a group of people come to think of as the good and right thing to do through shared moral inquiry and deliberation of contingent cases (Tallmon, 1995). From this perspective, there are no universal 'right answers', only more-or-less good reasons to arrive at more-or-less plausible conclusions. However, in a world dominated by the modernist desire to replace human agency with the impartial uniformity of evidence-based knowledge and procedural rules (Furedi, 2014; Sanderson, 2003; Sanderson, 2004), the primacy that rhetoric gives to the processes of persuasion and judgement and thus the exercise of freedom and choice in human affairs (Miller, 1990; Perelman & Olbrechts-Tyteca, 1971), is arguably the reason it has been treated with such suspicion in recent times.

Beyond the interactions and immediate context of the policymaking table, a rhetorical perspective orientates us towards the wider 'argumentative context' (Billig, 1987). In other words, it prompts an exploration of what is being taken for granted as 'common-sense', what is being presented as if unchallengeable, as common values (rhetorical 'topoi') acceptable to all (a 'universal audience' (Perelman & Olbrechts-Tyteca, 1971)), and what is being argued *against* (as a way of understanding what is being argued for). In Chapter 8, for example, I demonstrate how deliberations about breast

surgery reference ‘common-sense’ societal notions about cosmetic surgery and its weak claim on limited NHS resources. Rhetorical analysis thus becomes an investigation of wider societal discourses and ideology (Billig, 2001). It exposes “*the ways of thinking and behaving within a given society which make the ways of that society seem ‘natural’ or unquestioned to its members*” (Billig, 2001: p217). A central component of my research has been concerned with exploring this ideological role of language in rationing deliberations, and here I have found the ideas of Mikhail Bakhtin particularly helpful.

5.3 Bakhtinian ideas

Mikhail Bakhtin was a Russian linguist and philosopher writing in the 1920s and 30s within a Marxist intellectual context. It has been suggested that, since the English translation of his works in the 1980s, Bakhtin has come to be recognised as one of the most original thinkers about the nature of language in contemporary times (Billig, 1987: p17). There is some controversy over the authorship of Bakhtin’s writings, and thus his ideas are often attributed to the ‘Bakhtin Circle’ rather than Bakhtin alone (Roberts, 2012). I have followed this convention. The appeal of Bakhtinian ideas, and their relevance to my sense-making of the deliberations of rationing groups, lies in the way they illuminate language as a site of social struggle, the inherent dialogism of discourse, and the co-presence of opposing forces in language. These ideas have struck me as particularly well attuned to the often conflicting and ‘dilemmatic’ nature of rationing deliberations. Argumentation and everyday thinking are considered ‘dilemmatic’ in the

sense that they often contain contrary themes; for example, we might hold beliefs about nutrition based on scientific, population-based knowledge, and at the same time hold contrary views based on our individual, experience-based understanding of healthy eating (Huovila & Saikkonen, 2016).

For the Bakhtin Circle, language use is a fundamentally ideological process. When we use language we always express values and attitudes; we cannot use language without adopting a point of view or position from which we are speaking (Edmiston, 1994):

“No utterance can be put together without value judgement. Every utterance is above all an evaluative orientation. Therefore, each element in a living utterance not only has a meaning but also has a value.” (Volosinov, 1973: p105) (emphasis in original)

The notion of the ‘evaluative accent’ of words and phrases is one that I have found helpful in analysis of my data. For example, in Chapter 8 I explore the different evaluative accenting assigned to the phrase ‘cosmetic surgery’ (as superfluous beauty practice or justified medical intervention) in the context of discussions about breast surgery, and how this shapes the ‘struggle’ over the meaning and deservingness of an individual funding request.

Scholars such as Mehan, writing from a Bakhtinian tradition, conceptualise this struggle over the ambiguity of meaning in terms of a ‘politics of representation’, by which one mode of representing the world gains primacy over others (Mehan, 1996). Mehan illustrates the politics of representation with reference to his analysis of how a Californian education committee

constructs the identities of students as learning disabled, and how certain (institutional) representations come to dominate:

“... psychiatrists’ representations prevail over those of patients, professional educators’ representations override parents’ formulations.... More and more often in our increasingly technological society, when a voice speaking in formalized, rationalist, and positivist terms confronts a voice grounded in personal, common sense or localized particulars, the technical prevails over the vernacular.” (Mehan, 1996: p361)

In Chapter 6 I demonstrate how, as a sensitising concept, the politics of representation orientated me towards an exploration of how rationing panels construct certain truths about eligibility to health care from the ambiguity of communicative practices. I expose the way in which particular representations of what the NHS can and cannot provide are explicitly and implicitly constructed, promoted, negotiated and defended.

According to the Bakhtin Circle, the words we use are never simply a voicing of our own opinions and ideas. Rather, our language is ‘overpopulated’ with other voices, and the social practices and contexts they invoke:

“The word in language is always half someone else’s. It becomes one’s own only when the speaker populates it with their own intentions, their own accent, when they appropriate the word, adapting it to their own semantic and expressive intention.... Each word tastes of the context and contexts in which it has lived its socially charged life; all words and forms are populated by intentions.” (Bakhtin, 1981 cited in Maybin, 2001: p67)

Linking this notion of multi-vocality to the ideological nature of language, Bakhtin writes that: *“the ideological becoming of a human being... is the process of selectively assimilating the words of others”* (Bakhtin, 1981: p341). Bakhtinian ideas thus convey that we are neither completely

autonomous authors of what we say, nor simply the mouthpieces of others' viewpoints. The analytic question raised by a Bakhtinian perspective is 'who is doing the talking?', as voices that originate in one particular context are recontextualised and reinterpreted in another (Linell & Sarangi, 1998). Voice in this sense may refer to an individual person, or a broader societal discourse, such as the voice of medicine, the 'lifeworld' (Mishler, 1984), the voice of NICE, or the voice of austerity, for example. Invoking a voice also involves invoking an evaluative viewpoint, as Maybin explains:

"There are always in fact two layers of evaluation: the reported speech or writing conveys its own evaluative viewpoint, but the current speaker or writer also frames and evaluates this viewpoint in their turn (quite often in rather subtle ways), through the manner in which they reproduce and recontextualize the words they are quoting or reporting." (Maybin, 2001: p68)

In subsequent chapters I explore how those deliberating around the policymaking table bring not only their own voices to the table but recontextualise others' too, as a rhetorical resource to support an argument – for example, the patient voice, the voice of a referring clinician in the case of an individual funding referral, or the legal voice from a judicial review judgement.

Central to the ideas of the Bakhtin Circle is the dialogic nature of language. Meaning is constituted through dialogue: *"there are no preformed, orderly or constant relations between thoughts and words, but only ones which are 'formed' or 'developed' within a particular dialogue"* (Shotter, 1992: p2). Bakhtin expressed it thus: *"Human thought becomes genuine thought, that is, an idea, only under conditions of living contact with another and alien*

thought, a thought embodied in someone else's voice" (Bakhtin, 1984: p116).

In other words, ideological meaning and consciousness is located "*not within us, but between us*" (Steinberg, 1998: p852).

For the Bakhtin Circle all discourse is inherently dialogical, but in some communication dialogical elements are suppressed, "*to institute a single voice that smooths over or drowns out all the others*" (Torgerson, 2007: p6). Actors are able to realise power within discourse "*to the extent that they can suppress dialogue and convert it to a monologue*", that is, "*dampen or temporarily arrest the multivocality of meaning within discourse*" (Steinberg, 1998: p855). So whilst all communication is an act of co-authorship between speaker(s) and listener(s), in monologic forms of discourse the speaker privileges a single perspective and tries to impose meaning on a listener.

In contrast, in dialogic forms of discourse "*the speaker will tend to orient herself towards others with the anticipation that her utterance's meanings will be actively engaged and used as a thinking device in a collaborative process*" (Tuler, 2000: p5). In dialogic discourse, then, rather than opportunities for debate and reflection being shut down, critical reflection and questioning of implications and assumptions are encouraged, and new meanings actively generated (Hamilton & Wills-Toker, 2006). For example, a study of environmental public participation programmes in the United States explored how the structure of some public forums encourage sense-making discourse and collaborative learning, whilst other 'monologic' spaces privilege the voices of technical experts and government officials,

suppressing the ‘otherness’ of public opinion (Hamilton & Wills-Toker, 2006). In Chapter 9 I explore instances of both dialogic and monologic forms of discourse in my analysis of lay involvement and ‘ordinary’ knowledge in rationing deliberations.

Another key term in Bakhtinian theory is the ‘discursive heteroglossia’ of language. At every level of language use, different voices and speech genres cohabit, “*supplementing and contradicting each other, and intersecting or becoming hybridized in various ways*” (Maybin, 2001: p67), producing a ‘heteroglossia’ – a multiplicity of languages within speech, co-existing in a constant state of dynamic tension. The Bakhtin Circle conceptualised this tension in terms of an on-going, never finalised dialogue between authoritative ‘centripetal’ (closing off) discourses of centralisation (such as scientific truth, religious dogma) and ‘centrifugal’ (opening up) influences of language diversification. The latter are associated with more open, provisional and ‘inwardly persuasive’ discourse, between different social classes, age groups, etc. (Maybin, 2001). In presenting findings from my data, I explore the evident tensions in the deliberations of rationing groups between the centripetal forces of, for example, evidence-based medicine, and the centrifugal forces of individual patient narratives and experiential knowledge.

Echoing this oppositional, two-sided view of language, Billig’s work on arguing and thinking identifies the conflicting processes of categorisation and particularisation (Billig, 1987). While acknowledging the “*pervasive*

cognitive process” (Wilder, 1981 cited in Billig, 1987: p152) of categorisation (a process reflected in a variety of institutional and professional practices (Hall & Slembrouck, 2009; Mäkitalo, 2003; Starr, 1992; Stone, 1997)), Billig argues that this is too one-sided a view, underestimating “*the dynamism of human thought*” (Billig, 1987: p160). He suggests that although in our propensity to categorise “*we may behave like timid rule-following bureaucrats*”, there is also always the possibility of “*rule-creation, rule-breaking and rule-bending*”, or what he refers to as the “*inventive force of anti-logos*” (Billig, 1987: p160). Within this ‘two-sided’ view of human processes, there exists a continual argumentative momentum, “*oscillating between particularisation and categorisation*” (Billig, 1987: p171). In Chapter 6 I draw on these ideas to explore how institutional categories are invoked as ‘fixed entities’ to help organise and process people through the IFR process, and at the same time, how categories are contested and discursively constituted in deliberation, as participants move between generalisation and particularisation of a case.

5.4 Summary and conclusion

In this chapter I have outlined key concepts from rhetorical theory and the related work of the Bakhtin Circle of scholars, which have sensitised the analysis I present in Chapters 6 – 9 of this thesis. In recent years there has been a resurgence of interest among political theorists and other scholars in rhetorical theory (Garsten, 2011). However, the application of this theory to health policy analysis is still very much in its infancy (Russell et al, 2008; Malkowski et al, 2016). Studies that have taken a rhetorical perspective tend

to focus primarily on the rhetorical strategising discernible in institutional discourse, largely positioning rhetoric as interfering with and sometimes shutting down democratic deliberation (Hawkins & Holden, 2013; Jones & Exworthy, 2015; Tanenbaum, 2012).

Rarely do such studies explore rhetoric's potential to strengthen and open up debate. In the chapters that follow I explore how rhetoric can both compromise *and* enrich democratic deliberation. My approach to analysis encompasses rhetoric's affirmative role, exploring how rhetorical deliberation can facilitate independent thought and draw out wise judgements. From this perspective, rationality becomes redefined in terms of what a group engaged in deliberation come to agree as reasonable. Rhetoric, thus positioned, affirms the centrality of human authorship of the world (Garsten, 2011), and ultimately, according to scholars of rhetoric such as Miller (1990) and Perelman and Olbrechts-Tyteca (1971), offers a theory of human choice, fundamental to freedom itself:

“Only the existence of an argumentation that is neither compelling nor arbitrary can give meaning to human freedom, a state in which a reasonable choice can be exercised....If freedom was no more than adherence to a previously given natural order, it would exclude all possibility of choice; and if the exercise of freedom were not based on reasons, every choice would be irrational and would be reduced to an arbitrary decision operating in an intellectual void.” (Perelman & Olbrechts-Tyteca, 1971: p514)

6 Constructing the rationality of affordability in the rationing of health care

6.1 Introduction

In this chapter – the first of four ‘findings’ chapters – I explore how rationing panels negotiate the issue of affordability of health care in their localities. My particular interest is in decisions about the affordability of health care to individual patients, made by individual funding request (IFR) panels. The broader debate about the overall affordability of the NHS as a public health care system is beyond the scope of this thesis, though it forms an important context for this work. It is noteworthy, for example, that recent projections to 2030 by the Office of Budget Responsibility and Nuffield Trust indicate that, even taking account of rising costs and demands, and despite ministerial warnings to the contrary (Campbell, 2015a), the NHS remains sustainable and affordable through general taxation (Toynbee, 2016; Appleby, 2016; Licchetta & Stelmach, 2016)).

As discussed in Chapter 2, individual funding requests, whilst relatively small in numeric terms, are highly significant, both to the individual patient requesting treatment, and symbolically in defining the boundaries of NHS care. I am interested in how commissioning organisations, through the deliberations of IFR panels, construct certain truths about eligibility to health care, and the way in which particular representations of what the NHS can and cannot provide are explicitly and implicitly constructed and negotiated.

Sensitised by the theoretical lens of the politics of representation (see Chapter 5), I explore ambiguities over meaning and attempt to draw out the ideological effects of the rhetorical work discernible in the deliberations of primary care commissioning groups.

The data from which the findings in this chapter are derived reflect the heterogeneity of my data sources (see Chapter 4). I present data primarily from transcripts and field notes of ethnographic observations of IFR panel deliberations (both face-to-face and virtual). I also draw on observation of Priorities Forum meetings at which there was discussion of IFR policy development; interviews with panel members; policy guidance; minutes of meetings; and panel correspondence with referring clinicians and patients. As discussed in Chapter 4, a particular challenge I found in attempting a linguistic ethnographic analysis was the tension between anchoring analysis in the detail of the data, and the difficulty of capturing an analytic point in a specific and manageable segment of data. Sometimes in deliberations the overall argument and narrative stretched over multiple and extended interactions, and the analytic point emerged more from my taking a broad 'helicopter' view of the data than being able to pinpoint it in any particular excerpt. Thus the analysis of discursive practices I present in this chapter represents a middle ground between fine-grained interactional analysis and a broader interpretive approach to policy analysis (Shaw & Eyre, forthcoming).

Affordability is a significant criterion that local commissioning organisations list as pertinent to their IFR rationing decisions, alongside factors such as clinical and cost-effectiveness, patient safety, and national and local priorities (National Prescribing Centre, 2009a)³. As one local commissioning policy expressed the affordability question:

“[Commissioning organisations] are under a statutory duty to promote the health of the local community but are also under a duty not to exceed their annual financial allocation. This inevitably means that, from time to time, difficult choices may have to be made balancing the costs and benefits in any particular case against the resources available within the health economy.” (Elvin, 2011: p5)

At the same time, through the NHS Constitution, NHS England upholds the founding principles of the NHS, reassuring patients that the NHS provides a comprehensive service available to all, with access based on clinical need (Department of Health, 2015). Thus rationing panels have to navigate, through their everyday work practices, the tension between espoused national policy, which continues to support, in principle at least, the traditional NHS values of comprehensiveness and universality (Al-Zaidy, 2013a), and the constraints of limited financial budgets.

My observations of the Priorities Forum and IFR panels led me to identify the construct of affordability as a particularly troublesome and ‘dilemmatic’ aspect of rationing work. Affordability is dilemmatic in the sense that it is something that is argued both for and against (Billig et al, 1988), as the

³ In contrast to the position in England, it is noteworthy that in Wales a recent review of the IFR process concluded that: *“the public should be reassured that affordability is not part of the decision criteria for individual patients”* (Independent Review Group, 2017).

following extract from a Priorities Forum discussion on introducing affordability to the PCT's framework of principles, illustrates:

Director of Finance: "... through our panel, we have lots and lots of requests through from secondary care, from primary care in some instances, for procedures which we've not included within our budget, which we've not ever considered - it might be for new types of drugs, new types of procedures, some of which have very expensive revenue consequences.

And the issue is how do we deal with that? ...In one sense, through the principles we've set up, we can look at them and we can say, yes, this is cost effective or it's not cost effective, it's clinically effective, and so on. But, as it stands today, we can't afford those. And we therefore need to bring in the concept of affordability to some of these decisions, because they have a consequence.

And I think that's the bit that we're struggling with, because on one level we should be saying to all of those requests, [...] we could say we've not got a budget for it, we've not set it in our budget, so we're not going to approve any of it, that's it, nothing. But that's very difficult on one level to do. In one sense, if we were a completely rational organisation, we'd look at those, we'd say, well actually these are good things, which we should be doing, let's look at what we've actually budgeted for, and let's cancel other things. But it doesn't quite work like that really. And I think, whilst that might be a sort of logical approach, it can never really work like that."
[Priorities Forum meeting T5, Site A]

In this extract the Director of Finance grapples with the dilemma of what constitutes the 'rational' (logical) course of action when faced with requests to fund treatments that are considered cost and clinically effective but unaffordable. He makes an argument that it is both rational to fund particular treatments and rational to refuse to fund them. Similarly, my interviews with panel members exposed a sense that they struggled with the concept of affordability and whether it was appropriate for it to be a criterion in decision-making for the funding of individual treatments. While discussion of the affordability of health care was acknowledged to be a "fact of life" within the current financial climate of the NHS, it simultaneously evoked a sense of

unease, with comments such as *“should affordability go into our policy or not?”*; *“[affordability] is such a delicate thing to broach”*, and *“we run the risk of using [the IFR process] as a means to save money, and I don’t think we should”*.

Other researchers have similarly noted expressions of discomfort among NHS managers and clinicians with the increasing ‘economisation of discourse’ in the NHS, with the language of economics and finance increasingly dominating clinical and managerial talk (Greener & Powell, 2003; Hughes et al, 2011; Jones et al, 2004; Moffatt et al, 2013), but at the same time noting expressions of discomfort with and dissociation from this discourse, and the emotional and ethical difficulties of explicitly rationing health care to individual patients (Carlsen & Norheim, 2005; Owen-Smith et al, 2010; Walter et al, 2012; Dwarswaard et al, 2011). The difficulties of reconciling the principles of comprehensive health care for all based on clinical need with the demands of resource constraints has been referred to as the ‘double agent dilemma’ (Maybin & Klein, 2012).

Against this background, I sought to explore how IFR panels managed such tensions in practice. In this chapter I identify four discursive practices, that I argue helped to confer legitimacy to affordability as a guiding value of NHS health care: [1] categorising certain treatments as only eligible for NHS funding if patients could prove ‘exceptional’ circumstances; [2] representing resource allocation decisions as being not (primarily) about money; [3] indexical labeling of affordability as an ‘ethical’ principle, and [4]

recontextualising legal judgements supporting denial of NHS treatment on affordability grounds as 'rational'. The overall effect of these discursive practices, I suggest, was that denying treatment to patients became reasonable and rational for primary care commissioning groups even while they remained committed to the NHS's traditional values of comprehensiveness and universality.

A potential criticism of those who study discourse is that their research neglects or denies the material reality within which discourse and communicative practices occur. In this vein, the critic might argue that the question of affordability is less a discursive construction and more a reflection of whether or not there is money available to pay for a treatment. However, in the commissioning organisations I studied, both the PCT with a financial deficit and those in a healthier financial position continued to fund some IFRs and refuse others. Thus whilst not denying a material reality of restricted budgets and limited health care resources, my position is that it is nevertheless instructive to explore the discursive practices through which some treatments come to be considered affordable and others unaffordable. In line with my ontological position as an interpretivist researcher (see Chapter 1), my concern is to explore how the economic and political environment is rendered meaningful through discourse.

6.2 The category of exceptionality

As described in Chapter 2, the concept of exceptionality has emerged from legal judgments on IFR cases, in which judges have indicated that

commissioning organisations must always allow for the possibility of exceptions to any policy concerned with rationing health care to individuals. These judicial pronouncements have become incorporated into national and local policies, providing the rationale for IFR panels to deliberate over exceptional cases. In the commissioning organisations I studied exceptionality was variously defined – as *“significantly beyond the norm or usual circumstances and in itself quite unusual or uncommon”* [IFR policy document, Site B]; or as when the clinical outcome for a patient may be exceptional because *“they may not tolerate the usual and (possibly) cheaper treatment, or there may be evidence they would do far better than the average on the proposed treatment; and/or they may have exceptional social factors”* [IFR policy document, Site A]; or as when a patient:

“has clinical circumstances which, taken as a whole, are outside the range of clinical circumstances presented by at least 95% of patients with the same medical condition at the same stage of progression as the named patient could show that their clinical circumstances were sufficiently unusual that they could properly be described as being exceptional.” [IFR policy document, Site C]

In all the IFR cases I observed how categorisation of patients' circumstances into 'exceptional' or 'unexceptional' framed panels' deliberations and decision-making. Deborah Stone (1997) describes categories as mental constructs we put on the world to help us apprehend it and live in an orderly way. In institutions, categories are invoked to facilitate institutional tasks, *“generated historically and dialogically in order for institutions to be able to handle, or get a grip on, the ‘social dilemma’ that they are responsible for”* (Mäkitalo, 2003: p498). The category of exceptionality, I suggest, is key to understanding how decisions about what

the NHS will fund come to be constituted, negotiated and justified, as the following example from Site A illustrates. Some details of the case have been changed to protect confidentiality.

An ophthalmologist had requested that his 92 year old patient (Mrs Smith) be treated with ranibizumab (Lucentis) (which at the time had not been approved by NICE) for her deteriorating vision caused by wet age related macular degeneration (AMD). The policy in this PCT was to not fund ranibizumab unless there were exceptional circumstances and the panel were discussing (by email) whether this patient had 'exceptional circumstances' to justify funding.

The panel had received a letter from the patient's daughter in which she described her mother's AMD and other physical difficulties, including impaired mobility, increasingly bad hearing, and the fact that she was *"about to lose her long time partner to cancer"*. The daughter described her mother as *"a brave and determined woman"* but said *"I am frightened for her future"*. The daughter's understanding was that delay was a critical factor with AMD and that further loss of her mother's sight would increase her sense of isolation and diminish her self-confidence, leading to a marked deterioration in her quality of life and a *"possible impact on her ability to live independently"*.

The Chair of the panel (the PCT Medical Director) made the following observations:

- *“At the age of 92, it’s difficult to adjust to any change. Losing a ‘long-time partner’ (for whatever reason) can be devastating. On average, it takes about two years for someone to get over the loss of a spouse and things are never quite the same – but usually the pain, desolation and helplessness get a lot easier after two years. I’m less clear about the ability of an ‘average’ person aged 92 in these circumstances.*
- *Losing a long-term partner can also be a severe blow to the confidence – they are usually there to support, cajole, advise, share. This suddenly goes. And so can the confidence. A loss of confidence reduces independence and, crucially, an ability to do many of the important aspects of everyday living, like shopping, cooking, washing...*
- *Wet age-related macular degeneration can progress quickly. Not always, but it can occur in a matter of weeks.*
- *Mrs Smith will, presumably, be alone when her partner dies. If she has mobility problems then a fall becomes more likely. At her age, osteoporosis is more likely and a fall is thus more likely to result in a major injury such as a broken hip.*
- *Mrs Smith apparently has bad hearing. If she loses her central vision then she will be deprived of the TV, seeing her family and reading as well as having difficulty in listening to the radio or the TV or talking with people.*
- *All this in combination will probably put Mrs Smith at risk of developing clinical depression which could further compromise her ability to cope”. [Email, IFR panel, Site A]*

The Chair concluded that Mrs Smith’s circumstances were exceptional and recommended that the PCT fund the request. Other members of the IFR panel disagreed. For example, one commented:

“I cannot see why this lady comes into the exceptionality group re PCTs definition, in fact sadly her life seems to be relatively normal for a 92 year old. The anticipated loss of a partner (we don’t know when this is forecast) is devastating but given her age unfortunately reasonably likely regardless of the fact that her partner happens to have cancer and is presumably likely to die soon.

Sorry but I think this scenario could apply to many patients”. [Email, IFR panel, Site A]

And another member, the Director of Finance, commented:

“My main concern in this approach is that this patient still has reasonably good vision in both eyes. In all other cases where we have approved on the basis of exceptional circumstances the patient has been blind or almost so in their other eye. I am concerned about the precedent that we

would be setting in this case and that the number of other people who may then become 'exceptional' will contravene the affordability principle.

I still therefore find it hard to see why this patient is exceptional. My own personal experience of 90 year olds is that all of the above are true...
[Email, IFR panel, Site A]

This extract illustrates at an interactional level the discursive work that exceptionality achieves (or at least has the potential to achieve, with more or less success, depending on how other interactional factors are brought into play). Firstly, the category of exceptionality subtly changes what is fundamentally a *moral* dilemma for the panel about what value they should give to this particular 92-year old patient's quality of life (as illustrated by the Chair's attempts at moral reasoning) into a *technocratic* task of defining categorical fit and boundaries. The Director of Finance is concerned that the PCT cannot afford to provide ranibizumab to elderly patients who still have "*reasonably good vision in both eyes*", and she draws on the category of exceptionality to define such needs as 'normal', and thus (within the institutional rationality of IFR policy) as lying outside a claim on NHS resources. The discursive power of exceptionality that I observed in many IFR cases was that panels were able to say to referring clinicians and their patients that a request had been rejected on grounds of lack of categorical fit. Take for example the following extract (also quoted at the beginning of this thesis – see Chapter 1) from an IFR decision letter to the referring clinician (also concerning an IFR for ranibizumab for AMD):

"You have told us that Mrs M lives with her older husband and that they both live independently and care for each other. Apparently he has osteoarthritis and is due to have a hip replacement. You have said that were she to lose her sight then they would lose their independence. We do not consider that Mrs M's circumstances could be considered to be 'far beyond what is usual' and would expect Mr M's hip replacement to

enable him to become more mobile than he is now. Whilst we recognise that were Mrs M to lose her sight this would be very significant to her and would make her dependent on her husband, we do not consider that this makes her exceptional when compared with others with age-related macular degeneration”.

In both these cases, the technocratic task of categorising appears to create its own internal logic and rationality, creating abstract rules that serve to decontextualise and disembodify the specific case, and masking the more fundamental irrationality of a system that demands a binary (exceptional-unexceptional) classification of elderly patients with failing eyesight and co-morbidities and complex health care needs.

Secondly, returning to the data excerpt of Mrs Smith’s case, the construct of exceptionality serves to position the patient as a supplicant of health care. Entitlement to health care becomes something that must be argued for; it can no longer be considered a right. Use of the term exceptionality achieves ideological work in beginning to shift the rules of entitlement to NHS care.

Thirdly - and paradoxically - whilst exceptionality by definition demands special pleading, when considered in the context of the PCT’s public health (population-focused) role, it becomes potentially *unfair* special pleading. Unfairness ceases to be defined as *refusing* to fund a treatment for a patient with a particular clinical need, and becomes redefined as *agreeing* to fund it.

This is illustrated in the following excerpts from national guidance to PCTs:

“Exceptionality is essentially an equity issue that is best expressed by the question: ‘On what grounds can the PCT justify funding this patient when others from the same patient group are not being funded?’

The general duty of the PCT – as a tax payer funded service which is contributed to by all - is to be as fair as possible in the allocation of resources between different patients in the same clinical circumstances. So there is a heavy presumption that a treatment should not be funded for a few which is refused for the many....So a patient who is required to demonstrate exceptional clinical circumstances should do just that – demonstrate exceptionality as compared with other patients with the same condition and at the same stage of progression.” (Lock, 2009)

Ford has argued that the concept of exceptionality is a “*legal farce*”, linguistically ambiguous and differently interpreted by both the courts and PCTs, and hence having “*limited application clinically, morally and legally*” (Ford, 2012: p4). However, this dismissal of the construct overlooks the ideological work it achieves in [a] shifting the work of IFR panels towards technocratic categorisation and away from moral reasoning, [b] shaping the public perception of entitlement to NHS health care, and [c] positioning the work of IFR panels as adjudicating less over the affordability of health care and more over the common good of fairness and equity.

6.3 Representing resource allocation decisions as being not (primarily) about money

“The Chair then asked the patient if anyone had explained what this panel did and what the purpose of the meeting was. The patient said he thought it was to do with the funding problems with the NHS, he wasn’t that sure, but he guessed it was about funding, that this was a new treatment being recommended. At this point the patient seemed to be picking up from the head shaking and expressions of the panel members that this was perhaps not the case, so asked “is it not the money”? to which the Chair responded, “no, that’s not the prime consideration”. The lay member said “it really isn’t about money, it’s about clinical effectiveness” and the Director of Commissioning added that “we’re here to work out whether this is the best treatment for you”. [Field notes of IFR panel meeting C1, Site C]

“People seem to think we’re there just for the money, we’re not. I feel we’re there to ensure the patient is safe and is being given a safe treatment, and they’re being given something that has a reasonable chance of giving them a degree of success. I think that’s important for them to realise that we’re there, we’re not trying to say ‘no’ the whole time, and the reason for the ‘no’ may not be anything to do with the money. It may be just due to the fact that we don’t feel that what they’re being offered is going to give them any benefits, in longevity, in symptom reduction, whatever, and you know, could possibly make them feel worse.” [Interview with GP member of IFR panel, Site C]

These data extracts highlight how IFR panels emphasised aspects of their role other than the affordability element, in particular ensuring that the patient was being offered a safe treatment that would give them clinical benefit. In one of the three PCTs in my sample, the emphasis in deliberations was on efficacy and safety but there was also explicit acknowledgement of the panel’s affordability role (*“Our decisions on individual patient treatment requests do not concern whether it is clinically appropriate for a patient to have the treatment recommended by their clinical adviser, but whether it is appropriate for us to fund it.”* – Decision letter from Chair of IFR panel to referring clinician, Site A).

In the case from which the extracts above are taken, the patient, Mr A, (who had been invited to attend the panel meeting) suggested that if the IFR process was not – as had been indicated to him by his doctor and in the invitation letter he had received from the PCT – about funding then this should be explained to patients: *“If it’s beyond funding, then the letter that I was sent is not appropriate, it would be good if you explained that to patients in the letter”* [Field notes of IFR panel C1, Site C]. After Mr A had left the meeting the panel discussed whether they should consider renaming

the panel, given what they identified as the misleading emphasis on the word ‘funding’.

The safeguarding role of the panel was thought by panel members to be necessary for a number of reasons. IFRs were sometimes for novel treatments that clinicians sought to offer patients, but for which the evidence base was limited. As one GP panel member explained:

“Sometimes, you just wonder what it is that patients think they’re being given, and often, having the wool pulled over their eyes, they’re just being offered something and they’re blindly following like a lost sheep, saying yes if you say so I’ll have it, and you just think, is this right?”
[Interview with GP panel member, Site C]

Panel members spoke about such requests in terms of the ‘rule of rescue’ (see Chapter 7):

“Sometimes we have a patient that comes through panel who the rule of rescue applies to, and they’re very very poorly, and you think, you know, at what point does this consultant say, actually, we need to look at good end of life care, and enough’s enough. You know, it seems that they’re offering false [hope], particularly when you look at clinical effectiveness and evidence, that’s not there for this particular new drug or treatment, why are they putting their patients through this?” [Interview with Chair of IFR panel, Site C]

Another element of this perceived safeguarding role was ensuring that patients were informed of the risks of treatment. In Mr A’s case, the panel explicitly asked what information he had received:

Panel member: Can we ask you how much has been explained to you about the treatment? Anything about how dangerous is the treatment and the side-effects...?

Mr A (shaking head) they told me they will open me up, remove it or something. He gave me a leaflet. I was scared when I read it. I wasn’t told about the side effects until I read the leaflet.

Panel member: Did they tell you about putting drugs inside your stomach whilst you're on the operating table?

