Public participation in health

Theory, policy and practice in user involvement in cancer-genetics pilots

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"One person is a crank, two people are a pressure group, three people are public opinion."

(Gray, 2001: 262)

ABSTRACT

Public participation is an increasingly prominent policy in the United Kingdom and elsewhere. This thesis locates one example of participation within wider debates about the constitution of contemporary society, changing welfare-state governance, and the challenges of operationalizing such initiatives. It relates the particularities of this case to practical, policy and theoretical questions.

The thesis begins by considering the rise of participation in historical context, relating its aims to social-theoretical commentaries on late-modern society. This framework informs an examination of rationales for participation, an analysis of policy discourses on public involvement in health, and consideration of the challenges of making participation happen.

The remainder of the thesis presents the results of an empirical study of one example of participation: service-user involvement in a programme of pilot cancer-genetics services, managed by the third-sector organization Macmillan Cancer Support. Using interview, observational and documentary data collected over a three-year period, it offers a longitudinal perspective on the practice of involvement, drawing on various actors' perspectives. Considered over five empirical chapters are competing rationales for involvement put forward by different groups of actors, the micro-processes of involvement, and the varied outcomes of negotiations across the seven pilots studied.

In reconciling the theoretical and policy literatures with empirical findings, the thesis highlights certain tensions. Policy-level ambiguities permit the coexistence of multiple discourses about the purpose of involvement, the identity of those involved, and the influence it should command, resulting in conflict as participation is put into practice. Policies designed to avoid directiveness and facilitate local discretion create dilemmas