Mr A (looking bewildered) No, nothing like that. Since Dr S has left the NHS I haven't received good information. [Field notes of IFR panel meeting C1, Site C]

After the patient left the meeting, the panel discussed Mr A's case:

"There was a general discussion about how the patient 'hasn't any idea' about what's involved in the proposed treatment. They discussed possible explanations for this – that the patient seems to have dropped between two stools in terms of which doctor is taking responsibility for his care, and also perhaps he had been told more than he appeared to know but understandably hadn't taken it all in – 'when you're anxious, you don't always hear what's being said'. There was palpable concern that Mr A didn't know what he was coming for, that he was so sick, that such an invasive and potentially risky treatment was being proposed. The GP member commented 'how many times have we been here, lovely application from consultant outlining all the detail of a treatment and the patient knows nothing.'" [Field notes of IFR panel meeting C1, Site C]

The final decision in this case was to approve funding on the proviso, in the decision letter to the referring consultant, that the risks of treatment were explained:

"However, the evidence on safety shows significant risks of morbidity and mortality and Panel was concerned that the patient had not been fully advised of these risks. Therefore funding is provided with the proviso that all risks and benefits are fully explained to the patient by Mr X at XX and we ask that you include this stipulation within your referral to XX." [Decision letter from Chair of panel to referring consultant, Site C]

A particular concern among IFR panels was the influence of pharmaceutical companies in some requests. For example, two panels commented on the involvement of the drug manufacturer for Duodopa (a combination product containing two medications, levodopa and carbidopa, in the form of a gel, given via an infusion pump, that is said to give smoother absorption) in IFRs for patients with Parkinson's disease. The drug is expensive and the

component products are available much more cheaply (and generically) in tablet form. In one site the Chair of the IFR panel stated that he felt he had been subjected to *“quite a hard sales pitch”* when he met with an IFR patient and his wife and doctor and *“unexpectedly two representatives from the manufacturer”* [Email, IFR panel, Site A]. In another site, the minutes of a panel meeting noted:

“Panel ... were deeply concerned at the involvement of the key account executive from the drug manufacturer in the preparation of this case for submission. A conflict of interest such as this should have been declared, and they wished this to be noted to the referrer.” [Minutes of IFR panel meeting, Site C]

An emphasis on this important safeguarding role successfully moved the representation of the work of IFR panels away from the uncomfortable task of enacting affordability; it also contributed to constructing a view of IFR requests as sometimes of questionable legitimacy. Two further beliefs about IFRs commonly expressed by panel members added to this construction; firstly, that clinicians used panels as a more acceptable way of denying treatment to patients (*“Blaming the PCT can be a useful tool – it removes the nasty decision from the clinician”* [member of focus group discussion, Site A]), and secondly that some IFRs were clinicians’ attempts at *“gaming the system”*:

“...you get a little bit cynical sometimes ... because we’ve had referrals from an NHS consultant referring to himself privately in Harley Street, you know, that sort of referral behaviour, because they want to pioneer their new treatment they’re involved in. And that’s a clear conflict of interest.” [Interview with Chair of IFR panel, Site C]

To summarise, one representation of the work of IFR panels was as protecting patients from overzealous clinicians and/or drug company

commercial interests and as protecting clinicians from a direct rationing role in relation to their own patients. All this added legitimacy to the uncomfortable and difficult work that panels had to engage in, though mistrust and anger between referring clinicians and IFR panels sometimes occurred as clinical judgments were exposed to what was perceived by clinicians as unwarranted administrative scrutiny.

Similar discursive work was evident in deliberations of the Priorities Forum, with priority setting commonly represented as a task subtly set apart from rationing or cost cutting:

“In simple terms, and importantly, the role of the [...] Priorities Forum will be to determine whether [the] PCT should support ‘x’ or ‘y’ – not ‘x’ or ‘nothing’”. [Priorities Forum background paper, Site A].

According to this formal account, frequently repeated within Priorities Forum discussions, prioritising was about deciding which services had higher priority, rather than about saving money by ‘supporting nothing’ rather than ‘x’.

“Chair:what the Forum agreed when it was founded and that the Board endorsed, was that we would make judgements on priorities – that we wouldn’t say that we can save X pounds here and to put that in the bank so that the option is X or nothing. It will be, this is the founding principle – X or Y. If we can save money here, we will spend it here, because Y is a greater priority.” [Priorities Forum T1, Site A]

And in introducing an agenda item concerned with a proposal to shift resources from a local exercise referral scheme to cardiac rehabilitation services, the Chair of the Forum suggested:

“The argument of this paper is that there is a lack of evidence for what we are spending our money on, therefore we should be spending money where there is strong evidence for benefit and also there is evidence of

an unmet need. We're not suggesting that we cut spending here in order to support the deficit that the PCT has got. We're actually suggesting here that this is a straight shift of money from one area of treatment, where there is a paucity of evidence, to another area of treatment where there is a body of evidence and unmet needs". [Priorities Forum T6, Site A]

In this extract we see the linguistic work in marking out priority setting as something distinct from rationing, invoking a more positive sense of the activity in which the Forum was engaged. As with the IFR panel examples, resource allocation decisions were framed as being not so much about what the PCT could and could not afford to fund, but about the efficacy of service provision.

6.4 Indexical labelling of affordability as an ethical principle

Medical Director: "So what I'm asking is... would we think it appropriate to actually add an additional principle in here [to the PCT's Framework of Principles], which is to do with affordability? Can the PCT actually afford it?"

Director of Communications: ... that feels, am I right, it's one step further on than what we've been doing, in the line we've been using... I think we haven't sort of come out and said, 'We just can't afford to do it.' We've always managed to balance it out with, 'We can't afford to do X because it might not be clinically that good,' or whatever. 'But also we have to be mindful if we do X, we will not be able to do Y'. That's how we've sort of sold it a bit.

Medical Director: I think we've fudged it up to now by saying that.

Director of Communications: Yes, so now we're going to the next step". [Priorities Forum T5, Site A]

Public health adviser: "We feel that we should now try and get affordability as a principle into our ethical framework. [...]"

Panel member: The word is a hostage to fortune. Affordability is not ethical. I don't think affordability is the right word. It's not plausible to the man or woman in the street.

Public health adviser: I disagree. Affordability IS ethical. It's about the quality of the service we can provide". [Field notes of a regional priorities committee development day]

The work of all three IFR panels in my sample was explicitly framed within a set of locally developed ethical principles, commonly referred to as 'the ethical framework'. National guidance on IFR policy advises commissioning organisations that "*Decisions should be based on the best available evidence, take into account the appropriate ethical frameworks and comply with statutory requirements*" (National Prescribing Centre, 2009a: p11). In one PCT the ethical framework comprised a concise list of six principles (rational, inclusive, clear and open to scrutiny, investment and disinvestment decision within available finite resources, allocation of health care resources according to health needs, and promote consideration of a wide range of factors). Another PCT had a 10 page framework that included the principles of clinical effectiveness, cost effectiveness, affordability, equity, quality and safety, ethical consideration of respect for personal autonomy, beneficence, non-maleficence, distributive justice, general principles of mechanisms following NICE guidelines, based on good quality evidence, transparent, ethical and managerially robust, accountability, and ensuring probity. The third did not have a separate ethical framework but identified principles for decision-making (including equity, patient choice, healthcare need and capacity to benefit, needs of the community balanced against the needs of the individual and exceptional need, and affordability and availability of resources within the context of competing needs) in its main IFR policy.

Over the study period I observed PCTs discussing whether and how to introduce an explicit ‘affordability principle’ into their ethical frameworks, as illustrated by the extracts above. From the panels’ perspective, this provided a formal *ethical* justification for refusing requests on financial grounds. The linguistic term ‘indexicality’ refers to the way in which words used in communicative acts point to, or ‘index’ particular meanings in particular contexts (Blommaert, 2005; Garfinkel, 1994), and we see in this example how including affordability as a principle in an ethical framework served to give it particular meaning by linking it with ‘common good’ principles such as equity, transparency, inclusivity, and so on. In the context of IFRs, ethical frameworks are identified in policy guidance as providing the ‘right grounds’ (Hope et al, 1998) for decision-making (Austin, 2008), and thus, once affordability is listed as a principle in an organisation’s ethical framework, the ‘right’ basis for a particular decision comes to be affordability. When IFR panels deliberated and decided that they could not fund x because “*it would contravene the affordability principle*” (see data extract in Section 6.2 above) or that “*we must apply in full the affordability criterion in our principles framework*” [IFR decision letter to referring clinician, Site A], they were conveying more than simply the fact that the PCT had insufficient money; they were implying that it would be unethical to fund this particular request.

6.5 The role of the courts

“About 350,000 people are registered with [this PCT’s] GPs and we are therefore responsible for the health and health care of a lot of people. If we spend money or allocate other resources (e.g. staff time) in one area, or for one group of people or for one individual, then those resources

cannot be used for someone else. We therefore try to ensure that our resources are used to the benefit of the largest number of people. This inevitably means that it is not always possible for everyone to get exactly what they want or when they want it; we have to prioritise some services and treatments over others.

Our decisions on individual patient treatment requests do not concern whether it is clinically appropriate for a patient to have the treatment recommended by their clinical adviser, but whether it is appropriate for us to fund it. This responsibility has been recognised in the courts. I believe that probably the first time this was raised was in the 'Child B' case, when the judge said:

'I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much the cost, particularly when a life is potentially at stake.

It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet. Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients'. (Sir Thomas Bingham MR in R v Cambridge Health Authority ex parte B, 1995: 906)

This observation has been quoted with approval in a number of appeal judgments on individual patient treatment requests since and remains an accurate statement of the law." [Decision letter by Chair of IFR panel to referring clinician, Site A]

As described in Chapter 2, a paramount requirement of those allocating health care resources is that their decision-making is considered rational, with patients having the right to challenge decisions of public authorities they consider to be 'irrational' by way of judicial review (Maybin & Klein, 2012).

The rationality of decision-making was viewed by IFR panel members as achieved via a number of mechanisms. One was drawing on scientific research to ensure that decisions were evidence-based (although it was

acknowledged that often the evidence base for IFRs was, by their 'exceptional' nature, limited). Another was by reference to legal judgments, drawn from the texts of judicial review cases. In the above example we see how the Chair of the IFR panel quotes from Lord Bingham in the case of Jaymee Bowen who was referred to in the legal exchanges as Child B (see Section 2.7) to stress that a consideration of the affordability of health care by a PCT "*remains an accurate statement of the law*", and by implication, rational. Moreover, although there is some ambiguity as to what precisely the phrase "*this observation*" is referring to, one interpretation is that the principle of utilitarianism, i.e. allocating resources "*to the maximum advantage of the maximum number of patients*" also remains an accurate statement of the law.

Significantly, the letter quoted above truncates the legal judgment. Lord Bingham's comments on Child B continued as follows from the sentence cited in the letter: "*That is not a judgment which the court can make*". The socio-linguistic term 'recontextualisation' refers to "*the dynamic transfer-and-transformation of something from one discourse/text-in-context... to another*", involving a reframing and transformation of the original meaning (Linell & Sarangi, 1998: p2). In this example, we can see how the recontextualisation of the judge's words subtly shifts the emphasis in the meaning from being on *who* should make the decision (the health authority, not the courts) on to *how* the decision should be made (implicitly, according to the principle of utilitarianism).

Thus although the legal position expressed here is that the rationality of affordability is “*not within the province of a reviewing court*” (Syrett, 2004: p291) (because, as discussed in Chapter 2, the courts have indicated that their role in administrative decision-making is limited to matters of procedural reasonableness and not the substance of rationing choices), commissioning organisations have drawn upon the texts of judicial review judgments to claim legitimacy for the rationality of their utilitarian stance. This stance is further legitimised by the reminder (by legal advisers to commissioning organisations and by commissioning organisations to referring clinicians) that, unlike clinicians (who have a legal duty of care to their patients), commissioning organisations (both pre and post the 2012 Health and Social Care Act, i.e. both PCTs and CCGs) have only a *target* rather than a *direct* duty of care (Lock, 2007; Lock, 2014).

My data set contained other examples of how legal judgments became recontextualised to support the rationality of the commissioning organisation’s decision-making. For example, a series of legal cases have confirmed that when considering IFR cases, commissioning organisations do not have to take account of social factors in their assessment of exceptional circumstances. From her review of judicial reviews, Ford has summarised the legal position as being that “*In the absence of direct clinical implications, social factors do not have to be considered in the assessment of exceptional circumstances*” (Ford, 2012: p23). This position was widely interpreted by commissioning groups as meaning that they *could not* take social factors into account, an interpretation that was then given additional

legitimacy by being incorporated into the organisation's ethical framework.

The minutes of one IFR panel, for example, recorded that:

“Consultant proposes that the patient is exceptional due to concerns around the patient’s wife as a sole full-time carer. However this was found to be a social issue that Panel could not take into account as per the Ethical framework and was not accepted as a basis of clinical exceptionality” [Minutes of IFR panel meeting, Site C].

The implication for patients of this particular recontextualisation of legal judgements is discussed further in Section 8.6.

6.6 Summary and conclusion

In this chapter I have explored how the question of the affordability of health care to individuals has gained legitimacy, even within an NHS still publicly committed (through the principles set out in the NHS Constitution (Department of Health, 2015)) to traditional values of comprehensiveness and universality. I have explored the rhetorical work involved in achieving this legitimacy, through the discursive practices of categorising certain treatments as only eligible for NHS funding if patients could prove ‘exceptional’ circumstances; representing resource allocation decisions as being not primarily about money; the labeling of affordability as an ‘ethical’ principle, and recontextualising legal judgements supporting denial of NHS treatment on affordability grounds as ‘rational’.

Decisions about allocation of social goods and denial of health care raise fundamental questions about the legitimate exercise of moral authority. In Chapter 3 I presented arguments from Daniels and Sabin, suggesting that the legitimacy, or ‘accountability for reasonableness’ of bodies such as

priorities forums and IFR panels can be assured by certain procedural conditions: transparency about the grounds for decisions; appeals to rationales that all can accept as relevant to meeting health needs fairly; and procedures for revising decisions in light of challenges to them (Daniels, 2000). However, my research has opened up the 'black box' of process empirically (Hasman & Holm, 2005), demonstrating that decision legitimacy is more than a simple matter of delineating a core set of procedural conditions; it requires considerable rhetorical work, enabling affordability to become a principle that "*fair minded people can agree [is] relevant*" (Daniels & Sabin, 1998: p51) in the rationing of health care. Through this rhetorical work, particular representations of what the NHS can and cannot provide, and what it is 'rational' for the NHS to fund and not fund, are explicitly and implicitly constructed and negotiated.

In Chapter 5 I introduced the notion of the politics of representation – ideological struggles over different ways of representing the world (Mehan, 1996). The analysis I presented in this chapter suggests that the ideological effect of the rhetorical work of Priorities Forum and IFR panels in their deliberations about affordability is a shift towards a 'common sense' (Billig, 2001) that [a] entitlement to health care is no longer a universal right, [b] the NHS cannot provide all treatments, and [c] patients may be denied health care on financial grounds. And in the process, other criteria such as rescue and entitlement, which have historically attracted public support (Harrison, 1998; National Institute for Health and Care Excellence, 2006), become less relevant. Thus, deliberations by local rationing groups about tests and

treatments at the margins of NHS care have powerful consequences not only for individual patients but also for redrawing the wider ideological landscape of NHS care.

Other researchers have similarly reported on processes of legitimisation that contribute to a changing ideological landscape of the NHS and the retrenchment of entitlement to health care (Bohm, 2017; Hillman, 2014). Hillman, for example, notes how access to emergency care is restricted by the categorisation of patients into 'appropriate' and 'inappropriate' and the increasing rationalisation of the emergency department as a service to treat only acute trauma cases. Thus, Hillman concludes:

“the public refusal of access to emergency services works to re-affirm patients’ diminished expectations and makes clear that the receipt of care from public institutions is no longer given without patients having to work hard to justify their need.” (Hillman, 2014: p497)

In the next chapter I develop my exploration of the rationality of rationing, turning to an analysis of another dilemmatic aspect of rationing work – the tension between 'being rational' and 'being human' in resource allocation decisions.

7 Emotions, phronesis, and practical reasoning

7.1 Introduction

A recurring and troublesome theme to emerge from my observations of rationing panels was the tension panel members expressed between “*being human*” and “*being rational*” in their decision-making; the delicate balance, as the playwright Edward Albee described it, between the value of emotional engagement in clarifying what is important to us as human beings, and our fear of emotions getting in the way of rationality (Bottoms, 2005). On the one hand, emotional engagement, through “*stepping into the patient’s shoes*”, was considered an inevitable and productive component of being human, but at the same time, was something to be wary of and that needed to be contained, so as to keep panels “*on track*”. An IFR panel member expressed the tension in the following way:

“I think that’s what we all do when we’re looking at [requests for funding individual treatments], when we’re looking at any [request]: we think what if I was, or what if my mum, or what if my wife...? ... And as human beings, you know, we’re susceptible to that kind of influence, but we have this principles document and principles procedure, which keeps us on track.” [Interview with PCT member of IFR panel, Site A]

The dilemma expressed here points to the role of practical reason in rationing deliberations – a perspective on rationality that highlights the contribution of emotions, situated subjectivity and narrative reasoning in coming to understand what is rational. In this chapter, sensitised by the Aristotelian concept of ‘phronesis’ (see Chapter 5), I explore the enactment of practical reason in the rationing panels I studied. In Chapter 4 I quoted from Deborah Stone, suggesting that the field of interpretive policy analysis

has barely begun to fulfil its promise of paying attention to emotion in policy deliberations (Stone, 2013). This chapter attempts to make a contribution towards 'taking emotion seriously'.

I begin by presenting an in-depth case example from my ethnographic field notes of the deliberations of one IFR panel, together with interview data and associated documentation, to illustrate the way in which intuition, practical knowledge and emotional engagement are an integral part of and facilitate the processes of decision-making. I suggest that whilst an embodied, practical rationality emerges as a significant aspect of rationality in practice, it simultaneously has a problematic status in formal accounts of decision-making, which default to the normative discourses of rationalism. I then present interview and observational data to explore what 'being human' means in the context of rationing deliberations, and identify the tensions between being human and being rational, with reference to [a] debates about the benefits and dis-benefits of patients being invited to attend IFR panel meetings to represent their case; [b] the role of ethical frameworks and principles in decision-making; [c] consideration of the 'rule of rescue' in panel discussions, and [d] the language used to depict the process in which panels were engaged. Finally, I explore how emotional engagement ('being human') is inextricably linked to the ethicality of decision-making, and draw attention to the value of a narrative ethics in theorising my observations of panel deliberations.

7.2 A case example

The case I discuss here concerned a 63-year old woman (anonymised as Brenda) who had had extensive reconstructive surgery following cancer of the mouth. Her clinician had submitted a request to the IFR panel to receive funding for a course of hyperbaric oxygen therapy to try and repair the “*untenable state*” of her mouth and jaw. The IFR panel in Site C that considered her case comprised a director of nursing (the Chair), a consultant in public health, a public health registrar, a GP, a director of commissioning, a lay representative, and a pharmacist. In addition, the IFR manager was in attendance as note taker.

The panel began by discussing an evidence review prepared by the public health registrar, in which the limitations of the available evidence quickly became apparent. The rarity of the condition made a firm, unambiguous evidence base unlikely, and the limited evidence that had been identified did not easily relate to this particular patient and specific aspects of her condition. In an interview after the panel meeting, the public health registrar described how her response to the panel’s standard question of whether there was evidence to support a clinical effectiveness argument was invariably “*it’s hard to say’. I say pretty much the same, each time I come [to panel], ‘I can’t give you good evidence because necessarily there isn’t’!*” [Interview with IFR panel member, Site C].

At this particular IFR panel the patient and her clinician had been invited to attend and had chosen to do so. After brief introductions, the Chair invited

them to present their case. The clinician did most of the talking, perhaps partly because the patient's speech was badly impaired by her condition. My field notes from this part of the meeting read as follows:

"The surgeon explained that he felt that 'he couldn't leave poor Brenda in this state' and this is now 'last chance corral time', and that he could really only do one more attempt at surgery and if this doesn't work Brenda's going to be in a much worse state with her whole face collapsing. The surgery for the cancer appears to have been very successful, but the reconstruction hasn't been. The surgeon says: 'It occurs to me that hyperbaric therapy may stimulate her soft tissues and make the flap repair more likely to succeed. I know it's got a lousy reputation and that most PCTs [Primary Care Trusts] up and down the land won't fund it. There's no literature on this. But before coming to [xx hospital] I used to be at [yy hospital] and we had three other patients who had had a similar stormy course to Brenda and for the two we tried it on it worked' (with the third there was a funding issue). 'I don't know how it worked, but it did'.

The patient then spoke for a bit. It was difficult to understand her, but the panel Chair responded sensitively to her communication. Brenda talked about the constant pain she's in, how she's having to clear the excess saliva all the time, how she can only drink with a syringe (which she did during the meeting), and lifted her blouse to show her feeding tube. She had tears in her eyes at this point. When she'd finished talking the Chair asked her if there was anything else she wanted to add and Brenda simply said "just say yes" [Field notes of IFR panel meeting C2, Site C].

After a few questions from the panel members about clinical aspects of the proposed treatment, this part of the meeting was brought to a close, and the patient and clinician left. My field notes continued:

"Once the patient and doctor had left the room a panel member asked 'is it rule by rescue if we approve it'? Other panel members did not directly address this question, but one member commented 'it's very interesting that two out of the three cases the consultant had come across, when he treated them with the therapy, it was successful' (and the third wasn't treated because of the funding issue). There was a brief discussion about this being anecdotal evidence from the consultant and that they were having to take his word for it, to which one member responded that the consultant was presumably telling the truth as he'd know that they could always check up on it! Someone said that given the consultant's argument about the success he'd had previously, it wouldn't simply be rule of rescue if they agreed to fund it.

One member asked another how much PEG [percutaneous endoscopic gastrostomy] feeding costs (about £2K a month) and from this made the point that the intervention could pay for itself in six months, although they acknowledged that the consultant hadn't been completely clear about whether there would no longer be a need for PEG feeding. The GP member of the panel then said that he was going to stick his neck out and say yes to funding. 'I'm not sure it's based on any evidence review but the feeling I have is that we should fund it. It's a different situation to a drug treatment where you're throwing one drug after another.' The panel agreed that this was a truly individual case, that there would be the offset costs of the PEG feeding, and that if it works it's going to pay for itself very easily. The Chair said 'I think I'm hearing an approval?' The rest of the panel agreed and funding was approved". [Field notes of IFR panel meeting C2, Site C]

This case provides a rich illustration of the way in which an embodied, practical rationality works in 'necessary tension' (Jenkins & Barber, 2004) with formal rationality (in terms of consideration of evidence, attempts at some sort of cost-benefit analysis, attention to the formalised process of decision-making through measures such as including a lay representative on the panel and inviting the patient to attend) to facilitate decision-making. The critical turning point in the deliberation is when the GP says that he is going to "stick his neck out" and say yes to funding. He says: "I'm not sure it's based on any evidence review but the feeling I have is that we should fund it." We see here how the GP is conveying an explicitly intuitive rationality rather than more formal knowledge. He uses the persuasive language of 'sticking his neck out', and adds an argument that this case is different to ones where "you're throwing one drug after another" (meaning, perhaps, that he views this as a relatively discerning choice in the absence of explicit scientific evidence to support the decision).

Intuition in this context can be considered as a characteristic of expert judgement (Flyvbjerg, 2001), contrasting with the novice practitioner who tends to rely more on context-independent elements and rules when dealing with uncertainty and complex problems (Dreyfus & Dreyfus, 1986) (see Chapter 3). In Brenda's case, the GP appears to be drawing on his expertise in dealing with uncertainty, playing hunches, weighing up pros and cons, and so on. As Sanderson observes:

"...practitioners do not simply seek to deal with uncertainty on a 'technical' basis using evidence, but rather seek to cope with ambiguity on a 'practical' basis, making wise judgements about the appropriateness of ... action in relation to a range of technical, political, moral and ethical concerns." (Sanderson, 2006: p126)

The intuitive dimension of practical reason has been identified as playing a significant role in professional decision-making by a number of researchers. Calnan and colleagues' ethnographic study of NICE appraisal committees, for example, reported on decision-makers' use of rules of thumb and gut reactions based on intuition or tacit knowledge as common strategies for managing highly complex material (Calnan et al, 2017). Stolper et al identified gut feelings as a 'third track' in general practitioners' diagnostic reasoning, alongside analytic tracks of reasoning, arguing that analytical and non-analytical reasoning interact continuously (Stolper et al, 2011). Scourfield found that social workers drew on an *"entangled mixture of decision-making rationalities"* in making risk assessments of their clients, with references to policy and official guidance interwoven with references to previous experiences, personal narratives, 'gut feelings', and 'hunches', though they were reluctant to acknowledge its existence, tending instead to

rationalise with reference to scientific evidence, legislation or policy (Scourfield, 2011: p7).

This 'tidying up' of practical reasoning was evident in my data. In interviews, panel members' accounts of the decision-making process typically emphasised the instrumental and institutional aspects of rationality, highlighting how they weighed up all the evidence and took an objective view. In the recorded account of the above deliberation in the meeting notes, uncertainty in the decision-making process is suggested and the role of experiential knowledge recognised (*"Members agreed that, although not necessarily based entirely on evidence review, [this case] should be funded. It is about the surgeon's experience and desire for a better chance"* [IFR panel meeting notes, Site C]), but when this note becomes recontextualised in the formal decision letter from the panel to the referring clinician, the uncertainty has been written out and the role of evidence emphasised:

"The Panel welcomed feedback from Mr X [the surgeon] regarding his previous experiences with this treatment which showed it maximized the chance of successful flap repair. They noted that evidence supports the use of Hyperbaric therapy to stimulate tissues' healing capacity leading to a more successful surgical outcome. Panel agreed that this might enhance the functional restoration of bone with the added hope of ending PEG feeding in the future. This request was therefore considered appropriate and approved." [Decision letter from IFR panel Chair to referring clinician, Site C]

The formal documentation does not so much report on the reasoning and rationality of the deliberations as actively construct it, creating its own 'documentary reality' (Atkinson & Coffey, 1997).

7.3 Being ‘human’

In interviews, alongside ‘talking the talk’ of rationalism (Greener & Powell, 2003), panel members readily identified the ‘human’ component of their decision-making. “*Being human*” meant, as indicated in the quote at the beginning of this chapter, “*stepping into the patient’s shoes*”, and considering “*what if I was this patient, what if my mum, or what if my wife...*”? As one panel member put it, “*you can’t help that, it’s emotional, it’s intrinsic to our thought process.*” [interview with IFR panel member, Site B]

‘Being human’ also meant considering the family and wider life context of each case. The GP in the above case example contrasted his own perspective with that of non-clinical panel members: “*The facts do come in. [...] I probably see more how things impact on families, on friends, on work, on the environment... perhaps more than, you know, just the actual nitty-gritty of the complaint itself*” [Interview with IFR panel member, Site C]. Interestingly, the word ‘facts’ is used here by the GP to stress the validity of the concrete and particular (“*nitty-gritty*”) knowledge of this patient. It contrasts to the formal policy of most panels (including this one) that they should *not* take ‘social factors’ into consideration in their deliberation of IFR cases. Support for this position is drawn from legal judgements of IFR cases, although, as described in Section 6.5, the formal legal position is that panels are not *obliged* to (rather than *cannot*) take account of ‘social factors’ in their assessment of exceptional circumstances (Ford, 2012). Ford reports similar findings to mine, quoting from a GP IFR panel member who commented:

"Being human, we can none of us ignore the social. We're supposed to"
(Ford, 2013: p202).

In the two study sites in which I collected verbatim data from emails and audio-recordings (sites A and B), I was able to examine the naturalistic language used by panel members. Phrases such as *"it's difficult here..."*; *"sadly her life seems..."*, *"sorry but..."* conveyed emotional engagement (especially the emotion of compassion) but also hinted at a separation between their personal and professional moral selves (effectively, 'as a human being I feel x but as a professional I feel my position is/should be y'). MacIntyre has referred to this compartmentalisation of roles within institutional structures, resulting in a threat to moral agency, as the 'divided self' (MacIntyre, 1999).

In the case example above, the GP appears to have sufficient confidence in his own judgement to exercise his moral agency (in this case, against the conventionally accepted norms of evidence-based practice), enabled by a social setting that supports moral agency and practical deliberation (a panel culture that encouraged shared moral inquiry and critical reflection (Tallmon, 1995), and in which panel members showed confidence and trust in the GP's character and judgement as part of their collective experiential knowledge). Faced with the uncertainties of formal knowledge, the panel relies on the human attribute of 'ethos'; the constituents of which are described by Aristotle: *"beyond what can be demonstrated factually, we put*

our trust in people who have good sense (phronesis), good moral values (areté), and goodwill toward us (eunoia)” (Miller, 2003: p167).

7.4 The tension between being ‘human’ and ‘rational’

7.4.1 Benefits and dis-benefits of patient attendance at IFR panels

The dilemmatic nature of ‘being human’ and ‘being rational’ came across strongly in views expressed about the benefits and dis-benefits of patients being invited to attend IFR panel meetings and represent their case. Local policy on this aspect of IFR work varied considerably.

In Site C patients were encouraged to put their case forward to the IFR panel, and were allocated a ten-minute slot to present their case to the panel, followed by an opportunity for the panel to ask questions. In sites A and B patients were only invited to submit letters of representation which were then circulated and discussed between panel members, or to meet with a panel member or PCT administrator before the panel meeting. In other localities patients were invited to attend second stage, appeal meetings (Russell et al, 2011). This variation in local practice reflected the equivocal nature of national guidance current at the time of my fieldwork⁴:

⁴ A review of national and local policy documents available online at the time of writing (2017) indicates continued variation in guidance on this issue. For example, NHS England guidance states that: *“The patient/patient representative, or their clinical or non-clinical representative, is not entitled to attend the panel in person”* (NHS England, 2016: p14). One local CCG policy states: *“The patient (or a nominated representative) has the opportunity to attend the Panel to give a presentation of their case”* (NHS Basildon and Brentford CCG et al, 2016: p14), whilst another indicates that *“it is not appropriate for patients to attend the Panel and the Commissioners are not legally bound to invite them”* (NHS Herts Valleys CCG, 2017: p16).

“Should the process allow patients to present their case at IFR or appeal panels in person? There is no single answer to this.... This is a matter for PCTs. Some are not comfortable with patients presenting to panels, while others see it as a way to make their decisions more open and accountable”. (Austin, 2008: p8)

My data indicated that on the one hand, patient attendance was seen as meaning that panel members were able to hear the patient’s story first hand and gain insights into the patient’s circumstances that were not necessarily available from the formal documentation of the case. For panel members in Site C, a first-person narrative and the patient’s physical presence drew attention to both ‘hard facts’ (e.g. difficulty breathing, disfigurement) and the morally relevant features of a case. But most panel members from local commissioning groups that had no direct experience of patients attending an IFR panel thought that inviting patients risked them becoming too emotionally involved, and therefore less able to make an objective decision:

“I think you then run the risk of seeing this very emotional patient in front of you and you actually lose a little bit of the dispassionate decision-making process which has to happen. That doesn’t mean you’re not human, but you have to be divorced from the emotional pressure a patient will put on you in some way.” [Interview with IFR panel member, Site A]

Meanwhile, in their interview accounts, the members of panels that had adopted a policy of inviting patients to panel meetings expressed confidence that seeing and hearing from the patient directly did not prevent them from taking a balanced decision:

“... each time we’ve had a discussion around the table, it’s always come down to a clear clinical decision, based on the needs, the information of the patient there, and based on the outcomes.” [Interview with IFR panel member, Site C]

“... the lady came in and did her 10 minutes and there were questions from the panel, and she went out, and we all felt oh this is really really difficult, we all, all around the table, just wanted to let her have it [drug for advanced cancer]. But then you have to take a step back There wasn't the evidence. But I have to admit it was a harder decision to make seeing the patient face to face. [Interview with Chair of IFR panel member, Site C]

7.4.2 The role of ethical frameworks and principles

Panel members in my study all emphasised the important role of the organisation's formal ethical framework in *“mitigating the emotional impact”* on panel members through *“adherence to policy and ethical framework, training, and reliance on facts and evidence”* [Interview with IFR panel member, Site A]. Ethical frameworks were seen as an important counterbalance to subjectivity, helping to keep panels ‘on track’ and ensuring the emotional component of decision-making was *“reined in”*. This perspective is illustrated in the following extract from a Priorities Forum discussion in Site A, in which panel members deliberate the process of prioritising one service over another, and the ‘delicate balance’ between objectivity and subjectivity in their decision-making:

GP: “My problem is how you do it [prioritise].... I find it extremely difficult to judge between early intervention psychosis and IVF, for example. So perhaps the first thing we need is a list of what treatments, probably high cost treatments, that this PCT is funding. And the criteria we need to apply. I think we need a more fundamental look than just saying A versus B.”

Patient representative: “It depends whether you're in A, how important it is, whether you're in B, how important it is. People who sit at home waiting, you know, ‘I've only got two more days before my period, am I going to be pregnant?’ Unless, I think, you can really understand their feelings, I don't think it is possible to compare A with B. Each has such a great priority, to that particular patient. And that's what I think this Forum has to remember more than anything else. It's easy for us, but not so easy for the person sitting outside”.

Director of Nursing: "I guess, building on that, you have to recognise that we're all sitting here with our own personal experience, also being patients and our family being patients. And then when we make value judgements, some of that feeds into it".

Patient representative: "It is totally human nature, it can never be any different".

Chair: "Which is partly why we've got the principles so we've got a framework".

Director of Nursing: "Absolutely". [Priorities Forum meeting T1, Site A]

Observations across my three sites suggested that, paradoxically, the existence of ethical frameworks sometimes seemed to detract from, rather than stimulate, in-depth discussion of the specific ethical dilemmas in a particular case. Principles were cited but rarely explored; reference to them appeared to put ethical issues beyond debate. Thus, during a discussion about whether or not the commissioning organisation in Site A should approve funding for a high cost cancer drug, when the Chair of the panel commented: *"we won't fund things just because there's no alternative treatment available. It seems harsh but it's one of our principles"*, this statement seemed to be presented and interpreted as putting it beyond any further scrutiny or debate. This observation links to the arguments of ethics theorists discussed in Chapter 3, suggesting that ethical frameworks run the risk of serving more as 'litanies' (Marinker, 2006), to be *"recited dutifully"* (Giacomini et al, 2004: p20), closing down rather than opening up space for ethical deliberation (Marinker, 2006; Loughlin, 2002).

7.4.3 *The rule of rescue*

The tension between ‘being human’ and ‘being rational’ was also evident in IFR panels’ consideration of the ‘rule of rescue’; defined as situations in which society spends significant sums of money ‘rescuing’ identifiable individuals who are in imminent danger of death or distress (Jonsen, 1986; Sheehan, 2007). In the case example above, one panel member asks: *“is this rule of rescue if we agree to fund it?”* Anxiety about the rule of rescue was widespread among IFR panels, reflecting the strong and widespread steer in both national and local policy guidance that this rule should not guide decision-making. The NHS Confederation, for example, gave panels the following guidance:

“The need and urge to do something for the patient is very strong. Most of us share this impulse. PCTs, however, do not owe a direct duty of care to individuals and are not rescuers in any real sense. To give in to the impulse to “do something” can result in inconsistent and unfair decision making because agreed principles and policies are set aside in order to meet the needs of the decision maker (i.e. to feel good, avoid feeling bad, avoid unpleasantness or reduce risk).” (Austin, 2008: p6)

In contrast to this strong policy steer away from the rule of rescue, there is evidence of public and professional support for its application. A NICE Citizen’s Panel report on the rule of rescue concluded that *“allowing ‘exceptional case treatment’ was the mark of a civilised and humane society”*, and should sometimes be applied not only for the individual’s benefit, but also for the *“common good of the population”* (National Institute for Health and Care Excellence, 2006: p14). And the Chair of the British Medical Association Ethics Committee was quoted as saying: *“We would be opposed to ignoring a rule of rescue when it introduces a degree of flexibility*

around extreme cases. So what if you waste a few pounds if you are doing your best for humanity?" (Laurance, 2008).

Jonsen, a bioethicist, argues that *"Even the most evangelical utilitarian would find it difficult to expunge the rule of rescue from the psychological dynamics of technology assessors"* (Jonsen, 1986: p174). This 'strong imperative' can be conceptualised in terms of what Levinas called a *"pre-social morality"*, in which *"...[t]he other person's presence to us naturally elicits and compels a response on our part, a response that is moral and one that affirms a mutual contract in which we are each ultimately responsible to the other."* (Brannigan, 2012: p54). In other words, there is arguably something instinctively human about support for the rule of rescue.

In some of the IFR panel discussions we observed this strong imperative to resist the authority of the utilitarian principle and instrumental rationality, and to consider the value of rescue. In one case (considered by a panel to which patients were not invited), concerning the funding of sunitinib (an expensive cancer drug) for a young patient with advanced renal cell carcinoma, the direction of argument among the panel was initially to not fund:

"Ms JS is regrettably going to die from her disease and the costs of keeping her alive for a relatively short period of time are disproportionate. Given that we have limited resources and have to ensure that we make best use of them, under our principle of distributive justice I believe that we could do more good by utilising our resource in other areas with better health outcomes." [Email, IFR panel, Site A]

However, later in the discussion (conducted by email over a number of days), the Chair of the panel (who previously had supported the above

position, similarly arguing that *“if we were to fund this then we would be using money that could be used for others to greater and known benefit”*) revises his view, emphasising the specific utility of treatment in this particular patient on human grounds. He says: *“I’ve now spoken with the patient’s doctor and the situation is slightly different. I am now inclined to recommend that we fund this”*. He continued:

“Her disease is progressing faster than in most others because of the bulk of her metastases. She and her family have not really had enough time to come to terms with her impending death but a few extra weeks could enable this - there’s more than one ‘patient’ here. There is a reasonable chance that sunitinib will buy her a little bit of extra time and there is evidence that it improves reported quality of life (see my email below).

Looked at this way, she’ll be dead ‘soon’ but a small number of courses of sunitinib at £4,000 per course could make a big difference to her and - importantly - her family. I suggest that she can be regarded as ‘exceptional’ because without treatment her disease will progress at a much faster rate than it would in others.” [Email IFR panel, Site A]

Contributions such as this indicated that, although in theory the rule of rescue was to be avoided, there were occasions when panel members considered it appropriate.

7.4.4 ‘Muddling through’ or a ‘mechanism’ for decision-making?

The language used by panels to describe the process by which they came to decisions provided yet a further example of the dilemmatic tension between ‘being human’ and ‘being rational’. In the Priorities Forum meetings I observed there was both acknowledgement that in practice decision-making could be characterised as a process of collective sense-making, described as *“muddling through”*, and at the same time, a *“mechanism”* that would help with decision-making. Panels repeatedly searched for an explicit

calculus of priority setting that could “*make our decisions for us*”, and in this sense was conceptualised as somehow external to and separated from the members themselves. Whilst it was recognised that such a ‘mechanism’ was likely to remain elusive, frequent reference to it served a rhetorical purpose in positioning the Forum’s processes as a scientific, technical and explicit endeavour rather than a more emergent affair involving the inevitably messy process of human interactions (Hunter, 1997; Mechanic, 1997; Calnan et al, 2017; Moes et al, 2016).

7.5 Phronesis

My and others’ (Jenkins & Barber, 2004; Scourfield, 2011) data suggest that whilst an embodied practical rationality was clearly evident in deliberations of particular cases and in panel members’ accounts of their practices, this type of rationality tends to get written out of documented accounts of decision-making, particularly formal records, so that the picture of rationality that emerges is a ‘disembodied’ one that emphasises logical, rule-based reasoning.

This finding is perhaps unsurprising. Normative discourse about what constitutes good policymaking and good decision-making is firmly grounded in the modernist ideals of instrumental and institutional rationality – rational decisions are those based on scientific, disembodied, not embodied, narrative reasoning. Policy actors mobilise normatively oriented discourses; what Degeling (1996) refers to as the ‘sacred’ talk of policymaking, with its claimed values of objectivity, neutrality, and so on.

For example, in the Priorities Forum discussion quoted above, in which panel members deliberated the process of prioritising one service over another, a member counters the suggestion of the inevitability of emotional engagement in decision-making with the contention that good, ethical decision-making relies on formal expert knowledge:

“Surely what this Forum must try and do is not to be emotional, not to put yourself in the position of the person waiting, but try and come back to the evidence that we have. That’s all you can do. And people are always going to challenge the decision. But you have to go through it as rigorously as you can. So I think that’s just something you have to do. And we, as a Forum, we have to decide which has a greater priority. And yes, it’s invidious choosing between intervention on psychosis and IVF, but that’s the reality and there’s no point in us being here if we’re not prepared to face up to making those decisions. [...] ...ethics must in the end be about – in these contexts – be about making decisions on the evidence. And you have to have experts to give you that evidence.”
[Priorities Forum meeting T1, Site A]

Furthermore, in my data I observed how background papers for panel discussions focused on quantitative ‘hard’ data, rarely including a review of qualitative interpretive evidence. For example, in a Priorities Forum discussion about talking therapies, a GP member of the Forum indicated that he found the information in the background paper “*very difficult*” because all of the evidence in it was based on the assumption that mental illness could be defined as episodes of care:

“when in fact in the real world it is clear that mental illness is a dynamic condition and can’t be easily categorised and expressed as episodes of care.... the science and research base will give very precise definitions and use these to measure interventions but in real life this preciseness does not exist”. [Priorities Forum meeting T4, Site A]

Overall, across my case study sites, there was a striking contrast between the scientific rationality of background papers and the appeal to quantitative

language, and the more practical rationality that emerged from experiential knowledge and which played an important role in deliberations.

Jenkings and Barber note how the decisions of the local drug and therapeutic committees they studied are “*written so as to account for the decision in terms of scientific rationality, rather than the local rationality that was actually employed*” (Jenkings & Barber, 2004: p1765). This is not “*a duplicitous activity*”, they suggest, but reflects how “*members of the medico-scientific community have been taught to account for their activities; i.e. an account that forms a linear rational account of scientific process*” (Jenkings & Barber, 2004: p1765) and a ‘trust in numbers’ (Porter, 1995). In other words, the policy and legal context within which rationing panels are situated demand that decision-making is justified in this way. As one Chair of a resource allocation committee suggested to us, his role was to ensure that the panels’ reasons for decisions are framed within the formal criteria identified by local and national policy. Accountability, as a social accomplishment, is about learning the authoritative ways of making sense (Mäkitalo, 2003).

However, the *practice* of deliberations calls into question these formal accounts of decision-making. In practice, the dichotomies between objective and subjective knowledge, the universal and the particular, and cognition and affect, dissolve as panel members integrate different forms of knowledge to arrive at judgements about what they believe to be the right decision in the particular circumstances.

Here Aristotle's notion of phronesis provides a useful lens for theorising my observation of panel deliberations. Expanding on the introduction to the concept I gave in Chapter 3, phronesis, according to Dunne, is a *"habit of attentiveness that makes the resources of one's past experiences flexibly available to one and, at the same time, allows the present situation to 'unconceal' its own particular significance"* (Dunne, 1997: p305). Phronesis focuses on *"what is variable, on that which cannot be encapsulated by universal rules, on specific cases"* (Flyvbjerg, 2001: p57) and simultaneously involves warrants, values, emotions and commitment (Schwandt, 2003). The concept of phronesis encompasses an embodied view of human agency, in which the clarity required for wise judgements comes through an embodied capacity for dealing with ambiguity and meeting 'the other' (Benner, 2001). For example, an experienced nurse has acquired skills and judgement that go far beyond the acquisition of technical expertise – she has extensive experience of different situations and their particulars that gives her an intuitive feel for how to act in a given situation (Sayer, 2011).

Returning to my earlier analysis of the case example of Brenda, whose clinician had submitted a request to the IFR panel for funding for a course of hyperbaric oxygen therapy, we are able to interpret the GP's 'hunch' as expressing a critical and decisive interconnection between his clinical and experiential knowledge, his professional and personal values, his embodied sense of encountering the particular other, and importantly, the panels' confidence in his character and judgement as part of their collective

experiential knowledge (see Section 7.3). In this situation, and this particular set of social relationships, the GP expressed confidence in his own moral judgement and drew the panel into exercising their capacity for judgement, enabling them to come to what they consider to be the right decision. The panel reach, not so much a strictly evidence-based decision, but a *practical* decision to help “*the right person, to the right extent, at the right time, with the right aim, and in the right way*” (Aristotle, cited in Schei, 2006: p403).

7.6 Narrative ethics

My analysis of the data presented in this chapter illustrates the significance of a narrative approach to decision-making. Alongside accounts of the role of principles and ethical frameworks in deliberations, I observed how panel members skilfully invoked particular and personal forms of knowledge and emotion to draw out people’s engagement with their moral selves, and in this way successfully drew group members into exercising their capacity for human judgement. In other words, I observed how panels practiced a narrative ethics. Instead of focusing on the top down application of general rules or principles, a narrative ethics (sometimes known as virtue, rhetorical or Nicomachean ethics) focuses on the narrative telling of concrete particulars of individual cases, relational virtues and individual character (Greenhalgh, 2006; MacIntyre, 1984; Molewijk et al, 2011). Importantly, in narrative ethics the emotional reaction to the individual case is key, not something to be expunged or ‘reined in’, but integral to the process of reaching an ethical decision.

A conventional rationalist might argue that the GP in Brenda's case was simply swayed by the emotional pressure of the patient's plea to "*just say yes*" and the impulse to 'do something', and would consider such subjectivity 'irrational'. The narrative ethicist, however, would argue that the GP exhibited a particular pre-social sensibility that enabled him to "*bear witness*" to the patient's suffering and thus "*recognise and fulfil the duties incurred by intersubjective nearness*" (Charon, 2004: p34). For the narrativist, this sensibility is the fundamental starting point for the ethical decision; of intuitively knowing 'where to begin' (Aristotle, 2004) in persuading the panel of the rationality of 'saying yes'. And the GP's 'hunch' - his 'feeling of rationality' - illustrates the way in which emotion is 'woven into the very fabric' of his practical reasoning (Barbalet, 2001).

To date, little attention has been given to the role of narrative ethics in the difficult decisions facing rationing groups. Current debates about the ethical allocation of health care resources tend to invariably end up in a conceptual cul-de-sac: they review the different ethical principles and methodologies for decision-making and conclude that none can ultimately provide answers to the 'wicked problem' of resource allocation (Oswold & Cox, 2011). My analysis points to the value of applying a narrative lens to our understanding of rationing deliberations. The power of this alternative approach to ethics is that it offers a framework for resource allocators to be confident that their decisions on ethically complex issues will be good ones if they are *not* reduced to the dispassionate application of evidence and principles, but

rather, draw judiciously on the practical rationality of phronesis alongside more formal knowledge.

7.7 Summary and conclusion

In this chapter I have explored the enactment of practical reasoning in the rationing panels I studied. I have illuminated the tensions panel members experienced between 'being human' and 'being rational' in their decision-making. The normative discourses of evidence-based medicine and principlism support a view that rational decisions are those based on best evidence, that follow the right process and apply the right principles. However, as panels express and enact this position, they simultaneously demonstrate subtle phronetic skills and emotional engagement with the difficult decisions they face, helping them to judge what is the right thing to do in a concrete situation. My findings suggest that 'being human' and 'being rational' should not be thought of as in opposition to each other, but rather as constituting each other. As theorists of emotion and rhetoric suggest, emotionality and rationality can be conceptualised as continuous, with emotions helping to give salience, direction and purpose to reasoning (Barbalet, 2001; Fineman, 2003; Nussbaum, 2001; Townley, 2008).

8 'Low priority' treatments: the case of breast surgery

8.1 Introduction

An increasingly significant form of rationing in the NHS is the construction of local 'exclusion lists', specifying treatments that local commissioning organisations will not normally fund as part of the NHS 'package' of care (Audit Commission, 2011; Royal College of Surgeons of England, 2014) (see Chapter 2). These lists are variously referred to by commissioning organisations as 'low priority lists' or 'procedures of low clinical value' (terms that are used interchangeably despite subtly different meanings). In this chapter I take the example of breast surgery to explore how some treatments come to be deemed 'low priority' or 'low value' and thus not eligible for NHS funding.

As in the two previous chapters, I am interested in exploring the discursive practices and rhetorical work of rationing panels, representations of what the NHS can and cannot provide, and what it is considered 'rational' for the NHS to fund and not fund. And, as in earlier chapters, my analysis is grounded in sensitising concepts from rhetorical theory and Bakhtinian concepts (see Chapter 5). Additionally, in this chapter I draw on Yanow's conceptual framework for interpretive policy analysis as a heuristic device for structuring analysis and the presentation of this sub-set of my data (see Chapter 4).

Yanow identifies three categories of ‘symbolic artefacts’ that function as significant carriers of meaning: language, policy objects and acts (Yanow, 2000). Following Yanow, I illuminate how rationing decisions about breast surgery are contingent on [a] the *language* used by actors in panel discussions and minutes of their meetings, in particular the ‘evaluative accent’ given to certain words; [b] the work that *policy objects* such as guidelines and policy statements, referral letters from clinicians, patient representations, and legal judgements achieve in foregrounding particular concerns, and [c] the *act* of categorisation. I suggest that through the work of symbolic artefacts rationing panels create their own ‘interpretive communities’ within which rationality is locally constructed. In this sense, rationality does not so much derive from normative principles, but emerges as a situated, contingent accomplishment concerning ‘complex particulars’.

Breast surgery provides a particularly interesting case for studying the rationality of decisions about ‘low priority’ treatments. ‘Cosmetic’ surgical procedures are high on the list of ‘low priority’ treatments that NHS commissioning organisations will not normally fund (Maybin & Klein, 2012), and are among the commonest requests to IFR panels (Iacobucci, 2017a). Although, as indicated in Chapter 2, there are no systematically collected, national data on IFRs, breast surgery procedures are commonly listed in local commissioning organisations’ annual reports as in the top ten of non-drug IFR applications received (see, for instance, Bath and North East

Somerset Clinical Commissioning Group (2016) and NHS North West London (2012)).

My interest in the rationality of funding for breast surgery was prompted by the observation that such cases are commonly trivialised by the media and even by professionals as ‘boob jobs’, and used as an example of what the NHS should not spend limited resources on. Headlines such as *“Why did NHS pay for this woman’s 36DD breasts but refuse to pay £24,000 for an operation so this boy can walk?”* (Bentley, 2013) not only serve to trivialise breast surgery, but also point to the apparent absurdity of a decision to allocate NHS funding to it, whilst at the same time objectifying (and with an accompanying picture, overtly sexualising) a woman’s breasts. Against this background, breast surgery has become an easy target for disinvestment (Robinson et al, 2011a).

However, evidence suggests that some breast surgery offers significant health gain (Breuning et al, 2010; Klassen et al, 1996; Singh & Losken, 2012). One local guideline summarises the evidence on breast reduction surgery:

“Two systematic reviews and numerous primary studies conclude that breast reduction can reduce pain in shoulders, back and neck caused by large breasts. Patients generally express a high level of satisfaction following surgery. Other outcomes observed in research studies include improved psychosocial outcomes, psychological well-being, and quality of life. One cost effectiveness study calculated that the cost per quality-adjusted life year (QALY) for breast reduction was in the same range as that observed in hip replacement.” (South East Coast Policy Recommendation Committee, 2011).

Nevertheless, this particular guideline went on to recommend that:

“In the context of the resources available to provide healthcare for their populations, [the local commissioning organisations] consider the level of priority assigned to provision of breast reduction as low” (South East Coast Policy Recommendation Committee, 2011).

At national level, the NHS Modernisation Agency⁵ published guidelines for commissioners on when breast surgery should be NHS funded (NHS Modernisation Agency, 2005). They recommend that female breast reduction be available if a patient is suffering from neck ache, backache and/or intertrigo, conditional that a professionally fitted bra has not relieved symptoms, and the patient’s body mass index (BMI) is under 30; that NHS surgery for gynaecomastia is allowable in post-pubertal patients with a normal BMI, and that breast enlargement be provided on an exceptional basis for women with an absence of breast tissue unilaterally or bilaterally, or with a significant degree of breast asymmetry. Whilst these guidelines are now over 10 years old, the British Association of Plastic Reconstructive and Aesthetic Surgeons’ website indicates that they represent current best practice clinical guidelines (British Association of Plastic Reconstructive and Aesthetic Surgeons, 2015).

A study of local implementation of these guidelines found that they were only followed in full by 7% of local commissioning organisations, with significant variation between them regarding which treatments were funded, eligibility criteria and specified thresholds. The authors concluded that: “a

⁵ The NHS Modernisation Agency was established as an executive agency of the Department of Health in 2001. Its role was to modernise services and improve experiences and outcomes for patients. It was replaced by the NHS Institute for Innovation and Improvement in 2007.

'postcode lottery' exists in the UK for plastic surgery procedures, despite national guidelines" (Henderson, 2009). A more recent study focused specifically on access to surgery for gynaecomastia and similarly found wide variation in the eligibility criteria adopted by clinical commissioning groups (Stevens et al, 2015).

Information for patients on the NHS Choices website highlights the geographical variation in access to breast surgery, and is sometimes at variance with national guidance. The page on breast reduction states:

"The availability of breast reduction surgery on the NHS varies, depending on the eligibility criteria decided by your local clinical commissioning group (CCG). Some CCGs do not fund breast reduction surgery at all and others fund it selectively if you fulfil certain criteria." (NHS Choices, 2016b)

On surgery for gynaecomastia, the NHS Choices website makes no reference to recognised eligibility criteria, stating that:

"Normally, you'll need to pay for breast reduction surgery privately. But the NHS may provide this for you if you've had gynaecomastia for a long time, it has not responded to other treatments, and it's causing you a lot of distress or pain." (NHS Choices, 2016a)

The information on breast augmentation refers only to private sector provision, with no mention of the possibility of receiving NHS treatment, although a link to the British Association of Plastic Reconstructive and Aesthetic Surgeons' website leads to the following information:

Cosmetic breast augmentation is generally not available on the NHS so you will have to consult a plastic surgeon as a private patient and pay for the operation yourself. There are some exceptions to this rule. In some parts of the country the local NHS rules will allow consultations and operations for patients with small breasts in certain circumstances. These exceptional circumstances vary from region to region (British Association of Plastic Reconstructive and Aesthetic Surgeons, 2015).

The lack of national data on IFRs (see Chapter 2) means that there is no clear picture of the variation in IFR decisions about breast surgery. In one locality, approximately a fifth of ‘plastics’ cases considered by the IFR panel were approved for funding in 2009/10 (Healthcare Priorities Unit, 2010). In another, none of the nine breast surgery cases considered over a three month period was approved (Korhonen, 2011). There is additional variation in whether and how local commissioning organisations carry out pre-panel screening (‘triage’) of IFR referrals (undertaken by one or more individuals and led by either administrative or clinical staff), and the proportion of requests declined at this stage. In the two localities quoted above, a quarter and a third of all IFR cases triaged went to panel for review.

The wider context within which requests for NHS funding for breast surgery are considered is one of ambiguity and ambivalence about its status as a health care intervention (illustrated in the recent debate over whether the NHS should fund the replacement of faulty implants manufactured by Poly Implant Prothese (PIP) (Smith, 2012)). The clinical specialty of plastics typically draws a distinction between ‘reconstructive’ surgery (the correction of abnormality) and ‘cosmetic’ surgery (altering bodily appearance of patients presenting “*within the range of normality*”) (Burd, 2008). Both are underpinned by aesthetic principles addressing bodily form and function, and mental and physical health. However, critics point out that the boundary between ‘normal’ and ‘abnormal’ is always contested, and that distinctions between reconstructive and cosmetic, form and function, psychological and physical are “*dubious and misleading, given their inherent*

interconnectedness” (Naugler, 2009: p231). Nonetheless, as Naugler points out, these definitions and distinctions “*have important ramifications for the acceptance, accessibility and personal meanings of specific plastic surgery procedures*” (Naugler, 2009: p226). Other researchers have explored ‘cosmetic’ surgery’s precarious status between ‘beauty practice’, an ‘expression of identity’, and medical intervention in socio-cultural discourse (Gimlin, 2000; Gimlin, 2007). More prosaically, the word ‘cosmetic’ in everyday language is often used to convey superficiality, something “*without any real substance*” (Chambers English Dictionary).

Against this backdrop, I became interested in exploring how in practice panels made sense of funding requests for breast surgery, and how they constructed the rationality of their decision-making about these ‘low priority’ treatments. While the focus of this chapter is on breast surgery, I see the implications of my findings extending beyond breast surgery and individual funding requests. Breast surgery is one example of an increasing number of treatments for which restrictions on NHS access have been imposed through the introduction of eligibility and threshold criteria; other treatments, as indicated elsewhere in this thesis, include hysterectomy for menorrhagia, bariatric surgery, fertility treatments, hip replacement, cataract procedures, and gender reassignment (Audit Commission, 2011; Coronini-Cronberg et al, 2012; Maybin & Klein, 2012; Owen-Smith et al, 2013; Campbell, 2015b). Taken together, these restrictions represent a significant shift away from the notion of a universal and comprehensive NHS. At a time of unprecedented financial pressures, gaining insight into how the boundaries of NHS funding

are constituted and negotiated, and how rationality is constructed and accomplished in local NHS rationing practices, becomes increasingly salient. Furthermore, Klein et al have suggested that whilst in financial terms 'low priority' treatment lists represent very much the small change of NHS activities, they are nevertheless highly significant in that they:

"... appear to reflect a view - seldom clearly articulated, however - about the proper role of the NHS and the appropriate use of public funds... Implicit in the lists there is a distinction between deserving and undeserving patients." (Klein et al, 1995)

It is noteworthy that this quote comes from a paper published over 20 years ago, highlighting the enduring nature of the question of the rationality of low priority treatments.

My data set included 19 discussions (by email) about breast surgery in Site A (reflecting the large data set collected over a longer time period in this site (see Chapter 4)), one in Site B and two in Site C. Initially I looked at all 22 cases and then progressively focused in-depth on three case discussions, one from each study site, covering the three main breast surgery procedures: breast reduction, augmentation, and gynaecomastia.

As described in Chapter 4, data access varied across the three sites. Thus in the following section I present data from email discussions of an IFR panel in Site A, a transcript of an audio-recording of an IFR panel meeting in Site B, and field notes and associated documentation from observation of an IFR panel meeting in Site C. My interest in this chapter is in exploring common themes across my data concerning symbolic representation and the construction of meaning, rather than differences between data types and

modes of communication. Furthermore, as in the previous findings chapters, my focus on discourse and communicative practices should not be interpreted as a denial of the material reality of restricted budgets and limited health care resources. Rather, my concern is to explore how this material reality is rendered meaningful through the symbolic artefacts of language, policy objects and acts.

In the following description of cases, some details have been fictionalised to ensure anonymity and, as in previous chapters, the names given to patients are pseudonyms.

8.2 Case 1: a request for surgery for gynaecomastia

The first case is a referral of a 14 year-old boy (Jack) suffering from bilateral gynaecomastia. The local commissioning organisation has received letters from Jack's GP and a specialist breast surgeon:

It was a pleasure to review this extremely bright young man in clinic today along with his father.

Jack has been suffering from bilateral gynaecomastia from the age of seven, which has been gradually and progressively enlarging in size. His father had similar problems as a young man. This cosmetic impediment is causing Jack significant psychological stress and he finds it extremely embarrassing to undress in front of his peers. He is otherwise physically well developed with secondary sexual characteristics consistent with his age and has a slim frame.

[...]

Given the volume of his gynaecomastia he would most certainly require re-position of his nipple areola regardless of whatever kind of surgery he has. There may be some merit in combining liposuction with a more definitive procedure later on to positively influence the eventual cosmetic. Despite his age surgery could be offered to him as the problem is quite clearly present and appears to be largely fatty, incompatible with his physical frame. [Referral letter from breast surgeon to IFR panel, Site A]

The case is discussed by email over several weeks, by a panel of commissioning managers, both clinical and non-clinical (see Table 2). After an initial delay in the case being reviewed, a telephone call from the patient’s father indicating that his “*son is being bullied at school because of his condition and so the dad is obviously irate and would like some information*” [Email from IFR administrator to IFR panel], prompts consideration of the case. The ensuing discussion between panel members focuses on attempts to categorise the case in terms of the commissioning organisation’s funding mechanisms and whether or not the procedure is considered cosmetic. A decision is taken not to fund.

Table 2: IFR panel email discussion about Jack’s case of gynaecomastia

From	To	Email text
Assistant Director Public Health	Commissioning Manager	<i>Please circulate my view, thanks. We would normally refuse to fund this as it’s a cosmetic procedure, however we need to be sure about the following points:</i> <ul style="list-style-type: none"> • <i>significant adverse effect on activities of daily living</i> • <i>significant disfigurement</i> <i>and I think should request further information on these, in particular the first one. I also think we should seek the [Assistant Director of Children’s Commissioning] views since this request is for a 14 year old child.</i>
Chair of IFR Panel	Director of Commissioning cc Panel	<i>Could you have a look at this please. I’m not sure that it’s a contract exclusion and I wonder if it should be covered by PbR [Payment by Results].</i> <p><i>Breast reduction is normally something done to women with big breasts. The patient here is a young male with an unusual condition called gynaecomastia.</i></p> <i>This usually occurring in early adolescence and is a potential exception under the sector’s low priority treatments policy.</i>

		<p><i>If this were a contract exclusion then I'd say we could not fund it at present on affordability grounds, but I wonder if it could be classified as something under PbR and would not be considered to be a contract exclusion?</i></p> <p><i>Happy to discuss further.</i></p>
Director of Commissioning	Chair of IFR Panel; cc Panel	<p><i>I do not believe it is covered under PbR. I can find no reference to this under PbR. The consultant has also mentioned in his letter that it is cosmetic. We also have to bear in mind if [NHS hospital trust] carried out a procedure on a child they could apply a 78% uplift for the procedure from the adult tariff.</i></p>
Chair of IFR Panel	Director of Commissioning; cc Panel	<p><i>Thanks. If the consultant says that this is cosmetic and it's not covered under PbR then we must decline to fund this on affordability grounds and because of the low priorities treatment policy (noting that gynaecomastia is a potential exceptional circumstance in this policy).</i></p>
Assistant Director of Finance	Panel	<p><i>I consider this cosmetic and therefore suggest that we do not fund this.</i></p>
Director of Nursing	Panel	<p><i>Although I appreciate that this is very problematic for the individual this particular request is as outlined by the consultant surgery for cosmetic reasons therefore I suggest that we do not fund this particular request.</i></p>
Public health specialist	Panel	<p><i>I agree not to fund this procedure for cosmetic reasons.</i></p>

[Email discussion, IFR panel, Site A]

8.3 Case 2: a request for breast augmentation

The second case concerns a 48 year-old woman (Deborah) whose request was identified on the IFR summary form as “*plastics for breast asymmetry*”. The patient has a heart condition that required her to have a device fitted in her chest some years ago. When this was fitted she also had bilateral breast augmentation to camouflage the device. Complications resulted in the removal of one breast implant, causing breast asymmetry. The case was initially turned down at triage, but after letters of complaint from the patient’s

MP and a private plastic surgeon, was referred to the IFR panel. The panel (in Site C) had a policy of offering patients the option of giving a 10-minute representation of their request, although in this case the patient had chosen not to attend. The panel discussion focused on whether Deborah could be defined as 'exceptional' or not. After a lengthy discussion the decision was that Deborah was not exceptional and her request declined.

Below I reproduce an extract from my ethnographic field notes from observation of the IFR panel meeting at which Deborah's case of breast augmentation was discussed.

The IFR request was made in September 2011 by the patient's hospital consultant where the original treatment occurred. It stated:

'The patient's quality of life would be greatly impacted upon [if the treatment was not approved]. The patient is currently on antidepressants and does not feel comfortable to leave the house or have a sexual relationship with her partner as she will not allow herself to be seen undressed. The patient has a long history of [mental health condition], having the surgery could avoid any further deterioration in the patient's mental health'.

The request was turned down at triage one month later. The decision letter contained the following statement:

'The XXX Referral and Treatment Criteria, state that breast augmentation/revision of breast implant procedures are not routinely funded [and] ... psychological/psychiatric morbidity is not a criteria for funding aesthetic procedures. The IFR cannot take into account social, personal or emotional issues as we can only make decisions based on health needs. Therefore, while sympathetic to the fact that your patient may be disappointed, in accordance with IFR Policy, this application will not proceed to the IFR Panel and funding will not be provided'.

The agenda papers indicated that this decision letter prompted the patient to involve her MP [Member of Parliament]. The PCT customer services officer wrote to the Chair of the IFR panel, stating:

'The MP has written on her behalf seeking to have a positive impact on the IFR team's decision. In line with the NHS Complaints Procedure, I would be grateful if you could help me respond to his enquiry and either

reconsider the decision or provide me with a more detailed explanation of the reason why her request for the re-insertion of the breast implant has been denied’.

The documentation also included a letter from a private plastic surgeon whom the patient consulted, stating that the patient is:

‘at her wits end due to the cessation of her NHS treatment at the end of last year. ... My feeling as a plastic surgeon both privately and during the NHS full time is that she should have this done as she now has gross breast asymmetry which makes garment wearing problematic. Therefore there is a functional as well as a psychological benefit to this operation. She was also halfway through her treatment that was allowed on the NHS up until the middle of last year and I think it is unfair that it was stopped before finalisation. In addition, her heart condition means that surgery elsewhere is prohibitively dangerous as she needs cardiology and cardiothoracics to be present as well as a cardiac anaesthetist. This means I cannot do the surgery for her here. I think [the hospital] would be the most appropriate place for her to have this re-insertion of an implant’.

The Chair (Director of Nursing) summarised the above case history, noting the patient’s high anaesthetic risk. She asked the panel if they thought this patient was exceptional? The Director of Commissioning said that he didn’t see the patient as exceptional, although the circumstances leading to the request ARE exceptional, what she’s asking to have done ISN’T.

[...]

The public health consultant said that from the panel’s viewpoint they’re most concerned about the FUNCTIONAL benefits of a procedure. He quoted from the private consultant’s letter: ‘garment wearing [is] problematic. Therefore there is a functional as well a psychological benefit....’

There was agreement that this is not functional benefit in the sense that the panel defines it. The Chair said that functional benefit has to be clinical benefit.

The GP member then commented:

‘it’s a difficult one, how do we rationalise patients having implants after breast cancer surgery [the policy explicitly says it does not apply to patients undergoing breast reconstruction as part of treatment for breast cancer] but not for an infection such as this? [the implant had apparently originally been removed because of an infection and complications]. There’s a bit of me saying what’s the difference?’

[....]

The pharmacist suggested that the IFR request ‘boils down to an application for making someone symmetric who is asymmetric, so at the end of the day it’s a cosmetic procedure’.

The Director of Commissioning (who at the start had said he did not believe the patient was exceptional) seemed to agree with the GP that ‘if we do it for cancer patients then perhaps we should do it for this patient who genuinely needed the operation to have the [device] in the first place’.

At this point the panel were struggling and fumbling, clearly not at all sure where to take the discussion next. The GP, an authoritative member of the panel, had made a strong case for this patient to be treated as exceptional in the same way as the policy treats cancer patients as exceptional. At the same time, the referring clinician had not made a strong case for clinical benefit (within the narrow definition of clinical benefit being used by the panel) and there was a sense in which this was ‘at the end of the day’ cosmetic surgery, which the policy clearly says the PCT won’t pay for.

The GP repeated his views about personally not seeing the difference between this patient and cancer patients. The Director of Commissioning agreed with him, saying his view was the same as the GP’s.

The Director of Commissioning (trying to bring the panel to some decision I sensed) said ‘I don’t think this meets exceptionality in the broadest sense’ (now returning to his starting position). The Chair asked each panel member what they thought:

Pharmacist – ‘not exceptional’

Lay member – ‘not exceptional’

Chair – ‘not exceptional’

GP – ‘I think it is’.

Chair – ‘I’m sorry GP you’re outnumbered on this one. Is that OK?’

GP – ‘Yes, it’s OK’.” [Field notes of IFR panel meeting C5, Site C]

8.4 Case 3: a request for breast reduction surgery

The third case concerns a 38 year-old woman, Jane (see Table 3). Her GP reports that she is suffering from backache due to her large breasts and that “*the patient states physiotherapy and analgesia have not helped*”. The documents considered include a letter from the patient to her GP putting

forward her case for surgery, and a report from the local physiotherapy department, noting that the patient responded “*partially to the rehabilitation program and has been discharged*”. The case is considered by an IFR panel that meets weekly (Site B). They discuss the details of the physiotherapist’s report and patient’s letter and reach agreement that the case is exceptional and funding is approved subject to confirmation of the patient’s BMI.

Table 3: IFR panel discussion about Jane’s case of breast reduction

Speaker	Spoken words
Chair	Moving on to this case which is breast reduction, for back ache, we haven’t really... (inaudible)
CPH	How old is she? (pause whilst members look through papers including a report from a physiotherapist and a letter from the patient in support of her application)
ADPH	The physio report, doesn’t actually recommend, or what it says is that patient has responded partially [to
Chair	partially]
ADPH	the rehab programme and has been discharged.
Chair	mmm
ADPH	she needs a good bra
GP	I mean I think her letter actually says very much more [than
ADPH	yes] exactly
GP	anything, now it’s a question of whether, you know, she’s not had a relationship, she feels embarrassed, there’s obviously a psychological=
ADPH	hardly (inaudible) 38DD=
GP	=well if she is 4 foot 11 and quite a petite [frame
ADPH	what’s her] BMI?
GP	then that could well be large. And the fact that she has had three children will make them much more pendulous anyway so I could accept that she says they hang to her stomach and all the rest of it.
Chair:	I think the main thing here is that she hasn’t been referred, she doesn’t appear to have been referred to an orthopaedic surgeon [or
GP	breast] reduction, well
Chair	to get a second clinical opinion. We’ve got the GP’s opinion but she hasn’t had any MRIs or anything like that. We don’t know what the other potential factors could be.
GP	I don’t know that an MRI would help to be honest. I think there are much more psychological issues with this lady than the backache is to be honest neither here nor there. I am actually more concerned about the fact that she is withdrawing, she can’t pick up her child, she feels embarrassed to have an intimate relationship, umm
ADPH	She’s got a very young child, a 2 year old
GP	She’s got very young children, and I think [that’s
ADPH	yeah]

GP	that's making her exceptional personally and I would say, I would approve then
Pharmacist	(inaudible)
GP	I mean the only thing I could check is what her BMI is=
ADPH	=I think that's the only thing I wanted
GP	whether there is a, you know, if she was a BMI of 40 then maybe losing=
Pharmacist	weight
GP	weight would actually make them less heavy but she might still need a procedure to make [them
ADPH	I think] in principle we would agree but I mean I also want to know what her BMI is though

GP = general practitioner

ADPH = Assistant Director of Public Health.

Transcribing conventions: = no pause between speakers; [onset of overlapping talk;] end of overlapping talk.

[Extract from transcribed audio-recording of IFR Panel, Site B]

8.5 Symbolic language

A notable feature of the presentation and discussion of Jack's case is the evaluative function of the word 'cosmetic'. As discussed in Chapter 5, according to Bakhtin, all language is inherently evaluative and passes judgement on the world as it describes it (Maybin, 2001). In the referral letter, the consultant builds up a strong case of exceptionality (in line with the requirements of IFR decision-making – see Chapter 6), referring to the boy's "suffering", "significant psychological distress", "extremely embarrassing", "the volume of his gynaecomastia", all phrases that emphasise the validity of his exceptional status. Within the context of this description of 'exceptionality', the reference to the "cosmetic impediment" arguably emphasises the impediment rather than its 'cosmetic' nature. The dissonance between the two words is striking: an impediment is not merely 'cosmetic'. The consultant describes his treatment plan "to positively influence the eventual cosmetic"; the word 'cosmetic' here suggests a medical textbook meaning, i.e. surgery altering the appearance of the body.

However, in the email discussion the panel gives a very different evaluative accent to the word cosmetic. Here 'cosmetic' references a category of treatment in their low priority treatment policy that they "*normally refuse to fund*". By labelling the request 'cosmetic', the panel indexes a common sense institutional classification system that, in the words of Mary Douglas "*describes the way things are*" (Douglas, 1986), and the request easily loses its entitlement to funding. Moreover, at the same time as panel members give the word a new evaluative accent, they appropriate the surgeon's voice, saying "*The consultant has also mentioned in his letter that it is cosmetic*", and "*If the consultant says that this is cosmetic... then we must decline to fund...*". In other words, they attribute *their* (the panel's) evaluative accent to the *surgeon's* voice, introducing 'attributional distance' (Clayman, 1992) between themselves and their decision not to fund.

This example shows how the different evaluative accent of a single word functions to override the considerable work the consultant does to build a case for funding. Following Bakhtin, I suggest that the evaluative accent the panel gives to the word 'cosmetic' is not only a reflection of the here-and-now of policy discourse, but also contains echoes of 'historical and cultural scripts' (Mäkitalo, 2003), invoking societal views of cosmetic surgery more as 'beauty practice' than 'medical intervention' (Gimlin, 2007), and thus as something inherently undeserving of NHS funds.

The data extracts from the three case discussions contain other instances of the evaluative accenting assigned to specific words and phrases. The word 'functional' for example, acquires a number of meanings in relation to breasts. The breast functions as an organ of lactation and a secondary sexual characteristic as well as (pathologically) interfering with the functions of other organs and structures (e.g. the pectoral muscles and thoracic spine). As a surface structure, it also functions more symbolically as part of a healthy body contour and plays a significant role in gender identity.

In Deborah's case, the consultant makes a case that "*there is a functional as well as psychological benefit to this operation*" because "*she [the patient] now has gross breast asymmetry which makes garment wearing problematic*" – a comment that explicitly emphasises the breast's abnormal *biomechanical* function while also acknowledging its symbolic role in shaping body image and identity. However, the panel fails to engage with this definition of 'functional', stating that functional benefit has to be "*clinical benefit*".

In fact, although significant functional impairment (and the potential to reverse it) is sometimes identified as a relevant criterion for breast *reduction*, I found no guidelines referring to it for breast augmentation (for example to correct gross asymmetry). For breast reduction surgery, some commissioning organisations specified what they meant by significant functional impairment, but there was no consistency across organisations. In one locality, for example, the emphasis was on *social* function: "*Symptoms*

prevent the patient fulfilling routine work or educational responsibilities, or symptoms prevent the patient carrying out routine domestic or carer activities” (Bristol Clinical Commissioning Group, 2014). More commonly (as in Jane’s case below), guidelines defined functional impairment in terms of physical function, such as back or shoulder pain.

These examples of symbolic language illustrate how, in making their case for funding, clinicians use particular words, either because they are part of their everyday medical lexicon, or perhaps because they are aware of the rules which govern funding policies. However, each locality has different rules (and clinicians may deal with several commissioning organisations), and the rules are differently drawn upon and interpreted within IFR panel deliberations. Each decision is therefore contingent on how words come to acquire specific meanings in locally situated practice.

8.6 Symbolic objects

Taking Yanow’s second category of policy artefacts, I explore the role of documents as symbolic objects carrying meaning. A significant proportion of IFR panel activity involves interpreting and making sense of cases through considering documents - policy guidelines, referral letters, patient letters, and so on. Typically, as described in Section 4.3.2, a collection of papers relating to each case was circulated to panel members before the meeting (or as part of an email discussion). At the discussions I observed members spent time shuffling papers, looking back and forth between papers, and reading aloud from documents to draw the panel’s attention to specific

extracts. As previous research has shown, documents formed a critical part of the groups' sense-making activities, comprising "*articulating, debating and validating different readings*" of documents (Freeman & Maybin, 2011: p163), as they created a shared narrative of the case. In this section I explore the work that documents achieve in foregrounding particular concerns. Specifically, I explore how documents inscribe both institutional and patient framings of a funding request, creating a 'dilemma of attention' for panel members, as they struggle to attend to the patient's concerns on the one hand and institutional concerns on the other (Swinglehurst et al, 2011).

In Jack's case, the consultant's referral letter emphasised the psychological aspects of the patient's condition (although these were not discussed by the panel). Across my data set I noted that this emphasis on psychological factors was common in referral letters for breast surgery. I also noted that the NHS Choices website informs patients that whilst cosmetic surgery is rarely available through the NHS, it may occasionally be provided for psychological or other health reasons (NHS Choices, 2016c). We might assume that this explicit reference to psychological factors encourages patients and their doctors to emphasise such factors in arguing their case.

However, in Deborah's case, reference to psychological morbidity becomes a reason for *refusing* a request for funding. The initial 'triage stage' decision letter, in which the patient's doctor is informed that "*this application will not proceed to the IFR panel and funding will not be provided*", quotes from the

local policy document, stating that *“psychological/psychiatric morbidity is not a criteria for funding aesthetic procedures”* (incidentally, a clause that was added to the 2011 version of the policy document). The decision letter goes on to say: *“the IFR cannot take into account social, personal or emotional issues as we can only make decisions based on health needs”*. This latter sentence refers to a widely cited but erroneous interpretation of case law. As I set out in Chapter 6, a number of recent legal judgements have confirmed that when considering IFR cases, commissioning organisations do not *have* to take account of ‘social factors’ in their assessment of exceptional circumstances, but this legal position is frequently interpreted, as here, as meaning that they *cannot* take social factors into account. The overall effect of the decision letter containing these policy quotes is to suggest that reference to psychological factors in the request ‘ruled out’ its consideration as an IFR, and furthermore, the suggestion is that psychological morbidity, however profound, is not a ‘health need’.

This example shows how the local policy document is crucial in defining meaning. Reference to it serves to emphasise an institutional framing of the IFR and remove the need for deliberating the merits of the specific case at a panel meeting; it becomes a more or less straightforward case of ‘the policy says no’. In my interviews with panel members, respondents expressed concern about the increasingly significant role of pre-panel triage in the IFR process. They suggested that important perspectives (those of the patient, GP, or lay representative), widely seen as essential to fair deliberation of complex cases (Daniels, 2000; Klein, 2005), are being marginalised from

IFR decision-making, and superseded by an algorithmic, technocratic approach to potentially 'exceptional' cases, which by their very definition, should not be judged against a set of rules.

Policy guidance is only one type of IFR documentation. Additionally, there are referral and advocacy letters setting out the patient's case, and whether, how and to what extent these are brought into and able to influence discussions. In Deborah's case, after the initial rejection of the IFR at triage, letters from the patient's MP and a private plastic surgeon bring further authoritative voices to the table and prompt consideration of Deborah's case by the IFR panel, making it possible that the patient's framing of the case can take a hold (see next section). However, ultimately it is the institutional framing of exceptionality that dominates discussion and leads to a decision not to fund. Similarly, in Jack's case the patient's voice is conveyed through the consultant's referral letter and a phone call from the father, but in the ensuing email discussion it quickly evaporates and attention focuses on institutional concerns.

By contrast, in Jane's case the patient's voice is successfully privileged over the words in the policy documents by the GP framing the discussion in the patient's terms early on. The GP responds to another member who is summarising the physiotherapist's report, saying "*I think [the patient's] letter actually says very much more than anything...*". The patient's condition and circumstances quickly become the focus of attention, with the GP animating the patient's own words ("*she can't pick up her child, she feels embarrassed*

to have an intimate relationship...") (Goffman, 1981). The rhetorical work of the GP's contribution is apparent: she highlights the patient's role as a mother of three children, and she prefaces her animation of the patient's words by emphasising her concerns about *"the fact that [the patient] is withdrawing"*, adding her professional legitimacy to the patient's voice.

Interestingly, in Jane's case, far from being a reason NOT to fund, psychological morbidity is the explicit reason *for* the panel to fund the request. Even though the local policy states that: *"Funding should be considered if there are clear physical problems e.g. serious functional impairment, significant neck/back pain, intertrigo AND BMI < 30"*, the GP argues that *"there are much more psychological issues with this lady than..., the backache is to be honest neither here nor there"*, and successfully persuades the panel to agree in principle to fund Jane (once she has checked Jane's BMI with the GP).

My analysis of how these policy artefacts are drawn upon in panel discussions highlights how highly contingent the course of deliberation and decision-making can be. Which particular phrases or words from a policy are quoted, how they are interpreted, the different 'voices', in the Bakhtinian sense, that are present and brought into and frame discussion, all contribute to how panels create their own specific interpretation and narrative of the case, that leads them to a decision to fund or not.

A striking feature of all three cases was the *absence* of certain documents from discussion. Whereas a characteristic of many IFR cases was the sizeable amount of research evidence (literature reviews and/or original research papers) included as background documentation and brought into discussion, with breast surgery cases there was a surprising lack of reference to formal evidence. This contributes to the sense that breast cases were not taken as seriously as some other requests and did not warrant the attention to scientific research. This viewpoint was also reflected in some of the ‘common sense’ assumptions made about these requests. For example, my field notes record the Chair of an IFR panel introducing one case to the panel with the comment “*Today’s breast augmentation! Do we ever have a week when we don’t have one!*”, and another IFR panel member commenting in an interview that “*with the beauty interventions, we know to decline them, ... we don’t really think about it*”. Arguably, these comments reflect and reproduce deeply ingrained cultural views about the triviality and even comical nature of breasts and cosmetic surgery, what might be referred to as the ‘boob-job’ perspective.

8.7 Symbolic acts

Yanow’s third category of artefacts is ‘symbolic acts’. Here I focus on the act of categorising, as part of the process of deciding what to fund. As I have demonstrated in previous chapters, categorising can be seen as a fundamental part of institutional work, legitimatising what institutions do by describing the way things are in the social world (Douglas, 1986; Stone, 1997), enabling institutions to ‘sort things out’ (Bowker & Star, 2000), and

making possible the people-processing activities in which institutions are engaged (Mäkitalo, 2003). And crucially, I have suggested that the act of categorising involves moral evaluation; in the case of IFRs, deciding whether a patient is deserving of NHS funds.

My data highlight how individual funding requests involve a considerable amount of categorising, as panel members deliberate about whether a patient's case fits the IFR category or not, fits the category of exceptionality or not, is about psychological morbidity or not, and so on. The act of categorising may be quite obvious, or it may be more subtle and concealed.

In Jack's case, for example, the Chair of the panel comments:

“Breast reduction is normally something done to women with big breasts. The patient here is a young male with an unusual condition called gynaecomastia. This usually occurring [sic] in early adolescence and is a potential exception under the sector's low priority treatments policy.”
[Email, IFR panel, Site A]

This statement not only places Jack in a diagnostic category that is a “*potential exception*” under local policy, but also serves to set apart the category of “*women with big breasts*” applying for breast reduction from those with the “*unusual condition*” of gynaecomastia, emphasising the exceptionality (and arguably, therefore, deservingness) of young male cases of breast surgery requests. In the end, however, as I argued above, the labelling of Jack's request as ‘cosmetic’ trumps all other arguments, and his ‘exceptionality’ fails.

In Deborah's case the GP on the panel questions the categorisation of patients as set out in local policy. He says that he cannot really see the

difference between patients having implants after breast cancer surgery (which the NHS automatically funds) and this patient who is requesting re-insertion of an implant after clinical complications related to her heart condition. But later in the discussion, the community pharmacist member suggests that *“the request boils down to an application for making someone symmetric who is asymmetric, so at the end of the day it’s a cosmetic procedure”*, and eventually, after considerable discussion, the GP is outvoted and the request refused.

The pharmacist’s intervention is an example of what scholars of rhetoric refer to as argument by association (Perelman & Olbrechts-Tyteca, 1971). By dissociating asymmetry from the ‘deserving’ category of cancer patients, and associating it with the implicitly-agreed-to-be ‘undeserving’ category of a ‘cosmetic procedure’, ‘boiling down’ the case to one of asymmetry, the request easily fits the organisation’s policy not to fund (breast augmentation *“is not routinely funded within the local NHS for any patient group”*). Incidentally, a year earlier, the local policy *did* permit breast augmentation for gross asymmetry. The basis for this change in policy wording is unclear, especially given the national guidelines quoted earlier, stating that: *“exception should be made for women with a significant degree of asymmetry of breast shape and/or volume”* (NHS Modernisation Agency, 2005).

8.8 IFR panels as interpretive communities

In media and health policy debates much attention is paid to the so called ‘irrationality’ of the postcode lottery of health care, and the need to tackle ‘unwarranted variation’ in access to certain NHS treatments. The solution typically put forward is greater uniformity of local guidelines and policies, and improved adherence to the clinical evidence base. The British Medical Association for example recommends that commissioning organisations collaborate to ensure consistent policies concerning low priority treatments across localities, with greater reference to national guidelines (Al-Zaidy, 2013b).

Such recommendations have an intuitive appeal. It is undoubtedly difficult for patients to understand why in one locality breast augmentation may be eligible for NHS funding to correct asymmetry if *“there is a disparity of 2 or more cup sizes in the lower range (size C or below) or 3 or more cup sizes in the upper ranges (size D upwards)”* [IFR policy document, Site B], but in another locality the same procedure is ineligible for funding for any patient group. Or why in one locality significant psychological problems due to poor body image *is* permissible as an exceptional circumstance for breast reduction surgery, whereas in another locality psychological morbidity is not a criterion for funding it.

However, my analysis of the work of IFR panels suggests that ultimately the search for uniformity is an illusory policy goal. There exists a fundamental tension at the heart of the IFR system for rationing health care resources.

On the one hand it is a system predicated on and requiring case-based reasoning and judgement, to ensure that funding decisions are based upon individual patient circumstances (Keogh, 2011). On the other, it is a system that has evolved to become increasingly formalised and bureaucratised, with more and more emphasis on the use of pre-defined rules (eligibility criteria, attempts to define exceptionality, treatment thresholds, and so on). I observed a discernible tension for panel members between framing cases as complex instances of human suffering, involving moral engagement and emotionally and clinically challenging judgements, and instances of technocratic processing, involving instrumental negotiations over policy fit.

The turn to technocratic and rule-based reasoning is understandable in that it makes manageable the difficult tasks of rationing health care and critically appraising the clinical judgement of referring clinicians. The privileging of 'system' rules allows panel members to sidestep the fundamental ethical choices at the heart of IFR cases. But – and this is the real illusion of a standards based reasoning approach – rules must always be interpreted (Hunter, 1989). My findings suggest that, even if greater uniformity of local policies were achieved, and even if commissioning organisations adhered to the procedural requirements of institutional rationality (Owen-Smith et al, 2013), each local decision-making group will still create their own 'interpretive community' (Yanow, 2015) within which, through the subtleties of social interaction, local decisions will be justified. Rationality in this sense can never be simply a formal matter of applying normative principles and following institutional processes; it is irreducibly practical and contingent.

8.9 Summary and conclusion

In this chapter I have taken the case of breast surgery to explore the rationality of the funding of 'low priority' treatments in the NHS. My findings suggest that rationality is constructed moment by moment, with the 'rational' decision emerging from the micro-deliberations of the IFR panel about the contingencies of a particular case. In each case that I studied, the particular phrases or words that are used, or quoted from a policy document; how the 'evaluative accent' they are given is interpreted; the different 'voices' that are brought into and frame discussion; and how rhetorical strategies serve to position patients as deserving and undeserving of NHS funds, all contribute to how panels create their own specific interpretation and narrative of a particular case, that leads them to a decision to fund or not to fund. Sometimes we see the panels' decisions swayed by the instrumental framing of a formal rationality; at other times deliberation shifts towards a privileging of a more embodied and intuitive engagement with the particulars of the case, in other words, towards a more practical rationality. My findings concur with those of other researchers (Gkeredakis et al, 2011; Hughes & Doheny, 2011; Jenkins & Barber, 2004) who have explored the enactment of rationing practices close-up (see Chapter 3), and have noted the tension between different rationalities (Berg et al, 2001), concluding that:

"this tension will only be a fruitful one when the 'messiness' of practical rationality is not condemned from the clear-cut order of formal rationality, and will be taken for what it is: the necessary shape of professional health care work." (Berg et al, 2001: p95)

In the next chapter I shift my attention to a recurring theme to emerge from my data, namely, what in practice do lay people bring to deliberations about the rationing of health care?

9 Public participation, ‘ordinary’ knowledge and rationality

9.1 Introduction

In this chapter I explore public involvement in health care rationing decisions and the concept of lay or ‘ordinary’ knowledge. Public transparency and accountability have long been recognised as key tenets of rational decision-making (see Chapter 3); and patient and public involvement has become a mark of fair and sound decision-making in the NHS (Dyer, 2004; Hunter et al, 2016). Policy manifestations of this democratic ideal include the use of ‘mini-publics’ such as citizens’ juries (for example the creation of a Citizens Council at NICE as a way of public values informing decision-making (Davies et al, 2006; McIver, 1998; Weale et al, 2016)), public meetings, surveys and focus groups (as utilised in Oregon’s experiment of ranking health priorities based on public input (Dixon & Welch, 1991)), and lay representation on decision-making panels. The focus of this chapter is on this last form of public involvement.

Good practice guidelines recommend that local commissioners of health care appoint lay people to sit alongside clinical and managerial members of resource allocation panels (National Prescribing Centre, 2009a). For example, guidance from NICE to local clinical commissioning groups recommends that:

“Involving and engaging patients and the public at relevant stages of the decision-making process is an essential element of a robust and

transparent system. As key stakeholders, patients and public representatives must be supported to not only understand the complexity of the system, but be empowered to participate in how decisions relating to the allocation of scarce resources are made.” (National Institute for Health and Care Excellence, 2012: p4)

The case for public participation rests partly on enhancing the democratic legitimacy of rationing decisions by opening them to public scrutiny (“*an essential element of a robust and transparent system*”), and partly on epistemological assumptions about the type of knowledge necessary for good decision-making (Weale et al, 2016). The ‘ordinary wisdom’ and ‘common sense’ of public knowledge is seen as complementary and providing a healthy and productive counterbalance to expert, scientific, professional knowledge (Barnes, 2008; Stilgoe et al, 2006). The following extract from one commissioning organisation’s website emphasises the epistemological contribution that lay members are considered to bring:

“NHS XXX is recruiting additional Lay Members to bring a ‘real person’ perspective to the decision-making process within the XXX Individual Funding Request (IFR) and Appeal Panels.... Lay Members ensure that a broad set of perspectives are introduced to discussions, helping to balance reasoning with formal research evidence and cost-effectiveness data.” (Extract from local NHS website, 2012)

Two of the four panels I observed (a Priorities Forum in Site A and IFR Panel in Site C) included lay members (for details of the composition of these panels, see Chapter 4). Typically, two lay members attended the Priorities Forum, and at IFR panel meetings one lay member attended from a pool of two or three appointed lay people. For the Priorities Forum, potential lay members were identified through local patient and public networks; in the case of the IFR panel lay members were appointed through a locally advertised recruitment process. These people were variously and

interchangeably referred to as lay representatives, patient representatives or lay members.

At the time of study, the inclusion of lay members on priorities forums was commonplace, but less so on IFR panels. Since I completed my fieldwork (coinciding with the inception of clinical commissioning groups), my review of an ad-hoc sample of IFR policies published online suggests that lay involvement on IFR panels has become more common, although I was unable to find any systematically collected national data on this aspect of panel composition.

As indicated in my literature review in Chapter 3, previous research studies have found that whilst there is widespread support for the *principle* of lay involvement (Chisholm, A et al, 2009; Crawford et al, 2002; Greenhalgh et al, 2011; Mitton et al, 2009), there is a striking lack of clarity about the detail of what the role of a lay person is or should be, and a lack of evidence from observational studies about what lay people contribute in practice (Coast et al, 2002; Litva et al, 2002; Nathan et al, 2011). Dyer, for example, argues that despite “*a near universal acceptance of the idea of lay participation, the actual role of lay members is vague and inchoate*” (Dyer, 2004: p340). Some commentators have been critical of the widespread tendency to unquestionably assume that lay involvement is *prima facie* a ‘good thing’ (Abelson et al, 2007), and have suggested that lay involvement in resource allocation committees may sometimes be a vehicle for giving an appearance of democracy to difficult and unpopular rationing decisions; in other words, a

'technology of legitimation' (Harrison & Mort, 1998; Hunter et al, 2016; Klein, 2010; Lomas, 1997; Martin, 2008).

9.2 Frameworks for understanding lay involvement

Against this backdrop, I approached my data to explore the contribution of lay people in the deliberations of the panels I observed. Initially, I drew on the work of Habermas, one of the most highly-cited theorists in the field of deliberative democracy and public involvement, to inform my reading of the data (Habermas, 1987). Habermas draws a critical distinction between two basic social spheres of society: the 'lifeworld' and the 'system world'. The lifeworld is the everyday social world shared with others. It includes "*public opinion, norms and values, as well as individual experiences and behaviours*", and is "*the medium within which cultural and social integration is sustained and reproduced*" (Gibson et al, 2012: p537). By contrast, the 'system' comprises the "*steering media' of capitalist society*" (Gibson et al, 2012: p537), serving the interests of institutions and organisations. At the risk of over-simplification, we would perhaps expect professional experts on resource allocation panels to make abstracted and universal truth claims from the system world, and for the lay perspective to be situated in everyday experiences from the lifeworld.

Linked to these concepts are those of communicative and strategic action. Habermas defines communicative action as a consensual form of talk and interaction, orientated to understanding and agreement, whereas strategic action is orientated to the achievement of specific functional tasks. In

general terms, the lifeworld is reproduced predominantly through communicative action, and the system predominantly through strategic action (Greenhalgh et al, 2006). As described in Chapter 4 (see Section 4.2.1) the 'ideal speech situation', according to Habermas, is one characterised by interaction that is free from strategising and manipulation.

It is one where:

"...all who are competent to speak are able to do so, all speak with sincerity, all are allowed to question one another, and coercive forces (whether deriving from inter-personal relationships or wider, institutionalized power) that might inhibit such freedom to speak are neutralized. In short, the ideal speech situation comprises a set of rules and norms that encourage free debate and seek to 'bracket' forces at various social levels that might inhibit it." (Martin, 2012: pp165-6)

These Habermasian concepts have been widely used to consider the relationship between lay and professional perspectives (Gibson et al, 2012; Hodge, 2005; Newman & Clarke, 2009). Gibson et al, for example, suggest that in the context of patient and public involvement in health care, system-level imperatives might include economic considerations, the influence of professional bodies, and patient compliance with medical treatments. And they suggest that participatory forums, such as health committees comprising a mix of professional and lay members, can often be characterised by instances of strategic action, whereby:

"system imperatives come to dominate and distort the lifeworld resulting in certain 'pathologies' ...these 'pathologies' may include a lack of attention to service users' own perspectives, treating patients solely as a source of information which can be fed into a bureaucratic planning process and a tendency to treat healthcare decision making as a purely technical process, thus privileging the knowledge and expertise of technocrats over that of lay people." (Gibson et al, 2012: p538)

Habermas' ideas have been enormously influential in debates about public involvement in health care decision-making (most notably through the widespread adoption by national and local commissioning bodies of Daniels and Sabin's 'accountability for reasonableness' rules for deliberative processes (Daniels, 2000) – see Section 3.3.1). However, they have also been the subject of substantive criticism. Critics argue that the notion of an ideal speech situation is just that - an unattainable ideal that fails to take account of the full rhetorical complexity of deliberation in practice (Barnes, 2004; Young, 2000). Martin, for example, in his study of a national participatory forum, characterised the deliberations he observed as emotionally engaged, and often diverging from the substantive issue in hand (Martin, 2012). Similarly Davies et al, in their study of the deliberations of the Citizens Council of NICE, found that the deliberative ideal “*unrealistically sanitised*” what in practice were far messier interactions (Davies et al, 2006: p52).

Findings such as these chimed with my own observations of the panels I studied. Having begun my analysis with Habermasian concepts in mind, I increasingly found that they did not fit easily with the complexity and ambiguity of panel deliberations. For example, in practice I found lay people sometimes expressing 'system' values, and professionals expressing norms and values from the lifeworld. Any clear distinction between these worlds, and between lay and professional perspectives, and expert and ordinary knowledge, appeared less and less applicable. The categories with which I had begun my analysis seemed inherently unstable. Furthermore, I came to

realise that my initial analytic gaze, on the specific contribution of lay members, was perhaps a distorting one. My data were more consistent with the observation by other scholars that since deliberation is a collective activity it is not meaningful to isolate the role of any one member (Davies et al, 2006). Gradually, my attention turned to Bakhtinian ideas, which I found provided a theoretical lens more sensitive to the dynamic nature of the deliberations I had captured (see Chapter 5).

Like Habermas, Bakhtin sees language and communication as a site of social struggle over meaning, but rather than privileging a normative ideal and setting out clearly what 'good' deliberation looks like, Bakhtin offers a way of viewing deliberation as something more open, creative and 'unfinalisable' (Morson & Emerson, 1990).

As discussed in Section 5.3, Bakhtin rejects the suggestion that speakers 'own' thoughts and ideas that they bring 'pre-packaged' to the table. Thus, rather than thinking about what the lay person, the doctor, the manager 'brings' to the table, Bakhtin encourages us to explore how ideas and positions are constantly in a state of becoming, dynamically unfolding moment by moment. Bakhtin suggests that we constantly 'ventriloquate' the voices of others: "*we borrow not only their phrases and words, but also their points of view which become integral to our ideological framework for making sense of the world*" (Edmiston, 1994: p26).

Bakhtin's notion of the multi-vocality or 'discursive heteroglossia' of language (see Chapter 5) suggests that the production of meaning is always a contested process. The characterisation of a constant, never finalised dialogue between authoritative 'centripetal' discourses and the 'inwardly persuasive discourse' of centrifugal influences creates a more fluid picture than the binary dualism of the lifeworld and system world.

For Bakhtin, meaning is produced through a dynamic social process and always has the potential to shift. Whereas Habermas' notion of the ideal speech situation implies that inherent power imbalances can be partially overcome by adherence to certain procedural ground rules of deliberation that minimise the opportunity for strategic manipulation, for Bakhtinian scholars, power is ever present, conveyed in subtle but pervasive ways through, for example, what is taken for granted (the 'universal audience', see Chapter 5), and what seems normal and natural (Davies et al, 2006). At any moment in communicative interactions, actors are able to realise power through temporarily suppressing dialogue, converting it to a monologue. A monologue, according to Bakhtin, is when "*ideas are given the status of exclusive truth or presented as something which ought to be accepted without question*" (Edmiston, 1994: p27). However, the inherent or 'primordial' dialogism of language means there is always the opportunity for participants to resist monological tendencies. Thus Bakhtin's conceptualisation of deliberation is more emergent, more open to participants' creative agency and practical reasoning.

9.3 Exploring deliberations in practice

Sensitised by Bakhtin's theoretical ideas, I now turn to explore the deliberations of the Priorities Forum and IFR Panel I observed that included lay people in their membership. In addition to presenting data from interviews and observational field notes, I follow the format of the three previous findings chapters, drawing later in this section on an in-depth case example of deliberation to illustrate close-up the nature of deliberative practice.

My first overall observation of deliberations in practice concerns the problematic nature of labelling people as either 'real people' (lay members) or professionals. I found that notwithstanding these labels, the status of 'professional' and 'lay' was in practice quite blurred. It is perhaps a truism, but one that seems to be surprisingly often ignored, to say that professionals are also 'real people', and that a particular professional speaks as much as a local citizen, a woman, and a person with a disability, for example, as from her professional perspective. Referring to an earlier quote (see Section 7.4.2), as one member of the Priorities Forum, a director of nursing, commented:

"I guess ... you have to recognise that we're all sitting here with our own personal experience, also being patients and our family being patients. And then when we make value judgements, some of that feeds into it."
[Priorities Forum T1, Site A]

To which a lay member responded: *"It is totally human nature, it can never be any different."*

The lay people in my study, as other studies have similarly found (Dyer, 2004), mostly came from professional backgrounds (e.g. nursing, medical statistics, public and private sector management), and I noted that selection criteria for appointing lay members to panels identified core attributes that implied a professional background, for example, a good understanding of the principles of information governance, and experience of participating in discussions as a member of a multidisciplinary committee. Conversely, the Priorities Forum I observed included a local councillor, who defined her role as representing local community interests, although she did not formally occupy the lay member position. Similarly, GP panel members sometimes explicitly claimed to speak for particular patient groups. And surveys of local rationing panels (Adelphi Research UK, 2009; Russell et al, 2011) indicate that non-executive directors and health authority staff employed as patient advocate or patient and public involvement leads are commonly identified as standing in for the lay perspective.

Bakhtin's notion of multi-vocality provides a more nuanced and less static interpretation of the identities of panel members than the dichotomy of 'lay' and 'expert' permits. It allows us to consider individuals' contributions as representing not so much a single position (as much of the work on public representation implies), as a collection of voices, with individuals sometimes speaking as a patient, as a doctor, as a member of the public, from the voice of medicine, the voice of the life world, speaking as both a panel 'insider' and 'outsider', sometimes even within the same utterance.

In panel deliberations members rarely adopted single positions, and whatever the formal label of their role, they moved between different positions and identities as they talked and responded to others' contributions. For example, in a discussion about the priority the PCT should give to IVF treatment for infertility, a Director of Nursing contributed an argument about cost and clinical effectiveness and reflected that, *"I'm saying this from the position of having two healthy children and no intention of having any more"* [Priorities Forum T1, Site A]. In the same interaction, a lay member steered discussion to technical data on the number needed to treat when a piece of scientific evidence was being discussed. In a meeting of the IFR Panel, attended by the patient whose request for funding for a high-cost treatment was being considered, the lay member talked both from a 'lifeworld' perspective about his personal experience of his mother's treatment and also from a 'system' perspective, emphasising to the patient the Panel's focus on efficacy and safety of treatment rather than financial concerns (see Section 6.3, Chapter 6). In interviews, lay members positioned themselves as both 'insiders' and 'outsiders', simultaneously being part of a corporate decision-making structure while also depicting themselves as *'Joe Public'*.

A second and related finding to emerge from my data was the need to problematise the notion of 'ordinary' and 'expert' knowledge. The distinction between these types of knowledge is used so frequently that it has become a taken-for-granted truth, repeated in literature on patient and public involvement, policy documents, and commonly used by panel members

themselves (Elberse et al, 2011; van de Bovenkamp & Zuiderent-Jerak, 2015). The assumption is that lay people bring ‘a normality’ to discussions, they contribute ‘common sense’, experiential knowledge, and practical reasoning derived from lived experience. This is contrasted with the expert knowledge that professionals bring to discussions – a formalised, scientific, research-based, technocratic knowledge, as indicated in the quote from the NHS commissioning organisation earlier in this chapter (see Section 9.1) (Hogg & Williamson, 2001; Stilgoe et al, 2006).

Again, my data suggested this dichotomy to be an over-simplistic one that concealed a more complex picture. In practice, contributions contained a mix of types of knowledge and discourse genres. Specifically and significantly, I found that ‘ordinary’ knowledge and practical reasoning was as much a feature of expert, professional talk as lay contributions. Health professionals often contributed their experiential knowledge from the ‘frontline’ of general practice (see for example the quote later in this section from a GP about his perspective on hospital discharge of elderly people), from their experience as a patient, or from other aspects of their ‘lived experience’ (see for example the quote above from a Director of Nursing concerning IVF treatment).

Ordinary knowledge was invariably conveyed through the telling of anecdotes and stories, with a narrative genre interwoven with other discursive styles such as the presentation of research findings, hospital activity data or financial projections. We can see this in the following extract

(Table 4) from a discussion at a Priorities Forum meeting about the escalating costs of the provision of continuing care, in which members of the Forum discuss the question of whether and how the PCT can restrict patient choice to reduce spending on this aspect of care.

Table 4: Priorities Forum discussion about reducing the escalating costs of continuing care

Speaker	Spoken words
Medical Director (Chair)	Elspeth [consultant in public health medicine] and I went to visit the [specialist hospital for neuro-disability], and I went down there with the agenda of trying to make sure this was a very expensive place, it was very flash and it wasn't where we should be sending people, And Elspeth said that she could see me changing whilst I was there. And I came away thinking, this is an absolutely brilliant place because it's much more clinically effective and much more cost effective for people with these sorts of problems than many other sorts of care. And there's a real example, although it's anonymised in this paper, about a patient we've got, who is paralysed from the neck down, he's on a ventilator for nearly 24 hours every day, he's being cared for at home at an absolutely massive cost. About £350,000 a year. Always assuming that it was clinically appropriate for him to be at the [specialist hospital], and having discussed the generality of this with them, it would probably cost about £200,000 for him to be in the [specialist hospital for neuro-disability]. And in terms of clinical effectiveness, because of the skills that they've got there, because of the equipment that they've got there, because of the expertise and experience, it's very likely he'd have a very much better quality of care, a more clinically effective care. The disadvantage of course is that he wouldn't be at home, and his mates and his family would have to travel further to see him.
Lay member 1	And it's a long way to go.
Medical Director	It is quite a long way to go, yes.
Lay member 1	What are the chances of his rehabilitation eventually?
Medical Director	Well I didn't want to get too tied down with that particular individual, [but
Lay member 1	No, no] but that's just a dimension of it=
Medical Director	=But as a concept, and at that particular hospital, some people stay there for many, many years. Years, and years and years. But one example doesn't prove anything. But if I just give you one which stuck in my mind – there was a guy who had been involved in a motor accident, and had severe brain damage. He eventually got to the [specialist hospital for neuro-disability] and they helped him to use a computer, because there are special ways of using a mouse and whatever. And the first thing he wrote was a message to his wife, who he hadn't spoken to for 16 years, and he said, "I love you." Now, they were able to enable him to do that, which nobody else had been able to do, because they didn't have the

	expertise, the occupational therapy or whatever. Now, I don't want to get bogged down in that one case, but in terms of clinical effectiveness the argument could be that in certain circumstances, care in a special unit is more clinically effective than care at home or in the local hospital or whatever that might be.
Lay member 2	But you'll never change the [person's
Medical Director	I don't] want to get bogged down with particular examples.
Lay member 2	But I'm saying, from what, from the experience I've had as a district nurse for many, many years, home is home and you know, you know, deep down inside that they probably would be much, much better off with better care than any district nurses could give, we only sort of visited, we didn't have the amount of backup that they have now. But still, people would prefer to go, to have less chances if you like and still be in their own bed and in their own home than in the most wonderful places that you can think of. And I think that is something you just never can get over. Unless you turn round and say, "We will not be paying for certain types of patients to be nursed in their own home", and then wait for the bomb to drop.
Medical Director	That was actually my very next point because our second principle is cost effectiveness. And we say that we should not be paying for things which are not cost effective, other than in certain exceptional circumstances. And it may be that certain types of care are better provided in an institution, a hospital, special type of home, whatever it might be, than in the community. Or in a place that people just want to go to because it appears to them to be a nice place to be.

Transcribing conventions: = no pause between speakers; [onset of overlapping talk;] end of overlapping talk.

[Priorities Forum T2, Site A]

In this extract, the argument for clinical effectiveness is made in terms of the Medical Director's first-hand experience of visiting the specialist hospital and seeing for himself that *"this is an absolutely brilliant place because it's much more clinically effective and much more cost effective for people with these sorts of problems than many other sorts of care."* This is evidenced by telling two stories about individual patients, the second one a particularly emotive story, in which the specialist care of the hospital enables a disabled patient to write a message to his wife, telling her *"I love you"*. The Chair dissociates himself from the genre of storytelling (*"one example doesn't prove anything"* and *"I don't want to get bogged down with particular examples"*) while at the same time drawing on this very genre to construct a persuasive argument.

The lay member's contribution can be seen as bringing in the 'ordinary wisdom' of the patient's voice ("*home is home*") but at the same time, she expresses this from her *professional* perspective as a (now retired) district nurse. In his response to the lay member's contribution, the Medical Director effectively ignores her argument (that clinical effectiveness may not be the most important factor from a patient's perspective) to make a point about cost-effectiveness, but by beginning his contribution with "*that was actually my very next point*", implies agreement rather than disagreement. And in the next sentence the use of 'we' and 'our' depicts this as a shared framework that they have all signed up to as panel members.

This extract highlights the skilful rhetorical work at play. My interpretation is that the Chair's contribution is made all the more authoritative by its experiential, storytelling quality. It is the coalescing of the authoritative 'system' voice of the Panel's formal framework of ethical principles ("*our second principle is cost effectiveness*") with the inwardly persuasive discourse of 'ordinary' talk and everyday storytelling (see Section 7.6), combined with the ethos of the Chair's position as health professional and chair of the Panel, and additional rhetorical moves (such as the frequent use of three part lists, repetition, and the use of reported speech) that all contribute to establishing the credibility of a particular argument.

Furthermore, we are able to see how although ostensibly an interactive dialogue occurs between the speakers (albeit a rather imbalanced one in terms of the amount of talk), the Medical Director successfully converts this

into 'monologic discourse'. The alternative meanings and values being put forward by the lay member about "*home being home*" are suppressed by the closed and fixed meaning of the PCT's principles framework ("*our second principle is cost effectiveness... and we say that we should not be paying for things which are not cost effective*"). Although at the core of this extract there is an ideological struggle over meaning and values — what values should be brought to bear in decisions about the funding of people with continuing care needs? — the Medical Director manages to privilege a particular, authoritative perspective and in this instance the lay member's attempt to generate new meaning fails.

By contrast, in some panel deliberations I observed a more dialogic form of discourse. For example, in one discussion in which the IFR Panel discussed an individual funding request for an expensive treatment for a rare form of cancer, the lay member raised a number of questions: what alternative treatment might be available for the patient and what would be the implications of the Panel not approving funding? The Chair of the Panel responded to these questions by identifying them as important questions for the Panel to address, indicating her 'active-dialogic understanding' (Tuler, 2000) of the lay member's contribution. The questions prompted further discussion of the range of treatment options, the evidence about effectiveness, and the particular characteristics of the patient. They led to deeper questioning of the issues under discussion, keeping the dialogue going and open to new meanings.

In interviews, panel members tended to identify this sort of critically reflective questioning (one respondent expressed it as “*asking the damn fool questions*”) as the unique contribution of lay members. However, my observations suggested that this was not a role necessarily restricted to lay members; other members equally made contributions that acted as ‘thinking devices’, inviting responses that, if picked up on, could help to generate new meanings. One example came from a Priorities Forum discussion about hospital discharge, and consideration of a proposal to employ a consultant physician to expedite the discharge of elderly people from acute hospitals. Towards the end of a lengthy discussion, in which the dominant framing of the issue being put forward by PCT members of the Forum was that, in addition to the not aggressive enough discharge procedures of some clinicians, the payment system between acute trusts and PCTs had created perverse incentives for acute trusts to keep patients in hospital, a GP member raised some fundamental questions, drawing on his experiential knowledge:

GP: “I just think, I’m just trying to clarify one thing. I think we’re in danger of making a great big supposition, and that is, this has been mentioned twice about the perverse incentive to keep patients in beds. I don’t know where the evidence comes from. You probably are better informed than I am. But I would have thought it’s quite unlikely, certainly from where I’m looking from as a GP. I get the impression that they certainly want them out of the beds. So I think we’re in danger of making a supposition that there is a perverse incentive. I don’t think it’s really that”.

Medical Director: “I actually get the impression that maybe we do need to do some more work around that. And I just wondered if the outcome of that work ought to come back here before moving on”. [Priorities Forum T2, Site A]

In this instance, the GP manages successfully to reframe the policy issue under discussion. The GP’s contribution ‘keeps the conversation going’

(Schwandt, 2001; Torgerson, 2007), and when the additional work is brought back to the Forum at a future meeting, it is concluded that this extra work *“has been quite useful because it’s blown away some of the myths and some of the sort of conjectures that people were making as to what was going on”* (Extract from Priorities Forum T3).

It appears, then, that what is important is not necessarily *who* is asking the ‘damn fool’ questions (although in this instance arguably the ethos of the GP’s position was a persuasive factor), but the fact that such questions are seen as legitimate, and *how* they are responded to as part of the general process of making sense of the case under discussion. Thus a third finding to emerge from my data is that democratic discourse is facilitated not simply or necessarily by lay people sitting on committees and participating in discussion, but by *all* panel members contributing in ways that create opportunities for dialogic (generative) rather than monologic (authoritative) forms of discourse.

9.4 Summary and conclusion

In this chapter I have undertaken a Bakhtinian reading of my data to reconceptualise the question of what lay people might bring to deliberations about resource allocation. My findings suggest that, contrary to conventional thinking, ‘ordinary’ wisdom and a ‘real person’s perspective’ is something that professional members, as well as lay members, bring to discussions, and that, packaged within a narrative genre, can be used rhetorically to powerful effect. Analyses of lay involvement that perpetuate the dualism

between professional knowledge as comprising highly valued abstract and technical forms of knowledge, and lay people bringing another, but usually less valued form of knowledge (practical and experiential), neglect this critical characteristic of deliberation in practice, and falsely imply simplistic policy solutions.

Furthermore, my findings point to a potential role for the collective voices of *both lay and* professional panel members to disrupt and challenge the apparent monologue of technocratic discourse. A Bakhtinian perspective enables us to recognise the rhetorical nature of dialogue and the way in which authoritative discourse can “*temporarily arrest the multivocality of meaning within discourse*” (Steinberg, 1998: p855). The challenge, I suggest, is for *all* panel members to bring out the inherent dialogism of discourse in which meanings ‘can always be otherwise’, and so resist the imposition of fixed meanings.

A Bakhtinian analysis enables both an optimistic and realistic view of public participation in rationing deliberations. It is optimistic in the sense that lay people are not simply prisoners of the system world. Drawing on a Habermasian framework, Higgs and Jones come to the pessimistic conclusion that the promise of public participation in health care prioritisation is invariably a falsehood:

“asking the public ... is not so much about finding out what they think but rather ‘educating’ and ‘interpreting’ their views.... the only values that are accepted are those belonging to the system world and the only deliberation possible is that of accepting them”. (Higgs & Jones, 2001: p158)

By contrast, Bakhtinian theory maintains: “a concept of agency that recognizes human creativity and thereby encourages a practical orientation that would enhance action and judgement” (Torgerson, 2007: p7).

At the same time, it is a realistic view in that it does not privilege a normative ideal – a ‘communicative utopia’ of rational argument (Young, 2000), in which lay people have to learn the rules of reasonableness (Daniels, 2000), but rather allows us to explore the messiness and multitude of forms of speech in practice, the rhetoric, the storytelling, the anecdotes, etc., by both professionals and the public, that all contribute to how language is actually used. As Davies et al (2006) argue, conventional deliberation theory tends to be too cerebral and universalising in its ambition.

Davies et al also argue that the deliberative ideal, and thus what is generally considered to be appropriate forms of public debate, ultimately runs the danger of sapping citizens’ confidence in what they contribute to participatory forums. They argue that the focus on the rules of ‘good’ deliberation inevitably serves to define ‘unacceptable’ speech, and thus undermines the legitimacy of everyday talk that invariably includes emotive, subjective, divergent contributions (Davies et al, 2006). There are parallels here with my findings in Chapter 7, where I suggested that the dominant discourse of rationality marginalises and devalues the role of emotional engagement and subjectivity in judgements, and thus carries the danger of undermining rather than strengthening actors’ capacity to act (Myerson, 2000; Schwandt, 2001).

Commentators have called for greater clarity about the role of lay members on committees such as resource allocation panels (Dyer, 2004; Hogg & Williamson, 2001; Rosenberg-Yunger & Bayoumi, 2017), and the need for new 'knowledge spaces' "*within which both expert knowledge and forms of lay knowledge can interact with each other on an equal basis*" (Gibson et al, 2012: p536). Suggestions such as these that focus on lay people as 'representatives of society' or assume that it is only lay people that bring patients' interests and a particular type of knowledge fail to take account of the heteroglossia of deliberative practice. The contribution my research has made is to suggest a modest but also profound role for public participation: one that simply contributes, along with other members of deliberative forums, to keeping dialogue going, and thus brings to the fore the multivocality of meaning, offering the prospect of a reflexive and democratic mode of policy discourse (Torgerson, 2007).

10 Concluding reflections

10.1 Introduction

As I was nearing the completion of my thesis, several years downstream of the main period of data collection, reports in the national press of a judicial review of an IFR case caught my attention (Telegraph reporters, 2016). The case concerned a 17-year-old girl suffering from narcolepsy whose doctor had made an unsuccessful application to an IFR panel for her patient to be treated with sodium oxybate. At judicial review, the judge ruled in the patient's favour, suggesting that the IFR panel had made a "*totally irrational*" decision to refuse funding the girl's treatment (Lintern, 2016). Reading the judgement I was struck by the parallels between the rhetorical work and dilemmatic tensions evident in establishing a 'rational' decision on the case, and the findings presented in this thesis. I begin my final chapter with an exploration of this legal case, with the aim of demonstrating the on-going relevance of my research findings to current rationing practices and contemporary dilemmas in today's NHS.

In Section 10.3 I present a summary of the key themes to emerge from my thesis. In Section 10.4 I reflect on my methodology of rhetorical policy analysis, and in Section 10.5 I identify implications of my research for policy and practice. I end with some reflections on my personal journey as a researcher in undertaking this doctoral work (Section 10.6).

10.2 The case of *R (S) v NHS England (2016)*

Analysis of the legal judgement of the case of *R (S) v NHS England (2016)* highlights the different forms of rationality at work. The judge sets out the evidence base for the use of sodium oxybate, drawing on the formal rationality of evidence-based medicine. His summary of the scientific position is that:

“Many sufferers [of narcolepsy] can be treated effectively with a number of drugs which, without needing to go into detail, I shall call the usual treatment. But there are some, of whom the claimant is one, for whom the usual treatment is not effective. But there is a drug, sodium oxybate [...] It is effective for both adults and children and provides a real chance of enabling sufferers such as the claimant to live a normal life”. (Mr Justice Collins in *R (S) v NHS England, 2016: 2*)

The judge also invokes an institutional rationality in defining his role as being to judge on the procedural rather than the substantive aspects of the case:

“I must not substitute my own judgment for that of the panel. But I have not done this since, as I have set out, there were in my view failures by the defendant [NHS England] to have regard to all the matters raised by Dr Elphick [the patient’s consultant] and an altogether too restrictive application of exceptionality. The claimant qualified within the IFR policy...” (Mr Justice Collins in *R (S) v NHS England, 2016: 11*)

He concludes that: *“there has been a failure to apply the IFR policy correctly”*, in other words, the decision could be deemed irrational because institutional processes were not adhered to.

At the same time, a rhetorical reading of the legal judgement reveals appeals to a different sort of rationality. The judge comments *“I am conscious that it is not for me to strike down the decision in this case because I believe that it was too harsh and I have, as anyone would,*

enormous sympathy for the claimant". Here, the judge seems simultaneously to acknowledge and dismiss his emotional connection to the patient's case, nonetheless hinting at an embodied and intuitive engagement with the particulars of the case. At other points in his judgement the judge uses words or phrases that indicate a practical, everyday reasoning about the case, for example, in his statement that: *"I have no doubt that anyone reading the circumstances of this case would be surprised that sodium oxybate is not available for children generally and for the claimant in particular"*.

Accounts of the hearing quote the judge as referring to the *"absurd"* IFR policy, and NHS England's position as *"nonsense"* in relation to its stance on whether the girl's case was 'exceptional', words that highlight the role of pathos in his argumentation (Lintern, 2016). He concludes that: *"Any lay person looking at the facts of this case would not take the view that this was a reasonable decision to have made because it destroyed the girl's life"*. In appealing to the 'common sense' of a 'universal audience' of *"any lay person"*, and using the emotive language of 'destroying the girl's life', the judge invokes the moral components of the case.

Throughout his judgement the judge 'talks the talk' of a formal technocratic discourse (Greener & Powell, 2003), referring to NHS England's policy statements on exceptionality, and previous legal rulings which have indicated that IFR panels do not have to take social factors into account when determining exceptionality. At the same time, the judge implicitly

acknowledges the fundamental irrationality of a system that demands a binary classification of a patient as 'exceptional' or 'unexceptional', and that tries to place a boundary between a patient's social and medical conditions. In the final instance, the judge dismisses the technocratic system of categorisation, and settles on the "*ordinary meaning*" of exceptionality: "*exceptional can mean no more than a case which does not meet what is normal*". (While successfully appealing to a 'common sense' view here, the judge's statement still begs the question of how 'normal' is to be defined).

The judge makes a number of references to the patient's social circumstances, suggesting the relevance of non-clinical factors in his decision-making. He introduces S as someone who "*was academically very bright and the forecast was that she would and could expect to go to Oxbridge or certainly a highly regarded university*", and in his summing up states that "*No doubt the need for children to be able to achieve as they should is of fundamental importance*". Thus, although the judge explicitly acknowledges that his judgement should be based solely on the medical conditions of the case (according to a widely held interpretation of the legal position), he implicitly suggests otherwise.

The case also serves to highlight the unresolvable tensions inherent in rationing practices between the NHS values of comprehensiveness and universality, and the construct of affordability. The judge begins his ruling by setting out the dual obligations of NHS commissioners to promote a comprehensive service and, at the same time, to "*exercise its functions*

effectively, efficiently and economically". He states his view that this particular treatment for narcolepsy should be available on the NHS to all children, while also acknowledging the inevitability of funding decisions that restrict access to treatments and result in patient suffering. His concluding statement explicitly acknowledges the dilemmatic nature of rationing work:

"I wish to make it clear that there is no suggestion that any of those involved in the decisions lacked compassion or knowingly refused treatment they should have permitted. The difficulties facing them cannot be underestimated and I am sure that they regret the need to make decisions which result in suffering by individual patients". (Mr Justice Collins in *R (S) v NHS England*, 2016: 11)

Finally, the ruling in this case highlights the tension in rationing work between upholding individual rights and population interests. The judge remarks on the apparent paradox of the IFR system: on the one hand, *"the whole point of it is that there will be patients who are entitled to a particular treatment not available generally to others because of their exceptional needs"*, while at the same time, a common argument put forward against individual funding requests (and one advanced by NHS England here) is that *"a decision to treat some patients but not others has the potential to be unfair, arbitrary and possibly discriminatory"*. In other words, a system for ensuring that individual patients have fair access to treatment is also positioned as potentially unfair special pleading. The judge's use of the word 'entitled' is noteworthy, helping to build his argument, in this particular case, in favour of the patient's individual rights.

The parallels between my analysis of this new data extract and the findings I presented in Chapters 6 – 9 are striking. In the next section I summarise

how both illuminate the critical tensions and paradoxes that those involved in the rationing of health care have to negotiate.

10.3 The key themes of my thesis

The key tensions and paradoxes in the rationing of health care identified in this thesis are between [a] upholding the traditional values of a comprehensive and universal NHS, *and* working within increasingly constrained financial budgets; [b] accounting for the rationality of decision-making in terms of conventional rationalism, *and* coming to morally and emotionally engaged judgements based on practical knowledge and wisdom; [c] following system rules that address institutional concerns and guide categorisation and policy fit, *and* engaging in case based reasoning based on complex particulars, and [d] addressing individual rights *and* population interests. I have identified these tensions as dilemmatic, in the sense that they exist as contrary positions that are argued for and against (Billig et al, 1988).

Beyond these tensions lie fundamental questions that become ever more salient in an NHS experiencing unprecedented spending constraints (Toynbee & Walker, 2017). These are questions about who is deserving of NHS care and who is not? Which treatments is it considered appropriate for the NHS to provide and which not? What entitlement do citizens have to health care? And what can the NHS afford and what can it not?

My approach in this thesis has been not to attempt to answer these (arguably unanswerable) questions with reference to normative ideals and principles, but rather to explore how such questions are represented, interpreted, shaped and negotiated in micro-level rationing practices. In other words, my aim has been, in line with calls from researchers for more studies that explore policymaking 'as is' (Light & Hughes, 2001; Oliver et al, 2014; Gkeredakis et al, 2011), to illuminate 'the black box' of rationing practices.

I have sought to explore rationing deliberations as 'practical productions' (Fischer & Gottweis, 2012). Dunne refers to "*the fabric of practice as determining the form of rationality*" (Dunne, 2011: p19), and this describes well my findings concerning the rationality of rationing practices. I have demonstrated how, through practical productions, rationing groups create their own interpretive communities, and weave their own rationalities, and how locally situated and contingent the course of deliberation and decision-making can be.

At the same time, I have drawn attention to the constant interaction between situated practice and the broader argumentative context, and how the 'little d' discourses at the micro-level of social interaction and 'big D' discourses at a societal level (see Section 4.3.5) dynamically co-construct one another (Gee, 1999). Discussions about whether a local commissioning group should prioritise a particular service or fund a treatment for an individual patient are shaped by and shape broader societal discourses about the role

of the NHS and public funding. My concern has been with making linkages between language, social practices and context. And I have suggested that, alongside the ever-present creative agency of rationing groups to come to decisions they judge to be reasonable within the specific circumstances, there exists a discernible shift in the ideological landscape of the NHS towards a retrenchment of entitlement to health care.

10.4 Reflections on my methodology of rhetorical policy analysis

In exploring rationing practices I have been guided by my own novel methodological lens. It is novel in the sense that rather than utilise an 'off-the-shelf' methodology, I have drawn pragmatically and eclectically on theoretical ideas from both linguistic ethnography and interpretive policy analysis, sensitised by concepts from rhetorical theory and Bakhtinian ideas. And my work has incorporated an orientation towards action research and case study. In Chapter 4 I referred to Maclure's (2003) description of her 'promiscuous' and 'intentionally impure' approach in drawing on different methodological traditions to make sense of her research data, and her description fits my approach well.

In each of my findings chapters I adopted a slightly different approach to exploring rationing practices. This was in part a result of the origins of each chapter from discrete published papers, as described in Section 4.3. But it was also the result of choosing the lens that seemed most relevant to the data in hand. So, for example, in Chapter 6 I found that theoretical ideas

about the politics of representation enabled me to explore how rationing panels constructed certain truths about eligibility to health care from the ambiguity of communicative practices. In Chapter 7 the main sensitising concept I drew upon was phronesis, which enabled me to surface the emotional elements at play in deliberations, and to explore the notion of practical reason. In Chapter 8, Yanow's conceptual framework for interpretive policy analysis, which focuses on the symbolic language, objects and acts through which 'architectures of meaning' are created, facilitated my exploration of the work that not only language but also documents achieve, and the acts of moral evaluation involved in rationing decisions. In Chapter 9 the Bakhtinian notions of the multi-vocality or 'discursive heteroglossia' of language and monologic and dialogic forms of discourse opened up new ways of looking at the issue of public involvement and ordinary knowledge in rationing decisions.

Notwithstanding these distinct orientations, the commonalities in my analysis across the findings chapters enable me to identify some essential features of my approach to rhetorical policy analysis. First, the starting point of my analysis is that all policy practices, indeed all speech and communication, are unavoidably rhetorical. A common phrase used in the titles of academic analyses of policy is 'from rhetoric to reality', alluding to the idea of a 'real' policy position beyond rhetoric (Gold et al, 2005; Packwood, 2002). But as I argued in Chapter 5, rhetoric is not something that can be 'bracketed out' or expunged from speech, but an inherent part of all discourse, including policy discourse. My concern has been to explore all

rationing practices – deliberations of rationing groups, policy documents, legal judgements, and so on – as rhetorical work, as fundamental struggles over ideas and different ways of seeing the world (Stone, 1997).

Second, my rhetorical policy analysis has focused on exploring key elements of rhetoric, namely, logos, pathos and ethos, and how these elements are brought together as argumentative strategies in persuasive discourse. The in-depth study of rhetoric by rhetorical scholars extends beyond these essential elements, exploring many other aspects of rhetoric, for example, kairos (timing) (Segal, 2007) and humour (Perelman & Olbrechts-Tyteca, 1971). In this sense, my analysis has remained at a fairly broad level of rhetorical analysis, with an emphasis on the overall discursive features of rhetorical deliberation, and with a particular focus on the role of emotion, subjectivity and character work, alongside logos, in persuasive argument. Notwithstanding my limited focus, given the under-developed nature of rhetorical analysis of policy deliberations in the fields of linguistic ethnography (Shaw & Russell, 2015) and interpretive policy analysis⁶, I believe my work to be a valuable contribution.

Third, my rhetorical policy analysis has explored how rhetoric can both open up and close down debate, and thus enrich or compromise democratic deliberation. I have demonstrated how rhetorical moves in language use can serve to legitimise certain institutional framings, support the ‘monologic’

⁶ An examination of two recent textbooks (Copland et al, 2015; Wagenaar, 2011) on interpretive policy analysis and linguistic ethnography illustrates the lack of attention to rhetorical analysis, with rhetoric not even featuring in the books’ indexes.

tendencies of technocratic discourse, and suppress 'centrifugal' (diversifying) forces in deliberation. At the same time, I have drawn on the work of theorists such as Garsten (2006), and Young (2000) who argue for an affirmative view of rhetoric. In this vein, I have demonstrated how the processes of persuasion in rhetorical deliberation (the disclosure of ideas, careful listening, reflection on values, critical questioning, thinking things through in a way that evokes emotions and beliefs) has the potential to draw out our capacity for practical reasoning, and thus motivate the move from reason to wise judgements.

10.5 Implications for policy and practice

As described in Section 4.3 my work incorporated aspects of an action research approach, which meant that opportunities for organisational learning and discussions of the implications of my emerging findings for policy and practice were seen as an integral part of the study. In this section I discuss the key findings I explored with research participants and wider audiences, and reflect on the wider implications of my research.

10.5.1 Making visible the role of practical reasoning in rationing deliberations

The key finding I fed back to the panels I researched and other stakeholders involved with priority setting and the IFR process (see Section 4.3.5) concerned the role of practical reasoning in their deliberations. At the risk of over-simplifying the nuances my findings, I summarised my representations of rationing as shown in Table 5. This acted as a useful heuristic device to

prompt reflection and discussion with audiences about the inherent tensions in their work.

Table 5: Representations of rationing work

	Rationing as decision science	Rationing as fair and reasonable procedures	Rationing as rhetorical deliberation
<i>Epistemology</i>	Instrumental rationality	Institutional rationality	Practical reasoning
<i>Focus of attention</i>	Regularities and uniformities	System rules and processes	Uniqueness, concrete particulars
<i>Source of authority</i>	Scientific evidence, health economics	Legal judgements, organizational process	Personal knowledge and experience, character, emotional connection
<i>Method</i>	Evidence-based medicine, QALYs	Accountability for reasonableness framework	Argument, moral reasoning, persuasion
<i>'Good' rationing is a function of....</i>	Technical method	Transparency, accountability, public involvement	Wise judgement, moral engagement, phronesis

In certain respects I received a positive response to my findings. There was a sense that they chimed with and validated panel members' experiences; a recognition that, as Berg has suggested, practical reasoning is the "*necessary shape of health care work*" (Berg et al, 2001: p95). For example, at one stakeholder workshop at which I presented my findings, a participant supported my recommendation for greater recognition of the role of judgement in rationing work, commenting: "*... my bugbear is when everyone talks about evidence-based practice and [the] reality is with IFRs that there isn't much evidence. So we have to use judgement*".

Broader support for the significance of my findings for policy and practice came when Trish Greenhalgh and I were invited to join a steering group convened by NICE and the National Prescribing Centre to oversee the development of a competency framework to support the work of newly established CCGs. The aim was for the framework to act as both a training resource and a tool for reflective practice (National Institute for Health and Care Excellence, 2012). By feeding research findings into the competency framework's development, we encouraged the inclusion of a competency set on deliberation, reasoning and ethical judgement that emphasised [a] the role that local and experiential knowledge may play in improving the quality of judgements in decision-making, [b] how emotional engagement can support moral sensibilities and ethical judgements, and [c] the need for 'competent' CCGs to be able to discuss issues of ambiguity, complexity and uncertainty with an appropriate level of patience and tenacity (see Appendix 5).

We saw the inclusion of this competency set as a significant achievement in that it was the first time that formal guidance on local resource allocation decision-making explicitly acknowledged the role of practical reasoning. Furthermore, as important as the 'product' of the competency framework, was the *process* of developing the framework in helping to build the key relationships, reciprocities and commitments to enable this work to be taken forward. To further promote our ideas behind the inclusion of this

competency set in the framework I took the lead on writing a paper on its development with colleagues on the steering group (Russell et al, 2013).

Set against these examples of support for my research findings, I found that in other respects study participants struggled to engage with key messages. I came to realise that a common expectation was that I would be feeding back to panels on how they might make their decision-making more rational within instrumental and institutional conceptualisations of rationality (more evidence-based, improved processes of accountability). The suggestion to emerge from my research that we give greater legitimacy to a practice-oriented perspective on rationality involves a fundamental shift in what rationing groups conventionally classify as rational, and ultimately presents a challenge to mainstream health policy discourse.

10.5.2 Problematising patient and public involvement

As indicated in Chapter 9, it is now standard policy for rationing panels to include lay people, typically in the form of one or two lay members. To my knowledge, there are no systematically collected national data on this aspect of panel composition. Nor do we know, in the case of individual funding requests, what percentage of cases are considered by a system of pre-panel triage, which typically does not include lay representation (see Section 8.1). My data indicated an increasing trend towards decisions being taken at a pre-panel stage, with concerns expressed about the danger of decision-making becoming more technocratic rather than a deliberative process, with the consequence that lay and other significant voices (such as

that of local GPs) are excluded. A recommendation to emerge from this thesis is for data on the composition and activity of IFR panels to be systematically collected, collated and published so that we have an easily accessible national picture.

Debates about patient and public representation in academic literature point to the naivety of policy and practice that assumes that one or two lay members on decision-making panels can somehow represent “*the collective voice of the people*” or “*the public’s view ‘in the round’*” (Martin, 2009: p127). Notwithstanding the important issue of representativeness (Weale et al, 2016), my particular research focus was on exploring the notion expressed in policy documents that lay members brought a ‘real person’ perspective and ‘ordinary knowledge’ to decision-making, and how this played out in practice.

As demonstrated in Chapter 9, when I looked at deliberations close up, I found that the commonly assumed dichotomies between expert and ordinary knowledge, and between ‘real people’ and professional perspectives, dissolved. I also found that alongside the formal knowledge expressed by all panel members, were emotionally engaged instances of storytelling of personal experiences and anecdotes, and contributions from ‘ordinary knowledge’ that sometimes acted as thinking devices, opening up deliberations to further debate. These sorts of ‘non-rationalistic’ contributions from *all* panel members had the potential, I argued, to oil the wheels of deliberation, and to prompt new meanings and understandings of

issues under discussion. Thus my study has reframed the question of what lay people bring to rationing deliberations, shifting the analytic gaze on to a group's collective potential for dialogic forms of discourse (Edmiston, 1994).

My study has also exposed the problematic issue of patient attendance at IFR panels at which their cases are discussed, drawing attention to the ethical complexities of this aspect of practice (Russell et al, 2011). As indicated in Section 7.4.1, there is widespread variation in local policy, with some commissioning organisations permitting patient attendance and others prohibiting it. Again, there are no nationally collected data that maps the extent of variation in practice. Whilst my study raises questions about the feasibility and desirability of uniformity of local decision-making, given the inevitably situated, contingent nature of practice, on the issue of patient attendance it can be argued that there is a need for greater policy consistency. It is noteworthy that legal commentators have suggested that not allowing patients to attend IFR panels might even be considered procedurally improper, and could form the basis of a judicial review challenge, drawing on Article 6 of the Human Rights Act (the right to a fair hearing), although this argument has not been tested in the courts (Williams, 2011).

10.6 Reflections on my personal journey as a researcher

I end this thesis with some reflections on my personal journey as a researcher undertaking a DPhil.

When I began the research on which this thesis is based in 2005, as described in Section 4.2.1, I had no experience of studying the critical role of language in phenomena I was researching, and was unfamiliar with the fields of linguistic ethnography, interpretive policy analysis, and rhetorical theory. During the research period I undertook intensive courses in discourse analysis and linguistic ethnography, presented papers at Ethnography, Language and Communication and Interpretive Policy Analysis international conferences, and contributed (with Sara Shaw) a chapter to one of the first textbooks in the field of linguistic ethnography. In addition I published a number of papers in academic journals, as documented in Appendix 2. The research described in this thesis has enabled me to progress beyond the mainstay of my qualitative research practice prior to 2005, which could be characterised as predominantly focused on thematic analysis. It has opened my eyes to new ways of conceptualising research questions and studying social phenomena, and given me confidence in undertaking interpretivist research that is sensitive to both language use and social context.

10.6.1 Reflections on ethical research practice

My experience of undertaking this study has highlighted the complexity of ethical judgements in research practice. The danger of the current system of bureaucratic regulation of research ethics is that it creates the illusion that, in the words of Mattingly (2005: p461), *“it is possible to create a kind of contract between researcher and research participant guided by universal, context-free ethical norms that – if properly followed – will ensure the*

researcher's ethical behavior". In practice, notwithstanding the ethical code of practice I drew up as part of the process of gaining access to research sites, and the informed consent procedures I followed as per our research ethics committee approvals, I came to appreciate the greyness of much research ethics, particularly for studies involving ethnography and elements of action research (Copland et al, 2015; Murphy & Dingwall, 2007).

For example, in some situations, such as when I was invited to speak at a series of regional 'learning and sharing' events for IFR managers and panel members (see Section 4.3.5), there was an ambiguity about whether I was present in a research capacity, and thus the appropriateness of collecting and using data from audience discussion and workshop sessions. Similarly, when drawing on data extracts in the writing of my thesis, I was aware of the nuanced judgements to be made in balancing my ethical commitments to the research process and research participants in deciding what to include and exclude. In particular, when analysing email discussions and associated documentation from panel meetings, I needed to consider carefully what I judged to be part of the IFR panel discussion data set, and mull over these judgements with my supervisors. These and other instances drew my attention to the often-blurred nature of micro-ethical issues (Guillemin & Gillam, 2004), and the on-going ethical demands and responsibilities of everyday research practice.

Mainstream discourse about ethical research conduct pays little attention to the role of emotional engagement (Mattingly, 2005). Yet, as with the

arguments I have developed in this thesis concerning the value of emotions in providing a crucial stimulus for, and component of, ethicality in rationing decisions, so I have come to appreciate the vital and inevitable role of emotions in developing an ethical research practice. An emotional connection with my respondents and data not only supported sensitivity to the formal requirements of confidentiality, consent and anonymity, but also alerted me to 'ethically important moments' (Guillemin & Gillam, 2004). Such moments, I suggest, prompted a sense of moral responsibility in my choice of substantive topics for the findings chapters of this thesis. This point is exemplified in the following extract from my research diary notes (recorded after observing the IFR panel meeting at which Brenda's case, as described in Section 7.2, was discussed), and led me to identify the various dilemmatic tensions of rationing work as a central focus of my analysis:

"... my feelings of anger about the absurdity of a supposedly 'rational' policy that ends up with a group of committed people with good intentions having to judge whether a patient with a significant proportion of her mouth missing is exceptional or not, and whether the NHS should fund a treatment for her, a treatment that is freely and automatically available on the NHS to anyone returning from a diving holiday suffering from decompression sickness. And ends up with the poor patient in the position of supplicant. How did the NHS end up here?"

10.6.2 Reflections on the research process

Undoubtedly, if I were to start my research again there are a number of aspects I would approach differently. My introduction to linguistic ethnography, through a five-day intensive course (see Section 4.2.2), came nearly two years after I had begun to observe and collect data of Priorities Forum meetings. As described earlier, this course was, in research terms, a transformative experience, providing me with practical skills in using analytic

tools from linguistics and discourse analysis. Since registering as a doctoral student I have been able to apply this learning to the audio-recorded data I collected and transcribed as part of the Priorities Forum study; nevertheless I feel my sensibilities to the nuances of interaction and my recording of those nuances in field notes would have been enhanced had I already been exposed to the learning I acquired from this course.

As described in Section 4.3, I did not start the two research projects on which this thesis is based with the intention of developing the work into a DPhil. The two projects had their own specific research questions. The Priorities Forum study, which was part of a wider interdisciplinary programme of research on evidence, inference and enquiry, addressed the question of how a group of local policymakers utilise and reason with evidence. The research questions addressed by the IFR study were: what range of approaches is taken by commissioning organisations in deciding whether to fund IFRs? When deliberating on such decisions, how do IFR panel participants come to agree on what are considered reasonable judgements? And, how can a rhetorical analysis illuminate the substance and process of IFR deliberation?

The subsequent research question that I derived for this thesis, informed by these earlier questions and my growing interest in theories of rationality, was: how is rationality constructed and accomplished in NHS rationing practices? Of course in qualitative research it is not unusual for research questions to be modified and refined through a process of progressive

focusing as a study develops; still, arguably an explicit focus on constructs of rationality from the outset would have sharpened my research gaze, particularly in the Priorities Forum study (for example in designing interview questions, collection of policy documents, and the focus of observational field notes).

The trajectory of the research studies and my doctoral work has meant a time span of 12 years from when I first began collecting data to completing this thesis, which could be identified as a limitation of my research. Throughout the previous chapters I have drawn attention to significant policy developments and as far as possible included up to date contextual data. And I have made the case that the issues raised by my research continue to be as, and arguably more, relevant today as when my research began. Nevertheless, there is undoubtedly no substitute for immersion in the field when undertaking interpretive analysis, and my distance from the field in the later stages of this doctoral work has sometimes been a challenge.

I also want to reflect on both the advantages and disadvantages of undertaking a DPhil late in my research career and when I have semi-retired from academic work. The advantages have been to do with my substantial experience of the various stages of the research process, and the practical knowledge and confidence that comes with that experience, in contrast to the novice researcher embarking on a doctorate early in their career. The luxury of time has been another advantage: I feel I have been able to appreciate the process of writing this thesis largely unencumbered by the

demands of the day job of a contract researcher. Books that I had bought and borrowed whilst undertaking the funded studies and only had time to skim have been read at a leisurely pace.

The disadvantages were primarily to do with no longer being as engaged with the communities of practice that were so influential at earlier stages of the research process, when I was regularly attending conferences, workshops and data sessions. Whilst my supervisors provided excellent ongoing support and intellectual challenge, and there were some forums for discussing my work as a part-time DPhil student at Oxford, I have had to work hard to create opportunities for dialogue and cross-fertilisation of ideas that would normally arise as part of day-to-day work in an academic environment.

10.6.3 And finally

Typically, a doctorate leads to post-doctoral work, building on the ideas and arguments in the thesis. In my case I have retired from my main academic research post; nonetheless, I believe my work highlights important questions that could be taken forward in further research studies by others. As I began writing this concluding chapter, the BMJ reported a significant increase in IFRs in recent years, indicating that the *“rationing of treatment in the NHS in England is on the rise again, with patients around the country being denied access to care that just months ago was granted without question”* (Iacobucci, 2017a). Future research should explore the factors that are contributing to this rise in IFRs; how decisions about increasingly restrictive

eligibility and threshold criteria for treatments are negotiated, and thus how the rules of entitlement to health care are shifting in today's NHS. My work has demonstrated how interpretivist methodologies such as rhetorical policy analysis can explore questions such as these in ways that open up richly theorised understandings of how rationing is accomplished in practice.

References

- Abelson, J., Giacomini, M., Lehoux, P. & Gauvin, F.P. (2007) Bringing the public into health technology assessment and coverage policy decisions: from principles to practice, *Health Policy*, 82; (1) 37-50.
- Adelphi Research UK (2009) *A comprehensive survey of PCTs to evaluate local decision-making processes for funding new medicines*. London: National Prescribing Centre.
- Aggarwal, A., Fojo, T., Chamberlain, C., Davis, C. & Sullivan, R. (2017) Do patient access schemes for high-cost cancer drugs deliver value to society? Lessons from the NHS Cancer Drugs Fund, *Ann Oncol*, 0; 1-13.
- Al-Zaidy, S. (2013a) *Concepts of equity in the NHS. What do doctors understand by universality and comprehensiveness?* London: BMA Health Policy and Research Unit.
- Al-Zaidy, S. (2013b) *National versus local equity. How much variation is acceptable to doctors?* London: BMA Health Policy and Research Unit.
- Appleby, J. (2011) Can we afford the NHS in future? *BMJ*, 343:d4321.
- Appleby, J. (2016) *Is the NHS financially sustainable? Media briefing*. London: Nuffield Trust.
- Aristotle (1996) *Nicomachean ethics*. Harmondsworth: Penguin, cited in Schei, E. (2006) Doctoring as Leadership, *Perspect Biol Med*, 49; (3) 393-406: 403.
- Aristotle (2004) *Rhetoric*. London: Penguin.
- Ashcroft, R.E. (2006) Fair rationing is essentially local: An argument for postcode prescribing, *Health Care Anal*, 14; (3) 135-44.
- Ashforth, B. & Humphrey, R. (1995) Emotion in the workplace: a reappraisal, *Human Relations*, 48; (2) 97-125.
- Atkinson, P. & Coffey, A. (1997) Analysing documentary realities, in D Silverman (ed), *Qualitative research: theory, method and practice*, London: Sage pp. 45-62.
- Audit Commission (2011) *Reducing spending on low clinical value treatments*. London: Audit Commission.
- Austin, D. (2007) *Priority setting: an overview*. London: The NHS Confederation.
- Austin, D. (2008) *Priority setting: managing individual funding requests*. London: NHS Confederation Primary Care Trust Network.

- Austin, D., (2009) NHS Exceptional funding decisions, *Health Services Journal*, available from: <http://www.hsj.co.uk/comment/opinion/daphne-austin-on-nhs-exceptional-funding-decisions/1996368.article> [8 May 2009]
- Bacchi, C. (2000) Policy as discourse: What does it mean? Where does it get us? *Discourse: studies in the cultural politics of education*, 21; (1) 45-57.
- Bacchi, C. (2009) *Analysing policy: what's the problem represented to be?* Frenchs Forest, N.S.W: Pearson Education.
- Bailey, J. (2008) First steps in qualitative data analysis: transcribing, *Fam Pract*, 25; (2) 127-31.
- Bakhtin, M. (1981) Discourse in the novel, in M Holquist (ed), *The dialogic imagination*, Austin: University of Texas pp. 259-422.
- Bakhtin, M. (1984) *Problems of Dostoevsky's poetics*. edited and translated by C Emerson, Minnesota: University of Minnesota Press.
- Barbalet, J.M. (2001) *Emotion, social theory, and social structure: a macrosociological approach*. Cambridge: Cambridge University Press.
- Barnes, M. (2004) Affect, anecdote and diverse debates. User challenges to scientific rationality, in A Gray & S Harrison (eds), *Governing medicine: theory and practice*, Maidenhead: McGraw Hill/Open University pp. 122-32.
- Barnes, M. (2008) *Deliberating with Care: ethics and knowledge in the making of social policies*. Inaugural lecture, 24th April. Brighton: University of Brighton.
- Barnes, M., Knops, A., Newman, J. & Sullivan, H. (2004) The micro-politics of deliberation: Case-studies in public participation, *Contemporary Politics*, 10; (2) 93-110.
- Barrett, A., Roques, T., Small, M. & Smith, R.D. (2006) How much will Herceptin really cost? *BMJ*, 333; (7578) 1118-20.
- Bath and North East Somerset Clinical Commissioning Group (2016) *Individual Funding Request (IFR) Annual Report*. Bath: Bath & NE Somerset CCG.
- BBC News, (2016) IVF 'postcode lottery' on NHS criticised by fertility campaigners, *BBC News*, December 8, available from: <http://www.bbc.co.uk/news/uk-england-manchester-38243339> [28 April 2017]
- Benner, P. (2001) The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice, *Nursing Philosophy*, 1; (1) 5-19.
- Bentley, P. (2013) Why did NHS pay for this woman's 36DD breasts but refuse to pay £24,000 for an operation so this boy could walk? *Mail Online*, July 3, available from: <http://www.dailymail.co.uk/news/article->

[2350581/Why-did-NHS-pay-womans-36DD-breasts-refuse-pay-operation-boy-walk.html](#) [4 July 2013]

Berg, M., Meulen, R.T. & van den Burg, M. (2001) Guidelines for appropriate care: the importance of empirical normative analysis, *Health Care Anal*, 9; (1) 77-99.

Bevan, A. (1948) A message to the medical profession from the Minister of Health, *The Lancet*, 252; (6514) 24.

Billig, M. (1987) *Arguing and thinking: a rhetorical approach to social psychology*. Cambridge: Cambridge University Press.

Billig, M. (2001) Discursive, rhetorical and ideological messages, in M Weatherell, S Taylor & S Yates (eds), *Discourse theory and practice*, London: Sage.

Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D. & Radley, A., (1988) *Ideological dilemmas: A social psychology of everyday thinking*. Thousand Oaks, California: Sage.

Black, N. (2001) Evidence based policy: proceed with care, *BMJ*, 323; 275-9.

Blommaert, J. (2005) *Discourse: A critical introduction*. Cambridge: Cambridge University Press.

Blommaert, J. (2007) On scope and depth in linguistic ethnography, *Journal of Sociolinguistics*, 11; (5) 682-8.

Blumer, H. (1969) *Symbolic interactionism: perspective and method*. New Jersey: Prentice-Hall.

Bobbitt, P. & Calabresi, G. (1978) *Tragic Choices*. New York: Norton.

Bohm, K. (2017) *The transformation of the social right to healthcare*. London: Routledge.

Booth, W.C. (1974) *Modern dogma and the rhetoric of assent*. Chicago: University of Chicago Press.

Boseley, S., (2015) Postcode lottery for cancer drug as Nice rules Kadcyła too expensive, *The Guardian [online]*, November 17, available from: <https://www.theguardian.com/society/2015/nov/17/postcode-lottery-cancer-drug-nice-rules-kadcyla-too-expensive> [28 April 2017]

Bottoms, S.J. (2005) *The Cambridge companion to Edward Albee*. Cambridge: Cambridge University Press.

Bowker, G.C. & Star, S.L. (2000) *Sorting things out: classification and its consequences*. Cambridge, Mass: MIT Press.

- Brannigan, M.C. (2012) *Cultural fault lines in healthcare: reflections on cultural competency*. Lanham, Maryland: Lexington Books.
- Breuning, E.E., Oikonomou, D., Singh, P., Rai, J.K. & Mendonca, D.A. (2010) Cosmetic surgery in the NHS: applying local and national guidelines, *J Plast Reconstr Aesthet Surg*, 63; (9) 1437-42.
- Bristol Clinical Commissioning Group, (2014) Commissioning policy individual funding request: breast surgery (female), December 8, available from https://www.bristolccg.nhs.uk/media/medialibrary/2016/09/breast_surgery_female.pdf [19 January 2017]
- British Association of Plastic Reconstructive and Aesthetic Surgeons, (2015) Breast augmentation, available from: [http://www.bapras.org.uk/public/patient-information/surgery-guides/breast-enlargement - Available on NHS?](http://www.bapras.org.uk/public/patient-information/surgery-guides/breast-enlargement-Available-on-NHS?) [19 January 2017]
- British Association of Plastic Reconstructive and Aesthetic Surgeons, (2015) Clinical guidelines and regulation, available from: <http://www.bapras.org.uk/professionals/clinical-guidance> [9 January 2017]
- Bullock, H., Mountford, J. & Stanley, R. (2001) *Better policy making*. London: Centre for Management and Policy Making, Cabinet Office.
- Burd, A. (2008) Plastic, reconstructive and aesthetic surgery, *Medical Bulletin*, 13; (7) 25-7.
- Callahan, D. (2011) Rationing: theory, politics, and passions, *Hastings Center Report*, 41; (2) 23-7.
- Calnan, M., Hashem, F. & Brown, P. (2017) Still elegantly muddling through? NICE and uncertainty in decision making about the rationing of expensive medicines in England, *Int J Health Serv*, 47; (3) 571-94.
- Cameron, D. (2001) *Working with spoken discourse*. London: Sage.
- Campbell, D. (2012) NHS will have to ration further treatments, GPs warn, *The Guardian [online]*, February 27, available from: <http://www.guardian.co.uk/politics/2012/feb/27/nhs-treatment-rationing-gp-warning> [21 March 2012]
- Campbell, D., (2015) Jeremy Hunt raises doubts about long-term future of free NHS, *Guardian [online]*, July 16, available from: <https://www.theguardian.com/society/2015/jul/16/jeremy-hunt-raises-doubts-about-long-term-future-of-free-nhs> [4 October 2016]
- Campbell, D., (2015) NHS to 'extend rationing' of healthcare in bid to balance books, *Guardian [online]*, April 21, available from: <https://www.theguardian.com/society/2015/apr/21/nhs-to-extend-rationing-of-healthcare-in-bid-to-balance-books> [30 January 2017]

- Campbell, D. (2016) RNIB report: Patients in England face 15-month wait for cataract surgery, *The Guardian [online]*, September 21, available from: <https://www.theguardian.com/society/2016/sep/21/rnib-nhs-england-patients-15-month-wait-cataract-surgery> [27 April 2017]
- Carlsen, B. & Norheim, O.F. (2005) 'Saying no is no easy matter'. A qualitative study of competing concerns in rationing decisions in general practice, *BMC Health Serv Res*, 5; 70.
- Chambers, S. (2009) Rhetoric and the public sphere: has deliberative democracy abandoned mass democracy? *Political Theory*, 37; (3) 323-50.
- Channel 4, (2006) Britain's healthcare lottery, *Channel 4 Dispatches*, November 27, available from: <http://www.channel4.com/news/articles/dispatches/britains+healthcare+lottery/158300.html> [19 October 2015]
- Charles, A. (2017) Read all about it: media coverage of NHS rationing, *The King's Fund*, February 16, available from: <https://www.kingsfund.org.uk/blog/2017/02/read-all-about-it-media-coverage-nhs-rationing> [16 February 2017]
- Charon, R. (2004) The ethicality of narrative medicine, in B Hurwitz, T Greenhalgh & V Skultans (eds), *Narrative research in health and illness*, London: BMJ Books pp. 23-36.
- Chisholm, A, Briggs, K & Askham, J, (2009) *Not Nice. Can PCTs engage patients and the public in commissioning new health technologies?* Oxford: Picker Institute Europe.
- Clark, S. & Weale, A. (2012) Social values in health priority setting: a conceptual framework, *J Health Organ Manag*, 26; (3) 293-316.
- Clayman, S.E. (1992) Footing in the achievement of neutrality: the case of news-interview discourse, in P Drew & J Heritage (eds), *Talk at work: interaction in institutional settings*, Cambridge: Cambridge University Press pp. 163-98.
- Coast, J. (1997) Rationing within the NHS should be explicit: the case against, *BMJ*, 314; 1118-22.
- Coast, J. (2004) Is economic evaluation in touch with society's health values? *BMJ*, 329; 1233-6.
- Coast, J., Donovan, J., Litva, A., Eyles, J., Morgan, K., Shepherd, M. & Tacchi, J. (2002) If there were a war tomorrow, we'd find the money: contrasting perspectives on the rationing of health care, *Soc Sci Med*, 54; (12) 1839-51.
- Cookson, R., McDaid, D. & Maynard, A. (2001) Wrong SIGN, NICE mess: is national guidance distorting allocation of resources? *BMJ*, 323; 743-5.

Copland, F., Creese, A., Rock, F. & Shaw, S. (2015) *Linguistic ethnography: collecting, analysing and presenting data*. London: Sage.

Corden, G., (2008) Medicines watchdog attacks NHS 'postcode lottery' and drug costs, *The Independent [online]*, August 18, available from: <http://www.independent.co.uk/life-style/health-and-families/health-news/medicines-watchdog-attacks-nhs-postcode-lottery-and-drug-costs-900646.html> [19 October, 2015]

Coronini-Cronberg, S., Lee, H., Darzi, A. & Smith, P. (2012) Evaluation of clinical threshold policies for cataract surgery among English commissioners, *J Health Serv Res Policy*, 17; (4) 241-7.

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. (2002) Systematic review of involving patients in the planning and development of health care, *BMJ*, 325; (7375) 1263.

Crawford, R. & Emmerson, C., (2012) *NHS and social care funding: the outlook to 2021/22*. London: Nuffield Trust.

Crinson, I. (2004) The politics of regulation within the 'modernized' NHS: The case of Beta Interferon and the 'cost-effective' treatment of multiple sclerosis, *Critical Social Policy*, 24; (1) 30-49.

Daniels, N. (2000) Accountability for reasonableness, *BMJ*, 321; (7272) 1300-1.

Daniels, N. (2007) *Just health: meeting health needs fairly*. New York: Cambridge University Press.

Daniels, N. & Sabin, J. (1997) Limits to health care: fair procedures, democratic deliberation and the legitimacy problem for insurers, *Philosophy and Public Affairs*, 26; (4) 303-50.

Daniels, N. & Sabin, J. (1998) The ethics of accountability in managed care reform, *Health Aff (Millwood)*, 17; (5) 50-64.

Danis, M., Hurst, S.A., Fleck, L.M., Førde, Reidun & Slowther, A. (eds.), 2014, *Fair resource allocation and rationing at the bedside*, New York: Oxford University Press.

Davies, C., Wetherell, M. & Barnett, E. (2006) *Citizens at the centre: deliberative participation in healthcare decisions*. Bristol: Policy Press.

Dawid, P., Twining, W. & Vasilaki, M. (eds.), 2011, *Evidence, inference and enquiry*, Oxford: Oxford University Press.

Degeling, P. (1996) Health planning as context-dependent language play, *International Journal of Health Planning and Management*, 11; 101-17.

Denzin, N.K. & Lincoln, Y.S., (2011) *The Sage handbook of qualitative research*. Thousand Oaks: Sage.

- Department of Health (2012) *Health and Social Care Act 2012*. London: The Stationery Office.
- Department of Health (2015) *The NHS Constitution*. London: Department of Health.
- Dillon, A. (2015) Carrying NICE over the threshold, *NICE News, blog*, February 19, available from: <https://www.nice.org.uk/news/blog/carrying-nice-over-the-threshold> [30 April 2017]
- Dixon, J. & Welch, H.G. (1991) Priority setting: lessons from Oregon, *The Lancet*, 337; (8746) 891-4.
- Donnelly, L. (2011) Man who inspired Government cancer pledge is refused NHS treatment, *Telegraph [online]*, May 8, available from: <http://www.telegraph.co.uk/health/healthnews/8500506/Man-who-inspired-Government-cancer-pledge-is-refused-NHS-treatment.html> [9 May 2011]
- Donnelly, L. (2016) Patients wait up to 15 months for cataract ops, in 'devastating' lottery, *Telegraph [online]*, September 21, available from: <http://www.telegraph.co.uk/news/2016/09/21/patients-wait-up-to-15-months-for-cataract-ops-in-devastating-lo/> [28 April 2017]
- Dopson, S. & Fitzgerald, L. (2005) *Knowledge to action? Evidence-based health care in context*. Oxford: Oxford University Press.
- Douglas, M. (1986) *How institutions think*. Syracuse, NY: Syracuse University Press.
- Doyal, L. (1997) The rationing debate. Rationing within the NHS should be explicit. The case for, *BMJ*, 314; (7087) 1107-10.
- Dreyfus, H.L. & Dreyfus, S.E. (1986) *Mind over machine: The power of human intuition and expertise in the era of the computer*. New York: Free Press.
- Dryzek, J. (1987) Complexity and rationality in public life, *Political Studies*, 35; 424-42.
- Dryzek, J.S. (1993) Policy analysis and planning: from science to argument, in F Fischer & J Forester (eds), *The argumentative turn in policy analysis and planning*, Durham: Duke University Press pp. 213-32.
- Dryzek, J.S. (2000) *Deliberative democracy and beyond: liberals, critics, contestations*. Oxford: Oxford University Press.
- Duerden, M. (2010) From a cancer drug fund to value based pricing of drugs, *BMJ*, 341; c4388.
- Dunne, J. (1997) *Back to the rough ground: Practical judgment and the lure of technique*. Notre Dame, Indiana: University of Notre Dame Press.

Dunne, J. (2011) 'Professional wisdom' in 'practice', in L Bondi, D Carr, C Clark & C Clegg (eds), *Towards professional wisdom. Practical deliberation in people professions*, Farnham, Surrey: Ashgate pp. 13-26.

Dwarswaard, J., Hilhorst, M. & Trappenburg, M. (2011) The doctor and the market: about the influence of market reforms on the professional medical ethics of surgeons and general practitioners in the Netherlands, *Health Care Analysis*, 19; (4) 388-402.

Dyer, S. (2004) Rationalising public participation in the health service: the case of research ethics committees, *Health Place*, 10; (4) 339-48.

Eddama, O. & Coast, J. (2008) A systematic review of the use of economic evaluation in local decision-making, *Health Policy*, 86; (2-3) 129-41.

Edelman, M.J. (1985) *The symbolic uses of politics*. Urbana and Chicago: University of Illinois Press.

Edmiston, B. (1994) More than talk: a Bakhtinian perspective on drama in education and change in understanding, *NADIE Journal*, 18; (2) 25-36.

Edwards, N., Crump, H. & Dayan, M. (2015) *Rationing in the NHS*. London: Nuffield Trust.

Elberse, J.E., Caron-Flinterman, J.F. & Broerse, J.E. (2011) Patient-expert partnerships in research: how to stimulate inclusion of patient perspectives, *Health Expectations*, 14; (3) 225-39.

Elliott, J. (2000) Action Research, in R Davies (ed), *Coming to terms with research*, Norwich: University of East Anglia pp. 9-18.

Elvin, S. (2011) *NHS North Central London policy for individual funding requests (IFR). Low priority treatments*. London: NHS North Central London.

Elwyn, G., Greenhalgh, T. & Macfarlane, F. (2001) *Groups: A guide to small group work in healthcare, management, education and research*. Abington, Oxon: Radcliffe Publishing.

Entwistle, V., Watt, I., Bradbury, R. & Pehl, L. (1996) Media coverage of the Child B case, *BMJ*, 312; (7046) 1587-91.

Erickson, F. (1990) Qualitative methods, in R Linn & F Erickson (eds), *Research in teaching and learning, Volume II*, New York: Macmillan pp. 77-194.

Evans, J. (2000) A sociological account of the growth of principalism, *Hastings Center Report*, 30; (5) 31-8.

Feldman, M.S. & Orlikowski, W.J. (2011) Theorizing practice and practicing theory, *Organization Science*, 22; (5) 1240-53.

Fineman, S. (2003) *Understanding emotion at work*. London: Sage.

- Fischer, F. (1990) *Technocracy and the politics of expertise*. Newbury Park, Ca: Sage.
- Fischer, F. (2003) *Reframing public policy. Discursive politics and deliberative practices*. Oxford: Oxford University Press.
- Fischer, F. & Gottweis, H. (2012) *The argumentative turn revisited: public policy as communicative practice*. Durham, NC: Duke University Press.
- Flyvbjerg, B. (2001) *Making social science matter: Why social inquiry fails and how it can succeed again*. Cambridge: Cambridge University Press.
- Foot, C., Gilbert, H., Dunn, P., Jabbal, J., Seale, B., Goodrich, J., Buck, D. & Taylor, J. (2014) *People in control of their own health care. The state of involvement*. London: The King's Fund.
- Ford, A. (2012) The concept of exceptionality - a legal farce? *Med Law Rev*, 20; (2) 1-33.
- Ford, A. (2013) *Individual Funding Requests for cancer drugs and other treatments: a legal and ethical analysis of exceptionality. PhD thesis*. Manchester: The University of Manchester.
- Ford, A. (2015) Accountability for reasonableness: the relevance, or not, of exceptionality in resource allocation, *Med Health Care Philos*, 18; (2) 217-27.
- Forester, J. & Fischer, J. (1993) *The argumentative turn in policy analysis and planning*. Durham NC: Duke University Press.
- Foster, C. (2007) Simple rationality? The law of healthcare resource allocation in England, *J Med Ethics*, 33; (7) 404-7.
- Frankel, S., Ebrahim, S., Smith, G.D. & New, B. (2000) The limits to demand for health care, *BMJ*, 321; (7252) 40-4.
- Freeman, R., Griggs, S. & Boaz, A. (2011) The practice of policy making, *Evidence and Policy*, 7; 2; 127-36.
- Freeman, R. & Maybin, J. (2011) Documents, practices and policy, *Evidence & Policy*, 7; (2) 155-70.
- Friedman, A. (2008) Beyond accountability for reasonableness, *Bioethics*, 22; (2) 101-12.
- Furedi, F., (2014) Nudge: a war on moral judgement, *Spiked Review of Books*, June 20, available from: http://www.frankfuredi.com/article/nudge_a_war_on_moral_judgement [18 November 2015]
- Garfinkel, H. (1994) *Studies in ethnomethodology*. Cambridge: Polity Press.

- Garsten, B. (2006) *Saving persuasion. A defense of rhetoric and judgment*. Cambridge, MA: Harvard University Press.
- Garsten, B. (2011) The Rhetoric Revival in Political Theory, *Annual Review of Political Science*, 14; (1) 159-80.
- Gee, J.P. (1999) *An introduction to discourse analysis theory and method*. New York: Routledge.
- Giacomini, M., Hurley, J., Gold, I., Smith, P., & Abelson, J. (2001) 'Values' in Canadian health policy analysis: what are we talking about? Ontario: Canadian Health Services Research Foundation.
- Giacomini, M., Hurley, J., Gold, I., Smith, P. & Abelson, J. (2004) The policy analysis of 'values talk': lessons from Canadian health reform, *Health Policy*, 67; 15-24.
- Gibson, A., Britten, N. & Lynch, J. (2012) Theoretical directions for an emancipatory concept of patient and public involvement, *Health*, 16; (5) 531-47.
- Gibson, B. (2003) Framing and taming 'wicked' problems, in V Lin & B Gibson (eds), *Evidence-based health policy: problems and possibilities*, Victoria, Australia: Oxford University Press pp. 298-310.
- Gillespie, T. (2014) Father continues the fight after NHS refuses vital operation for his daughter suffering with gastroparesis, *Sutton Guardian [online]*, September 5, available from: http://www.suttonguardian.co.uk/news/11452499.Father_continues_the_fight_after_NHS_refuses_vital_funding_to_treat_his_daughter/ [2 October 2015]
- Gimlin, D. (2000) Cosmetic surgery: Beauty as commodity, *Qualitative Sociology*, 23; (1) 77-98.
- Gimlin, D. (2007) Accounting for cosmetic surgery in the USA and Great Britain: A cross-cultural analysis of women's narratives, *Body & Society*, 13; (1) 41-60.
- Gkeredakis, E., Swan, J., Nicolini, D. & Scarbrough, H. (2011) *Rational judgement revisited: practices of deliberation in healthcare funding decisions*. Submitted to the *Organisational Learning, Knowledge and Capabilities conference 12-14 April*. Coventry: University of Warwick.
- Glynos, J., Howarth, D., Norval, A. & Speed, E. (2009) *Discourse analysis: varieties and methods*. Essex: University of Essex National Centre for Research Methods.
- Goffman, E. (1981) *Forms of talk*. Philadelphia: University of Pennsylvania Press.

- Gold, S.K.T., Abelson, J. & Charles, C.A. (2005) From rhetoric to reality: including patient voices in supportive cancer care planning, *Health Expectations*, 8; (3) 195-209.
- Golden-Biddle, K. & Locke, K. (1993) Appealing Work: An Investigation of How Ethnographic Texts Convince, *Organization Science*, 4; (4) 595-616.
- Gottweis, H. (2007) Rhetoric in Policy Making: Between Logos, Ethos, and Pathos, in F Fischer, G Miller & M Sidney (eds), *Handbook of public policy analysis: theory, politics, and methods*, Boca Raton, FL: CRC Press pp. 237-50.
- Gray, M., Swift, S., Suleman, M., Hakes, D., Qualie, M., Mitchell, A., Dutch, S. & Beasley, N. (2012) *Value based clinical commissioning of elective surgical care*. London: NHS Right Care.
- Green, J. (2000) Epistemology, evidence and experience: evidence based health care in the work of Accident Alliances, *Sociology of Health and Illness*, 22; (4) 453-76.
- Green, J. & Thorogood, N. (2004) *Qualitative methods for health research*. London: Sage.
- Greener, I. & Powell, J. (2003) Health authorities, priority-setting and resource allocation: a study in decision-making in New Labour's NHS, *Social Policy and Administration*, 37; (1) 35-48.
- Greenhalgh, T. (2006) *What seems to be the trouble? Stories in illness and healthcare*. Oxford: Radcliffe.
- Greenhalgh, T. & Russell, J. (2009) Evidence-based policymaking: a critique, *Perspect Biol Med*, 52; (2) 304-18.
- Greenhalgh, T., Humphrey, C. & Woodard, F., (2011) *User Involvement in Health Care*. Oxford: Wiley-Blackwell.
- Greenhalgh, T., Kushner, S. & Russell, J. (eds.), 2015, *Case study evaluation: Past, present and future challenges*, Bingley, Emerald.
- Greenhalgh, T., Robb, N. & Scambler, G. (2006) Communicative and strategic action in interpreted consultations in primary health care: a Habermasian perspective, *Soc Sci Med*, 63; (5) 1170-87.
- Guillemin, M. & Gillam, L. (2004) Ethics, reflexivity, and ethically important moments in research, *Qualitative inquiry*, 10; (2) 261-80.
- Gutmann, A. & Thompson, D. (2002) Deliberative democracy beyond process, *Journal of Political Philosophy*, 10; (2) 153-74.
- Habermas, J. (1987) *The theory of communicative action*. Boston: Beacon.

- Hajer, M. & Wagenaar, H., (2003) *Deliberative policy analysis: understanding governance in the network society*. Cambridge: Cambridge University Press.
- Hall, C. & Slembrouck, S. (2009) Professional categorization, risk management and inter-agency communication in public inquiries into disastrous outcomes, *British Journal of Social Work*, 39; (2) 280-98.
- Hall, C., Slembrouck, S. & Sarangi, S. (2006) *Language practices in social work: categorisation and accountability in child welfare*. London: Routledge.
- Ham, C. (1999) The role of doctors, patients and managers in priority setting decisions: lessons from the 'Child B' case, *Health Expectations*, 2; (1) 61-8.
- Ham, C. & Coulter, A. (2001) Explicit and implicit rationing: taking responsibility and avoiding blame for health care choices, *J Health Serv Res Policy*, 6; (3) 163-9.
- Ham, C. & Robert, G., (2003) *Reasonable rationing. International experience of priority setting in health care*. Maidenhead: Open University Press.
- Hamilton, J.D. & Wills-Toker, C. (2006) Reconceptualizing dialogue in environmental public participation, *Policy Studies Journal*, 34; (4) 755-75.
- Hammersley, M. (2013) *What's wrong with ethnography?* London: Routledge.
- Harrington, J. (2016) *Towards a rhetoric of medical law*. London: Routledge.
- Harris, J. (1987) QALYfying the value of life, *J Med Ethics*, 13; (3) 117-23.
- Harrison, S. (1998) The politics of evidence-based medicine in the United Kingdom, *Policy and Politics*, 26; (1) 15-31
- Harrison, S. (2002) New labour, modernisation and the medical labour process, *Journal of Social Policy*, 31; (3) 465-85.
- Harrison, S. & Dowsell, G. (2001) The selective use by NHS management of NICE-promulgated guidelines: a new and effective tool for systematic rationing of new therapies? in A Miles, J Hampton & B Hurwitz (eds), *NICE, CHI and the NHS reforms - enabling excellence or imposing control?* London: Aesculapius Medical Press.
- Harrison, S. & Mort, M. (1998) Which champions, which people? Public and user involvement in health care as a technology of legitimation, *Social policy and administration*, 32; (1) 60-70.
- Harrison, S. & Smith, C. (2003) Neo-bureaucracy and public management: the case of medicine in the National Health Service, *Competition & Change*, 7; (4) 243-54.

- Hasman, A. & Holm, S. (2005) Accountability for reasonableness: opening the black box of process, *Health Care Anal*, 13; (4) 261-73.
- Hasman, A., McIntosh, E. & Hope, T. (2008) What reasons do those with practical experience use in deciding on priorities for healthcare resources? A qualitative study, *J Med Ethics*, 34; (9) 658-63.
- Hawkins, B. & Holden, C. (2013) Framing the alcohol policy debate: industry actors and the regulation of the UK beverage alcohol market, *Critical Policy Studies*, 7; (1) 53-71.
- Healthcare Priorities Unit (2010) *Annual report on individual funding requests 2009-10*. Oxford: NHS Oxfordshire.
- Hedgecoe, A.M. (2006) It's money that matters: the financial context of ethical decision-making in modern biomedicine, *Sociol Health Illn*, 28; (6) 768-84.
- Henderson, J. (2009) The plastic surgery postcode lottery in England, *Int J Surg*, 7; (6) 550-8.
- Higgs, P. & Jones, I.R. (2001) Finite resources and infinite demand, in G Scambler (ed), *Habermas, critical theory and health*, London: Routledge pp. 143-62.
- Hillman, A. (2014) 'Why must I wait?' The performance of legitimacy in a hospital emergency department, *Sociology of Health & Illness*, 36; (4) 485-99.
- Hodge, S. (2005) Participation, discourse and power: a case study in service user involvement, *Critical Social Policy*, 25; (2) 164-79.
- Hogg, C. & Williamson, C. (2001) Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees, *Health Expectations*, 4; (1) 2-9.
- Holm, S. (1998) Goodbye to the simple solutions: the second phase of priority setting in health care, *BMJ*, 317; (7164) 1000-2.
- Hope, T., Hicks, N., Reynolds, D., Crisp, R. & Griffiths, S. (1998) Rationing and the health authority, *BMJ*, 317; 1067-9.
- House of Commons Health Committee (2006) *NHS charges. Third report of session 2005-6*. London: The Stationery Office.
- Hughes, D. & Doheny, S. (2011) Deliberating Tarceva: A case study of how British NHS managers decide whether to purchase a high-cost drug in the shadow of NICE guidance, *Soc Sci Med*, 73; (10) 1460-8.
- Hughes, D., Petsoulas, C., Allen, P., Doheny, S. & Vincent-Jones, P. (2011) Contracts in the English NHS: Market levers and social embeddedness, *Health Sociology Review*, 20; (3) 321-37.

Hunter, D. (1995) Rationing: the case for 'muddling through elegantly', *BMJ*, 311; (7008) 811.

Hunter, D. (1997) *Desperately seeking solutions. Rationing health care*. Harlow, Essex: Longman.

Hunter, D.J., Kieslich, K., Littlejohns, P., Staniszewska, S., Tumilty, E., Weale, A. & Williams, I. (2016) Public involvement in health priority setting: future challenges for policy, research and society, *J Health Organ Manag*, 30; (5) 796-808.

Hunter, K.M. (1989) A science of individuals: Medicine and casuistry, *Journal of Medicine and Philosophy*, 14; (2) 193-212.

Hunter, K.M. (1996) Narrative, literature, and the clinical exercise of practical reason, *Journal of Medicine and Philosophy*, 21; (3) 303-20.

Huovila, J. & Saikkonen, S. (2016) Establishing credibility, constructing understanding: The epistemic struggle over healthy eating in the Finnish dietetic blogosphere, *Health*, 20; (4) 383-400.

Iacobucci, G. (2017a) Pressure on NHS finances drives new wave of postcode rationing, *BMJ*, 358; j3190.

Iacobucci, G. (2017b) NHS in 2017: the long arm of government, *BMJ*, 356; j41.

Independent Review Group (2017) *Independent review of the individual patient funding request process in Wales: Report for the Cabinet Secretary for Health, Wellbeing and Sport, Welsh Government*. Cardiff: Welsh Office.

Jenkins, N. & Barber, N. (2004) What constitutes evidence in hospital new drug decision-making? *Soc Sci Med*, 58; 1757-66.

Jones, I.R., Berney, L., Kelly, M., Doyal, L., Griffiths, C., Feder, G., Hillier, S., Rowlands, G. & Curtis, S. (2004) Is patient involvement possible when decisions involve scarce resources? A qualitative study of decision-making in primary care, *Soc Sci Med*, 59; 93-102.

Jones, L. & Exworthy, M. (2015) Framing in policy processes: a case study from hospital planning in the National Health Service in England, *Soc Sci Med*, 124; 196-204.

Jonsen, A. (1986) Bentham in a box: technology assessment and health care allocation, *Law Medicine and Health Care*, 14; 172-4.

Joyce, P. (2001) Governmentality and risk: setting priorities in the new NHS, *Sociology of Health and Illness*, 23; (5) 594-614.

Keogh, B. (2011) *Access to services. Letter to SHA Medical Directors 21/09/11*. London: Department of Health.

- King, C.S. (2000) Talking beyond the rational, *The American Review of Public Administration*, 30; (3) 271-91.
- Klassen, A., Fitzpatrick, R., Jenkinson, C. & Goodacre, T. (1996) Should breast reduction surgery be rationed? A comparison of the health status of patients before and after treatment: Postal questionnaire survey, *BMJ*, 313; (7055) 454-7.
- Klein, R. (1993) Dimensions of rationing: who should do what? *BMJ*, 307; (6899) 309-11.
- Klein, R. (2005) A middle way for rationing healthcare resources, *BMJ*, 330; (7504) 1340-1.
- Klein, R. (2010) Rationing in the fiscal ice age, *Health Econ Policy Law*, 5; (4) 389-96.
- Klein, R. & Williams, A. (2000) Setting priorities: what is holding us back - inadequate information or inadequate institutions? in A Coulter & C Ham (eds), *The global challenge of health care rationing*, Buckingham: Open University Press.
- Klein, R., Day, P. & Redmayne, S. (1995) Rationing in the NHS: the dance of the seven veils - in reverse, *Br Med Bull*, 51; (4) 769-80.
- Klein, R., Day, P. & Redmayne, S., (1996) *Managing scarcity: priority setting and rationing in the National Health Service*. Buckingham: Open University Press.
- Korhonen, T. (2011) *Individual funding request panel quarterly report*. Swindon: NHS Swindon.
- Laurance, J. (2008) NHS should not save patients' lives if it costs too much, says watchdog, *Independent [online]*, August 12, available from: <http://www.independent.co.uk/life-style/health-and-families/health-news/nhs-should-not-save-patients-lives-if-it-costs-too-much-says-watchdog-891501.html> [8 June 2011]
- Leach, J. (2000) Rhetorical analysis, in Bauer (ed), *Qualitative researching with text, image and sound*, Thousand Oaks, CA: Sage pp. 207-26.
- LeBaron, C. (2008) Microethnography, in W Donsbach (ed), *The International Encyclopaedia of Communication*, Oxford: Blackwell pp. 763-72.
- Lefstein, A. (2005) Thinking about the technical and the personal in teaching, *Cambridge Journal of Education*, 35; (3) 333-56.
- Licchetta, M. & Stelmach, M. (2016) *Fiscal sustainability and public spending on health*. London: Office for Budget Responsibility.

- Light, D. & Hughes, D. (2001) Introduction: A sociological perspective on rationing: power, rhetoric and situated practices, *Sociology of Health and Illness*, 23; (5) 551-69.
- Lindblom, C. (1959) The science of muddling through, *Public Administration Review*, 19; (2) 79-88.
- Linell, P. & Sarangi, S. (1998) Discourse across professional boundaries, *Text*, 18; (2) 143-57.
- Lingard, L. (2007) The rhetorical 'turn' in medical education: what have we learned and where are we going? *Adv Health Sci Educ Theory Pract*, 12; (2) 121-33.
- Lintern, S. (2016) Judge criticises NHS England for 'totally irrational' drug decision, *Health Services Journal [online]*, May 4, available from: <https://www.hsj.co.uk/sectors/commissioning/judge-criticises-nhs-england-for-totally-irrational-drug-decision/7004512.article> [2 May 2017]
- Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J. & Morgan, K. (2002) 'The public is too subjective': public involvement at different levels of health-care decision making, *Social Science & Medicine*, 54; (12) 1825-37.
- Lock, D. (2007) *Judicial review, individual funding requests and exceptionality*. London: Mills and Reeve.
- Lock, D. (2009) *Local decision-making judicial review script. What it is; what it is not; when it is used and how it works*. Liverpool: National Prescribing Centre.
- Lock, D. (2014) GPs and the law on commissioning services, *GP Law*, available from: <http://www.gplaw.co.uk/chapter-5-gps-and-the-law-on-commissioning-nhs-services> [3 June 2017]
- Locock, L. (1998) *Explicit rationing within the NHS quasi-market: the experience of health authority purchasers 1996-97. PhD thesis*. London: London School of Economics.
- Lomas, J. (1997) Reluctant rationers: public input to health care priorities, *J Health Serv Res Policy*, 2; (2) 103-11.
- Loughlin, M. (1996) Rationing, barbarity and the economist's perspective, *Health Care Analysis*, 4; 146-56.
- Loughlin, M. (2002) *Ethics, management and mythology*. Abingdon, Oxon: Radcliffe.
- MacIntyre, A. (1984) *After virtue: a study in moral theory*. Notre Dame: University of Notre Dame.

- MacIntyre, A. (1999) Social structures and their threats to moral agency, *Philosophy*, 74; (3) 311-29.
- MacLure, M. (2003) *Discourse in educational and social research*. London: Sage.
- Majone, G. (1989) *Evidence, argument and persuasion in the policy process*. New Haven CT: Yale University Press.
- Malkowski, J., Scott, J. & Keranen, L., (2016) Rhetorical approaches to health and medicine, *Oxford Research Encyclopaedia of Communication*, available from:
<http://communication.oxfordre.com/view/10.1093/acrefore/9780190228613.001.0001/acrefore-9780190228613-e-180> [2 March 2017]
- Marinker, M. (2006) Health policy and the constructive conversationalist, in M Marinker (ed), *Constructive conversations about health. Policy and values*, Oxford: Radcliffe.
- Martin, D., (2014) NHS blows millions on boob jobs and facelifts and taxpayers foot the bill, *Mail Online*, July 9, available from:
<http://www.dailymail.co.uk/news/article-2681287/NHS-blows-millions-boob-jobs-facelifts-Taxpayers-foot-bill-cosmetic-surgery-doubles-ten-years.html>
 [15 October 2015]
- Martin, D., Pater, J. & Singer, P. (2001) Priority setting decisions for new cancer drugs: a qualitative case study, *Lancet*, 358; 1676-81.
- Martin, G.P. (2008) Ordinary people only: knowledge, representativeness, and the publics of public participation in healthcare, *Sociology of Health & Illness*, 30; (1) 35-54.
- Martin, G.P. (2009) Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements, *Critical Public Health*, 19; (1) 123-32.
- Martin, G.P. (2012) Public deliberation in action: emotion, inclusion and exclusion in participatory decision making, *Critical Social Policy*, 32; (2) 163-83.
- Mattingly, C. (2005) Toward a vulnerable ethics of research practice, *Health*, 9; (4) 453-71.
- May, R. (1994) *The courage to create*. New York: WW Norton & Company.
- Maybin, J. (2001) Language, struggle and voice: the Bakhtin/Volosinov writings, in M Wetherall & S Taylor (eds), *Discourse theory and practice*, London: Sage pp. 64-71.
- Maybin, J. (2013) *Knowledge and Knowing in Policy Work: A case study of civil servants in England's Department of Health*. PhD thesis. Edinburgh: University of Edinburgh.

Maybin, J. & Klein, R., (2012) *Thinking about rationing*. London: King's Fund.

Maynard, A. (1996) Rationing health care, *BMJ*: 313; (7071) 1499.

Maynard, A. (2012) The Maynard Doctrine: £200 million National Cancer Drugs Fund - nice price for Big Pharma; nasty for NICE, *Health Policy Insight*, available from: <http://www.healthpolicyinsight.com/?q=node/526> [18 October 2010]

Mayor, S. (2009) NICE rules that drug used in advanced liver cancer is not cost effective for the NHS, *BMJ*, 339; b4956.

Mäkitalo, A. (2003) Accounting practices as situated knowing: Dilemmas and dynamics in institutional categorization, *Discourse studies*, 5; (4) 495-516.

McIver, S. (1998) *Healthy Debate? An independent evaluation of citizens' juries in health settings*. London: King's Fund.

McMillan, J., Sheehan, M., Austin, D. & Howell, J. (2006) Ethics and opportunity costs: have NICE grasped the ethics of priority setting? *J Med Ethics*, 32; (3) 127-8.

Mechanic, D. (1997) Muddling through elegantly: finding the proper balance in rationing, *Health Affairs*, 16; (5) 83-92.

Mehan, H. (1996) The construction of an LD student: a case study in the politics of representation, in M Wetherell, S Taylor & S Yates (eds), *Discourse theory and practice*, London: Sage pp. 345-63.

Merlo, G., Page, K., Ratcliffe, J., Halton, K. & Graves, N. (2015) Bridging the gap: exploring the barriers to using economic evidence in healthcare decision making and strategies for improving uptake, *Appl Health Econ Health Policy*, 13; (3) 303-9.

Milewa, T. (2008) Representation and legitimacy in health policy formulation at a national level: Perspectives from a study of health technology eligibility procedures in the United Kingdom, *Health Policy*, 85; (3) 356-62.

Miller, C. (1990) The rhetoric of decision science, or Herbert A. Simon says, in H Simons (ed), *The rhetorical turn. Invention and persuasion in the conduct of inquiry*, Chicago: Chicago University Press pp. 162-84.

Miller, C.R. (2003) The presumptions of expertise: the role of ethos in risk analysis, *Configurations*, 11; 163-202.

Mishler, E. (1984) *The discourse of medicine: Dialectics of medical interviews*. Norwood, NJ: Ablex.

Mitton, C., Smith, N., Peacock, S., Evoy, B. & Abelson, J. (2009) Public participation in health care priority setting: A scoping review, *Health Policy*, 91; (3) 219-28.

Moberly, T. (2012) 90% of PCTs are now rationing care, *GP Online*, June 19, available from: <http://www.gponline.com/exclusive-90-pcts-rationing-care/article/1136671> [14 October 2015]

Moberly, T. (2012) GPs fighting for patient care as rationing hits access, *GP Online*, November 19, available from: <http://www.gponline.com/exclusive-gps-fighting-patient-care-rationing-hits-access/article/1160171> [19 April 2017]

Moes, F., Houwaart, E., Delnoij, D. & Horstman, K. (2016) Contested evidence: a Dutch reimbursement decision taken to court, *Health Econ Policy Law*, 12; (3) 325-44.

Moffatt, F., Martin, P. & Timmons, S. (2013) Constructing notions of healthcare productivity: the call for a new professionalism? *Sociol Health Illn*, 36; (5) 686-702.

Molewijk, B., Kleinlugtenbelt, D. & Widdershoven, G. (2011) The role of emotions in moral case deliberation: theory, practice, and methodology, *Bioethics*, 25; (7) 383-93.

Moreira, T. (2011) Health care rationing in an age of uncertainty: a conceptual model, *Soc Sci Med*, 72; (8) 1333-41.

Morse, A. (2015) *Investigation into the Cancer Drugs Fund*. London: National Audit Office.

Morson, G.S. & Emerson, C., (1990) *Mikhail Bakhtin: creation of a prosaics*. Stanford, California: Stanford University Press.

Murphy, E. & Dingwall, R. (2007) Informed consent, anticipatory regulation and ethnographic practice, *Soc Sci Med*, 65; (11) 2223-34.

Murray, T. (1987) Medical Ethics, moral philosophy and moral tradition, *Soc Sci Med*, 25; 637-44.

Myerson, D. (2000) If emotions were honoured: a cultural analysis, in S Fineman (ed), *Emotion in organizations*, London: Sage pp. 167-83.

Myerson, G. (1994) *Rhetoric, reason and society: rationality as dialogue*. London: Sage.

Nathan, S., Johnston, L. & Braithwaite, J. (2011) The role of community representatives on health service committees: staff expectations vs. reality, *Health Expect*, 14; (3) 272-84.

National Audit Office (2015) *Investigation into the Cancer Drugs Fund*. London: Department of Health and NHS England.

National Institute for Health and Care Excellence (2006) *Citizen's Council Report: the Rule of Rescue*. London: NICE.

National Institute for Health and Care Excellence (2012) *Local decision making competency framework*. London: National Institute for Health and Care Excellence/National Prescribing Centre.

National Prescribing Centre (2009a) *Supporting rational local decision-making about medicines (and treatments). A handbook of good practice guidance*. Liverpool: National Prescribing Centre.

National Prescribing Centre (2009b) *Defining guiding principles for processes supporting local decision making about medicines*. London: Department of Health.

Naugler, D. (2009) Crossing the cosmetic/reconstructive divide: the instructive situation of breast reduction surgery, in CJ Heyes & M Jones (eds), *Cosmetic surgery: a feminist primer*, Farnham, Surrey and Burlington, VT: Ashgate pp. 225-38.

Newdick, C. (2006) 'Exceptional circumstances' - access to low priority treatments after the Herceptin case, *Clinical Ethics*, 1; (4) 205-8.

Newdick, C. (2007) Judicial review: low-priority treatment and exceptional case review, *Med Law Rev*, 15; (2) 236-44.

Newdick, C. (2009) *Legal and ethical aspects of local decision-making about medicines and treatments*. Liverpool: National Prescribing Centre.

Newdick, C. (2014) Health care rights and NHS rationing: turning theory into practice, *Revista Portuguesa de Saúde Pública*, 32; (2) 151-7.

Newman, J. & Clarke, J., (2009) *Publics, politics and power: remaking the public in public services*. London: Sage.

NHS Basildon and Brentford CCG, NHS Castlepoint & Rochford CCG, NHS Southend CCG & NHS Thurrock CCG, (2016) Individual funding requests policy, available from: <http://castlepointandrochfordccg.nhs.uk/about-us/key-documents/policies/corporate-policies/907-individual-funding-request-policy/file> [26 June 2017]

NHS Choices, (2016) Breast reduction (male), available from: <http://www.nhs.uk/Conditions/cosmetic-treatments-guide/Pages/breast-reduction-male.aspx> [19 January 2017]

NHS Choices, (2016) Breast reduction on the NHS, available from: <http://www.nhs.uk/conditions/Breast-reduction/Pages/Introduction.aspx> [19 January 2017]

NHS Choices, (2016) The NHS guide to cosmetic procedures, available from: <http://www.nhs.uk/Conditions/cosmetic-treatments-guide/Pages/is-cosmetic-surgery-available-on-the-NHS.aspx> [19 January 2017]

NHS Commissioning Board (2013) *Commissioning policy: individual funding requests*. London: NHS Commissioning Board.

- NHS England (2016) *Interim standard operating procedure: the management of individual funding requests*. London: NHS England.
- NHS Herts Valleys CCG, (2017) Individual funding requests policy, available from: <http://hertsvalleysccg.nhs.uk/your-health-and-services/individual-funding-requests> [26 June 2017]
- NHS Modernisation Agency (2005) *Information for commissioners of plastic surgery. Referrals and guidelines in plastic surgery*. London: NHS Modernisation Agency.
- NHS North West London (2012) *Individual funding request report 2011/12*. London: NHS NW London.
- Nicolini, D. (2009) Zooming in and out: Studying practices by switching theoretical lenses and trailing connections, *Organization Studies*, 30; (12) 1391-418.
- Nicolini, D. (2012) *Practice theory, work, and organization: an introduction*. Oxford: Open University Press.
- Nussbaum, M. (2001) *Upheavals of thought: The intelligence of emotions*. Cambridge: Cambridge University Press.
- Oliver, K., Lorenc, T. & Innvær, S. (2014) New directions in evidence-based policy research: a critical analysis of the literature, *Health Res Policy Syst*, 12; 34.
- Oswold, M. & Cox, D., (2011) *Making difficult choices: ethical commissioning guidance for general practitioners*. London: RCGP Ethics Committee.
- Owen-Smith, A., Coast, J. & Donovan, J. (2009) "I can see where they're coming from, but when you're on the end of it ... you just want to get the money and the drug." Explaining reactions to explicit healthcare rationing, *Soc Sci Med*, 68; (11) 1935-42.
- Owen-Smith, A., Coast, J. & Donovan, J. (2010) The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals, *J Health Serv Res Policy*, 15; (1) 14-20.
- Owen-Smith, A., Kipping, R., Donovan, J., Hine, C., Maslen, C. & Coast, J. (2013) A NICE example? Variation in provision of bariatric surgery in England, *BMJ*, 346; f2453.
- Packwood, A. (2002) Evidence-based policy: rhetoric and reality, *Social Policy and Society*, 1; (3) 267-72.
- Parsons, W. (1995) *Public policy: an introduction to the theory and practice of policy analysis*. Aldershot: Edward Elgar.

- Parsons, W. (2002) From muddling through to muddling up. Evidence based policy-making and the modernisation of British government, *Public Policy and Administration*, 17; (3) 43-60.
- Peacock, S., Mitton, C., Bate, A., McCoy, B. & Donaldson, C. (2009) Overcoming barriers to priority setting using interdisciplinary methods, *Health Policy*, 92; (2-3) 124-32.
- Perelman, C. & Olbrechts-Tyteca, L. (1971) *The new rhetoric: a treatise on argumentation*. Notre Dame, Indiana: University of Notre Dame Press.
- Persad, G., Wertheimer, A. & Emanuel, E.J. (2009) Principles for allocation of scarce medical interventions, *The Lancet*, 373; (9661) 423-31.
- Polanyi, M. (1983) *The tacit dimension*. Gloucester, MA: Doubleday.
- Porter, T.M. (1995) *Trust in numbers: the pursuit of objectivity in science and public life*. Princeton, N.J: Princeton University Press.
- Potter, J. (1996) *Representing reality: discourse, rhetoric and social construction*. London: Sage.
- Rampton, B. (2007) *The micro-analysis of interactional discourse in linguistic ethnography: an illustration focused on the job interview*. Kings College London: Ethnography, language and communication course materials.
- Rampton, B., Maybin, J. & Roberts, C. (2015) Theory and method in linguistic ethnography, in J Snell, S Shaw & F Copland (eds), *Linguistic ethnography: interdisciplinary explorations*, Hampshire: Palgrave Macmillan pp. 14-50.
- Rampton, B., Tusting, K., Maybin, J., Barwell, R., Creese, A. & Lytra, V., (2004) UK Linguistic Ethnography: A discussion paper, available from: http://www.lancaster.ac.uk/fss/organisations/lingethn/documents/discussion_paper_jan_05.pdf [18 February 2016]
- Rein, M. & Schon, D. (1993) Reframing policy discourse, in F Fischer & J Forester (eds), *The argumentative turn in policy analysis and planning*, Durham NC: Duke Avenue Press pp. 145-66.
- Richards, M. (2008) *Improving access to medicines for NHS patients*. London: Central Office of Information.
- Roberts, A., Marshall, L. & Charlesworth, A. (2012) *A decade of austerity? The funding pressures facing the NHS from 2010/11 to 2021/22*. London: Nuffield Trust.
- Roberts, C. & Sarangi, S. (2004) Theme-oriented discourse analysis of medical encounters, *Med Educ*, 39; 632-40.

Roberts, J.M. (2012) Discourse or dialogue? Habermas, the Bakhtin Circle, and the question of concrete utterances, *Theory and Society*, 41; (4) 395-419.

Robertson, R. (2016) Six ways in which NHS financial pressures can affect patient care, *The King's Fund*, March 31, available from:

<https://www.kingsfund.org.uk/publications/six-ways> [16 February 2017]

Robinson, S., Dickinson, H., Freeman, T. & Williams, I. (2011a) Disinvestment in health - the challenges facing general practitioner (GP) commissioners, *Public Money & Management*, 31; (2) 145-8.

Robinson, S., Dickinson, H., Williams, I., Freeman, T., Rumbold, B. & Spence, K. (2011b) *Setting priorities in health*. Birmingham: Health Services Management Centre and Nuffield Trust.

Robinson, S., Williams, I., Dickinson, H. & Freeman, T. (2012) Using narrative analysis to explore the performance of decision making at primary care trusts in England, available from:

<http://www.download.bham.ac.uk/hsmc/suzanne-robinson.pdf> [12 January 2014]

Rosenberg-Yunger, Z.R.S. & Bayoumi, A.M. (2017) Evaluation criteria of patient and public involvement in resource allocation decisions: a literature review and qualitative study, *Int J Technol Assess Health Care*, 33; (2) 270-8.

Royal College of Surgeons of England (2014) *Is access to surgery a postcode lottery?* London: RCS Publishing.

Rumbold, B., Alakeson, V. & Smith, P. (2012) *Rationing health care. Is it time to set out more clearly what is funded by the NHS?* London: Nuffield Trust.

Russell, J. & Greenhalgh, T. (2009) *Rhetoric, evidence and policymaking: a case study of priority setting in primary care*. London, UK: Research Department of Primary Care and Population Health, UCL eprint, available from: <http://discovery.ucl.ac.uk/15560/1/15560.pdf> [12 January 2014]

Russell, J. & Greenhalgh, T. (2010) Rhetoric, evidence and policymaking: a case study of priority setting in primary care, in P Dawid, W Twining & M Vasilaki (eds), *Evidence, inference and enquiry*, London: British Academy, Oxford University Press pp. 267-90.

Russell, J. & Greenhalgh, T. (2011) Policy making through a rhetorical lens, in J Glasby (ed) *Evidence, Policy and Practice: Critical Perspectives in Health and Social Care*, Policy Press pp. 49-69.

Russell, J. & Greenhalgh, T. (2012) Affordability as a discursive accomplishment in a changing National Health Service, *Soc Sci Med*, 75; 2463-71.

- Russell, J. & Greenhalgh, T. (2013) Being rational and being human: How National Health Service rationing decisions are constructed as rational by resource allocation panels, *Health*, 18; (5) 441-57.
- Russell, J., Greenhalgh, T., Burnett, A. & Montgomery, J. (2011) "No decisions about us without us"? Individual healthcare rationing in a fiscal ice age, *BMJ*, 342; d3279.
- Russell, J., Greenhalgh, T., Byrne, E. & McDonnell, J. (2008) Recognizing rhetoric in health care policy analysis, *J Health Serv Res Policy*, 13; (1) 40-6.
- Russell, J., Greenhalgh, T., Lewis, H., Mackenzie, I., Maskrey, N., Montgomery, J. & O'Donnell, C. (2013) Addressing the 'postcode lottery' in local resource allocation decisions: a framework for clinical commissioning groups, *J R Soc Med*, 106; (4) 120-3.
- Russell, J., Swinglehurst, D. & Greenhalgh, T. (2014) 'Cosmetic boob jobs' or evidence-based breast surgery: an interpretive policy analysis of the rationing of 'low value' treatments in the English National Health Service, *BMC Health Serv Res*, 14; 413.
- Saarni, S. & Gylling, H. (2004) Evidence based medicine guidelines: a solution to rationing or politics disguised as science? *J Med Ethics*, 30; 171-5.
- Sanderson, I. (2003) Is it 'what works' that matters? Evaluation and evidence-based policy-making, *Research Papers in Education*, 18; (4) 331-45.
- Sanderson, I. (2004) Getting evidence into practice; perspectives on rationality, *Evaluation*, 10; (3) 366-79.
- Sanderson, I. (2006) Complexity, 'practical rationality' and evidence-based policy making, *Policy & politics*, 34; (1) 115-32.
- Sayer, A. (2011) *Why things matter to people: Social science, values and ethical life*. Cambridge: Cambridge University Press.
- Schei, E. (2006) Doctoring as Leadership, *Perspect Biol Med*, 49; (3) 393-406.
- Schwandt, T. (2001) Understanding dialogue as practice, *Evaluation*, 7; (2) 228-37.
- Schwandt, T.A. (2003) 'Back to the Rough Ground!' Beyond theory to practice in evaluation, *Evaluation*, 9; (3) 353-64.
- Scourfield, P. (2011) Intuition and rationality in assessing risk: disentangling the law, folklore and sod's law, *Paper presented to the British Sociological Association Risk conference, April 2011*.

- Segal, J.Z. (2007) Illness as argumentation: a prolegomenon to the rhetorical study of contestable complaints, *Health*, 11; (2) 227-44.
- Segar, J., Checkland, K., Coleman, A. & McDermott, I. (2015) Thinking about case studies in 3-D: researching the NHS clinical commissioning landscape in England, in J Russell, T Greenhalgh & S Kushner (eds), *Case study evaluation: past, present and future challenges*, Bingley: Emerald pp. 85-106.
- Shaw, S. & Eyre, L. (forthcoming) Policy - sites and situations, in K Tusting (ed), *Handbook of linguistic ethnography*, London: Routledge.
- Shaw, S. & Russell, J. (2015) Researching health policy and planning: The influence of linguistic ethnography, in J Snell, S Shaw & F Copland (eds), *Linguistic ethnography: interdisciplinary explorations*, London: Palgrave Macmillan pp. 129-46.
- Shaw, S., Copland, F. & Snell, J. (2015) An introduction to linguistic ethnography, in J Snell, S Shaw & F Copland (eds), *Linguistic Ethnography: interdisciplinary explorations*, Hampshire: Palgrave Macmillan pp. 1-13.
- Sheehan, M. (2007) Resources and the rule of rescue, *Journal of Applied Philosophy*, 24; 352-66.
- Shotter, J. (1992) Bakhtin and Billig: monological versus dialogical practices, *American Behavioral Scientist*, 36; (1) 8-12.
- Sibbald, S.L., Singer, P.A., Upshur, R. & Martin, D.K. (2009) Priority setting: what constitutes success? A conceptual framework for successful priority setting, *BMC Health Serv Res*, 9; 43.
- Simon, H.A. (1978) Rationality as process and as product of thought, *The American Economic Review*, 68; (2) 1-16.
- Simon, H.A. (1991) Bounded rationality and organizational learning, *Organization Science*, 2; (1) 125-34.
- Simons, H. (2015) Interpret in context: Generalizing from the single case in evaluation, *Evaluation*, 21; (2) 173-88.
- Singer, P., Martin, D., Giacomini, M. & Purdy, L. (2000) Priority setting for new technologies in medicine: qualitative case study, *BMJ*, 321; (7272) 1316-8.
- Singh, K.A. & Losken, A. (2012) Additional benefits of reduction mammoplasty: a systematic review of the literature, *Plast Reconstr Surg*, 129; (3) 562-70.
- Smith, N., Mitton, C., Davidson, A. & Williams, I. (2014) A politics of priority setting: Ideas, interests and institutions in healthcare resource allocation, *Public Policy and Administration*, 29; (4) 331-47.

Smith, R. (2012) NHS bill for PIP breast implant scandal is almost £2m so far, *Telegraph [online]*, October 13, available from: <http://www.telegraph.co.uk/health/healthnews/9605030/NHS-bill-for-PIP-breast-implant-scandal-is-almost-2m-so-far.html> [24 September 2013]

Snape, D., Kirkham, J., Britten, N., Froggatt, K., Gradinger, F., Lobban, F., Popay, J., Wyatt, K. & Jacoby, A. (2014) Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study, *BMJ Open*, 4; (6) e004943.

Snell, J., Shaw, S. & Copland, F. (eds.), 2015, *Linguistic ethnography: interdisciplinary explorations*, Basingstoke, Hampshire: Palgrave Macmillan.

South East Coast Policy Recommendation Committee (2011) *Policy recommendation: breast reduction*. Brighton: SEC Health Policy Support Unit.

Stake, R. (1995) *The art of case study research*. London: Sage.

Starr, P. (1992) Social categories and claims in the liberal state, *Social Research*, 59; (2) 263-95.

Steinberg, M.W. (1998) Tilting the frame: considerations on collective action framing from a discursive turn, *Theory and Society*, 27; (6) 845-72.

Stevens, R.J., Stevens, S.G. & Rusby, J.E. (2015) The "postcode lottery" for the surgical correction of gynaecomastia in NHS England, *Int J Surg*, 22; 22-7.

Stilgoe, J., Irwin, A. & Jones, K., (2006) *The received wisdom. Opening up expert advice*. London: Demos.

Stolper, E., Van de Wiel, M., Van Royen, P., Van Bokhoven, M., Van der Weijden, T. & Dinant, G.J. (2011) Gut feelings as a third track in general practitioners' diagnostic reasoning, *Journal of general internal medicine*, 26; (2) 197-203.

Stone, D. (1997) *Policy paradox. The art of political decision making*. New York: WW Norton.

Stone, D. (2013) *Taking emotion seriously: the promise of interpretive policy analysis*. Vienna: Keynote address to the Interpretive Policy Analysis Conference, July 2013.

Strech, D., Synofzik, M. & Marckmann, G. (2008) How physicians allocate scarce resources at the bedside: a systematic review of qualitative studies, *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 33; (1) 80-99.

- Swinglehurst, D., Greenhalgh, T., Russell, J. & Myall, M. (2011) Receptionist input to quality and safety in repeat prescribing in UK general practice: ethnographic case study, *BMJ*, 343; d6788.
- Syrett, K. (2004) Impotence or importance? Judicial review in an era of explicit NHS rationing, *The Modern Law Review*, 67; (2) 289-304.
- Syrett, K. (2007) *Law, legitimacy, and the rationing of healthcare: a contextual and comparative perspective*. Cambridge, New York: Cambridge University Press.
- Syrett, K. (2011) Health technology appraisal and the courts: accountability for reasonableness and the judicial model of procedural justice, *Health Econ Policy Law*, 6; (4) 469-88.
- Tallmon, J.M. (1995) Casuistry and the role of rhetorical reason in ethical inquiry, *Philosophy & Rhetoric*, 28; (4) 377-87.
- Tanenbaum, S.J. (2012) Reducing variation in health care: the rhetorical politics of a policy idea, *J Health Polit Policy Law*, 38; (1) 5-26.
- Taylor, R. & White, S. (2000) *Practising reflexivity in health and welfare*. Buckingham: Open University Press.
- Telegraph reporters (2016) Judge overturns 'absurd' NHS decision not to treat narcoleptic 17-year-old, *Telegraph [online]*, May 5, available from: <http://www.telegraph.co.uk/news/2016/05/05/judge-overturns-absurd-nhs-decision-not-to-treat-narcoleptic-17/> [24 April 2017]
- Tenbenschel, T. (2000) Health prioritisation as rationalist policy making: problems, prognoses and prospects, *Policy and Politics*, 28; (3) 425-40.
- The Lancet (2010) New £50 million cancer fund already intellectually bankrupt [editorial], *The Lancet*, 276; (9739) 389.
- This is Staffordshire (2011) Life-or-Death High Court verdict is a "death sentence" for former PC, *The Sentinel [online]*, April 8, available from: <http://www.stokesentinel.co.uk/Ruling-death-sentence-Tom/story-12535080-detail/story.html> [29 October 2015]
- Thornton, S. (2011) Cancer Drugs Fund is not a fair allocation of NHS resources, *BMJ*, 342; d621.
- Torgerson, D. (2007) Policy discourse as dialogue: emergent publics and the reflexive turn, *Critical Policy Studies*, 1; (1) 1-17.
- Townley, B. (2008) *Reason's neglect: rationality and organizing*. Oxford: Oxford University Press.

Toynbee, P. (2016) We can afford the NHS. The question is whether we are willing to pay for it. *The Guardian [online]*, September 22, available from: <https://www.theguardian.com/commentisfree/2016/sep/22/we-can-afford-nhs-health-service> [29 September 2016]

Toynbee, P. & Walker, D. (2017) *Dismembered: How the Conservative attack on the State harms us all*. London: Guardian Faber Publishing.

Triggle, N. (2017) Cancer Drugs Fund 'huge waste of money', *BBC News*, April 28, available from: <http://www.bbc.co.uk/news/health-39711137> [28 April 2017]

Tuler, S. (2000) Forms of talk in policy dialogue: distinguishing between adversarial and collaborative discourse, *Journal of Risk Research*, 3; (1) 1-17.

van de Bovenkamp, H.M. & Zuiderent-Jerak, T. (2015) An empirical study of patient participation in guideline development: exploring the potential for articulating patient knowledge in evidence-based epistemic settings, *Health Expectations*, 18; (5) 942-55.

Van de Ven, A. & Schomaker, M. (2002) The rhetoric of evidence-based medicine, *Health Care Manage Rev*, 27; (3) 89-91.

Volosinov, V. (1973) *Marxism and the philosophy of language*. Cambridge, Mass: Harvard University Press.

Wagenaar, H. (2011) *Meaning in action: interpretation and dialogue in policy analysis*. Armonk, NY: M.E. Sharpe.

Walter, A., Chew-Graham, C. & Harrison, S. (2012) Negotiating refusal in primary care consultations: a qualitative study, *Fam Pract*, 29; (4) 488-96.

Waymack, M.H. (2001) Daniels on justice and healthcare: laudable goals - questionable method, *Am J Bioeth*, 1; (2) 28.

Weber, M. (1978) *Economy and society: an outline of interpretive sociology*. Berkeley, CA: Univ of California Press.

Weale, A., Kieslich, K., Littlejohns, P., Tugendhaft, A., Tumilty, E., Weerasuriya, K. & Whitty, J.A. (2016) Introduction: priority setting, equitable access and public involvement in health care, *J Health Organ Manag*, 30; (5) 736-50

Weick, K.E., Sutcliffe, K.M. & Obstfeld, D. (2005) Organizing and the process of sensemaking, *Organization science*, 16; (4) 409-21.

West, D. & Welikala, J., (2015) Survey: Third of CCGs consider limiting access amid cash squeeze, *Health Service Journal [online]*, available from: <https://www.hsj.co.uk/leadership/barometers/ccg-barometer/survey-third-of-ccgs-consider-limiting-access-amid-cash-squeeze/5084354.article> [28 April 2017]

Wetherell, M., Taylor, S. & Yates, S., (2001) *Discourse theory and practice: a reader*. London: Open University/Sage.

White, S. (2011) Fabled uncertainty in social work, in L Bondi, D Carr, C Clark & C Clegg (eds), *Towards professional wisdom: practical deliberation in the people professions*, Farnham, Surrey: Ashgate Publishing pp. 171-86.

Wilder, D.A. (1981) Perceiving persons as a group: categorization and intergroup relations, in D Hamilton (ed), *Cognitive processes in stereotyping and intergroup behavior*, Hillsdale, NJ: Lawrence Erlbaum Associates pp. 213-57, cited in Billig, M. (1987) *Arguing and thinking: a rhetorical approach to social psychology*. Cambridge: Cambridge University Press: 152.

Williams, I. (2015) Receptive rationing: reflections and suggestions for priority setters in health care, *J Health Organ Manag*, 29; (6) 701-10.

Williams, I. & Bryan, S. (2007) Cost-effectiveness analysis and formulary decision making in England: findings from research, *Soc Sci Med*, 65; 2116-29.

Williams, I., Robinson, S. & Dickinson, H. (2011) *Rationing in health care: the theory and practice of priority setting*. Bristol: Policy Press.

Williams, J. (2011) *Legal context of individual funding requests*. Presentation at IFR Learning and Sharing Event, NICE/NPC, 2nd November: Bristol.

Williams, J. (2014) *What does Rose v Thanet tell us about the status of NICE guidelines in priority setting?* available from: <http://www.mills-reeve.com/rosevthanet/> [19 January, 2016]

Williams, S. (2000) Is rational choice theory unreasonable, in M Archer and J Tritter (eds), *Rational choice theory*, London: Routledge, cited in Townley, B. (2008) *Reason's neglect: rationality and organizing*. Oxford: Oxford University Press: 178.

Wilson, P.M., Booth, A.M., Eastwood, A. & Watt, I.S. (2008) Deconstructing media coverage of trastuzumab (Herceptin): an analysis of national newspaper coverage, *J R Soc Med*, 101; (3) 125-32.

Winton, S. (2013) Rhetorical analysis in critical policy research, *International Journal of Qualitative Studies in Education*, 26; (2) 158-77.

Wishart, A. (2009) The unbearable cost of living, *The Times [online]*, June 7, available from: <https://www.thetimes.co.uk/article/the-unbearable-cost-of-living-rkl2bh50pmm> [9 June 2009]

Wood, M., Ferlie, E. & Fitzgerald, L. (1998) Achieving clinical behaviour change: a case of becoming indeterminate, *Soc Sci Med*, 47; 1729-38.

Yanow, D. (1996) *How does a policy mean? Interpreting policy and organizational actions*. Washington, D.C: Georgetown University Press.

Yanow, D. (2000) *Conducting interpretive policy analysis*. Thousand Oaks, Ca: Sage.

Yanow, D. (2015) Making sense of policy practices: interpretation and meaning, in D Torgerson, A Durnova, M Orsini & F Fischer (eds), *Handbook of critical policy studies*, Cheltenham, Glos: Edward Elgar Publishing pp. 401-21.

Young, I.M. (2000) *Inclusion and democracy*. Oxford: Oxford University Press.

Appendix 1: Supervisor statement

This is to confirm that with respect to the published papers, research reports to Leverhulme and NIHR, and book chapters which Jill Russell coauthored with me (and in some cases with other authors), and which form the basis of the findings chapters of her thesis, my own and others' input was minor. In each case, Jill led the design and development of the empirical study, conducted all the fieldwork either alone or with minimal input from me, led on the analysis of the data, sought my feedback on drafts and incorporated my suggestions (or, sometimes, defended her own position), and drove the paper through the editorial system to publication, including in some cases preparing lengthy responses to reviewers' feedback. I confirm that my own input was no more than would have been standard as a supervisor on a DPhil.

A handwritten signature in black ink, appearing to read 'P. M. Whaley', with a horizontal line underneath the name.

Appendix 2: Publications and presentations

Publications

Shaw S and **Russell J** (2015) Researching health policy and planning: The influence of linguistic ethnography. In Snell J, Copeland F and Shaw S (eds). *Linguistic Ethnography. Interdisciplinary explorations*. London, Palgrave.

Russell J, Swinglehurst D, Greenhalgh T (2014) 'Cosmetic boob jobs' or evidence-based breast surgery. An interpretive policy analysis of the rationing of 'low value' treatments in the English National Health Service. *BMC Health Services Research*. 14: 413.

Russell J and Greenhalgh T. (2013) Being 'rational' and being 'human': How NHS rationing decisions are constructed as rational by resource allocation panels. *Health*, 18; (5) 441-57.

Russell J, Greenhalgh T, Lewis H, MacKenzie I, Maskrey N, Montgomery J, and O'Donnell C (2013) Addressing the 'postcode lottery' in local resource allocation decisions: developing a competency framework for clinical commissioning groups. *Journal of the Royal Society of Medicine* 106: 120–123.

Russell J and Greenhalgh T (2012) Affordability as a discursive accomplishment in a changing National Health Service. *Social Science and Medicine* 75: 2463-2471.

Russell J, Greenhalgh T, Burnett A, Montgomery J. (2011) "No decisions about us without us"? Individual healthcare rationing in a fiscal ice age. *BMJ*; 342:d3279

Russell J and Greenhalgh T (2011) Rhetoric, evidence and policymaking: a case study of priority setting in primary care. In Dawid P, Twining W, Vasilaki M (eds) *Evidence, Inference and Enquiry*. British Academy, London (distributed by Oxford University Press).

Russell J and Greenhalgh T (2011) Policymaking through a rhetorical lens. In Glasby J (ed) *Evidence, policy and practice: critical perspectives in health and social care*. Policy Press, London.

Greenhalgh T and **Russell J** (2009) Evidence-based policymaking: a critique. *Perspectives in Biology and Medicine* 52, 2: 304-18.

Russell J, Greenhalgh T, Byrne E, McDonnell J (2008) Recognising rhetoric in healthcare policy analysis. *Journal of Health Services Research and Policy* 13, 1: 40-46

Talks and conference presentations

Russell J The rationality of rationing: a rhetorical policy analysis of deliberations about resource allocation in the NHS. Presentation as part of 2nd year DPhil presentations, Green Templeton College, University of Oxford, May 2016.

Shaw S and **Russell J** Researching health care policy and planning: what can a dialogue between linguistic ethnography and interpretive policy analysis add? Presentation at the Interpretive Policy Analysis international conference, July 2016.

Russell J and Greenhalgh T. Public participation in practice: a Bakhtinian perspective on lay involvement in health care rationing deliberations in the English NHS. Paper presented as part of a panel on 'Making Expertise Public: Dilemmas, Conflicts and Controversies' at the 8th International Interpretive Policy Analysis conference, Vienna, July 2013.

Russell J The dilemma of the rule of rescue in individual funding request decision-making. Presentation to UCL Social Values in Resource Allocation seminar series. February 2013.

Russell J, Swinglehurst D and Greenhalgh T. Enacting the 'postcode lottery' in health care: the case of breast surgery in the English National Health Service. Paper presented at Explorations in Ethnography, Language and Communication conference, Copenhagen, September 2012.

Russell J and Greenhalgh T. Emotionality in deliberations about the rationing of health care resources. Paper presented as part of a panel on 'The emotional turn in policy analysis: theory and interpretation'. Interpretive Policy Analysis conference, The Netherlands, July 2012.

Russell J and Greenhalgh T. Affordability and the ghost of Nye Bevan. Paper presented at Society for Academic Study of Primary Care Madingley conference, Cambridge, Feb 2012.

Russell J and Greenhalgh T. "No decisions about us without us"? Individual healthcare rationing decisions in a fiscal ice age. Poster presentation at North American Primary Care Group conference, Banff, Canada, November 2011.

Russell J and Greenhalgh T. Commissioning as categorising: a discourse methodology. Paper presented as part of a symposium on commissioning of health care in a time of transition at the annual Social Policy Association conference, Lincoln, July 2011.

Russell J and Greenhalgh T. Managing risk in NHS rationing decisions: categories, roles and rhetoric. Paper presented to the British Sociological Association risk study group conference, London, April 2011.

Russell J and Greenhalgh T. "No decisions about us without us?" Presentation on patient and public involvement in IFR decisions for NICE/National Prescribing Centre learning and sharing events in Manchester, Bristol, London and Leeds, September 2010 - February 2011.

Russell J. Rationing talk: a rhetorical analysis of resource allocation deliberations in the NHS. Paper presented as part of a symposium on Language, ideas and policy at the annual Social Policy Association conference, Lincoln, July 2010.

Russell J and Greenhalgh T. Representations of rationing work in the NHS. Conference paper presented at the second annual conference on Explorations in Ethnography, Language and Communication, University of Aston, Sep 2009.

Russell J, Greenhalgh T, Byrne E and McDonnell J. Rhetorical argumentation, evidence and policymaking. Presentation at the British Academy conference on Enquiry, Evidence and Facts, 13-14th December, 2007, London.

Russell J and Byrne E. The use of evidence in health care policymaking: a study of priority setting in primary care. Invited presentation to the London School of Economics 'How well do facts travel' research groups, May 2007.

Russell J. A rhetorical analysis of priority setting in primary care. Presentation to the Public Health Ethics conference, University of Birmingham, May 2007.

Burnett A, Greenhalgh T and **Russell J.** Towards ethical resource allocation in primary care trust. Poster presentation to NICE 2006 (annual conference of National Institute for Health and Clinical Excellence), December 2006

Appendix 3: Checklists of interview questions

Checklist for interviews with members of the Priorities Forum

1. Can you tell me a bit about the work you do? We're interested in the sorts of decisions you are involved in making, and the processes involved in coming to decisions about health policy issues.

2. What would you say are the key skills you need to do your work well?

3. Everyone these days talks about the ideal of evidence base policy. How evidence-based do you think decision making/policy making is in this Primary Care Trust? Why do you say this? How evidence-based CAN and SHOULD it be?

4. We're hoping to attend some Priorities Forum meetings later in the year. Can you tell me a bit about what sources and sorts of information is used in these meetings to help the Forum come to decisions?

5. One perspective on policymaking is that it's about the art of persuading others. Often in the field of health policy decisions the evidence isn't that clear cut, and can be quite ambiguous. How do you and colleagues go about persuading each other, or coming to agree on decisions?

6. What do you see as the main problems and challenges with taking forward policy initiatives in this PCT?

7. What three things would you identify that would improve the quality of policy making in this PCT?



Individual Funding Request study

Checklist for interview with IFR panel members

1. How do you see your role as an IFR panel member and the role of other members?
2. What works well and not so well with the IFR process?
3. Which are the most challenging and most straightforward cases you have to consider?
4. How are differences of opinion between panel members resolved?
5. How does the panel reconcile conflicting principles for decision-making?
6. Is there an emotional element to discussions?
7. How could the IFR process be improved?
8. Some IFR panels include lay membership and/or patient representation on panels. What are your views about this?
9. How do you see the current policy changes taking place in the NHS impinging on the IFR process?
10. Any other comments?

Appendix 4: Ethical code of practice and data management policy

NIHR Research for Patient Benefit research project exploring individual funding requests in the NHS

1. The project received ethical approval from UCL Research Ethics Committee in May 2009. The project grant transferred from UCL to Queen Mary, University of London in September 2010 and Queen Mary Research Ethics Committee confirmed ethical approval in October 2010.
2. Each informant will be given a summary of the study protocol and an opportunity to ask questions prior to responding to an invitation to be involved in the study. Committees/panels will be invited to give collective approval through the Chair, in addition to approval of individual members.
4. Consent will be obtained from informants prior to each instance of data collection, including one to one interviews, ethnographic observation of work relating to IFR case preparation, and IFR panel discussions. The specific form of recording (written notes, audio recording, video recording) will be agreed as part of the consent process.
5. Informed consent will include the right of informants to withdraw their consent without reason at any point in the study.
6. Informants will have the right to ask for anything they deem sensitive to be removed from written records, either at the time of their recording or at any time afterwards.
7. Any audio and video recordings and verbatim transcripts will be treated as strictly confidential and will not be shown to anyone outside the research team.
8. During data collection events, the researcher(s) will aim to ensure that no patient names or identifiable details are recorded. Any notes and audio recordings will be checked immediately after each episode of data collection to ensure that no identifiable patient data is stored by the research team.
9. All research data will be stored with regard to its confidentiality. Password protection will be used on all audio recordings and transcriptions of audio recordings stored on computer to ensure that access is restricted to the research team.
10. Recorded research data will only be retained for the period of the research study, after which time all recordings will be deleted.

11. The principal investigator, Professor Trisha Greenhalgh, will have control of, and act as custodian for, the data generated by the study. The project's data management processes will be monitored by the project advisory group.

12. The analysed results of the study will be written up for publication in reports to the funding body and in peer reviewed journals. The findings will be presented in general and anonymised terms, unless individual informants and organisations wish to be identified. The research team will consider all verbatim quotes in such publications for their sensitivity, appropriateness and fairness. Informants will be given the opportunity to check the use of any verbatim quotes prior to publication.

Appendix 5: Competency set on deliberation, reasoning and ethical judgement

Competency framework

Deliberation, reasoning and ethical judgement

Decision-making groups should allow for deliberation, debate and reasoning when making collective group decisions. The judgement and ethical considerations of individuals within groups are an integral element of the decision-making process and should be considered alongside the factual evidence presented.

Specific skills	Underpinning knowledge and abilities
Engages in and facilitates deliberative processes to support ethical judgement in decision-making	<p>Understands the role and importance of the clear articulation of reasons both for and against a proposal</p> <p>Identifies and questions personal assumptions and the assumptions of other members of the group</p> <p>Understands the relevant ethical element of a discussion or exchange</p> <p>Possesses a thorough understanding of the organisation's ethical framework, its role and limitations</p> <p>Shows a willingness to explore and understand a personal moral position in relation to the ethical framework</p> <p>Recognises that emotion may impact on ethical engagement with an issue and could serve as well as hinder good judgement</p> <p>Understands the wide variety of evidence and the role that different kinds of evidence (such as local and experiential knowledge) may play in improving the quality of judgements</p> <p>Shows an appreciation of the role of 'devil's advocate' to explore alternative options</p> <p>Has the ability to discuss issues of ambiguity, complexity and uncertainty with appropriate level of patience and tenacity</p> <p>Understands and respects the variety of stakeholder positions influencing the decision-making process including, individual, collective and public perspectives</p>

From: National Institute for Health and Care Excellence (2012) *Local decision making competency framework*. London: National Institute for Health and Care Excellence/National Prescribing Centre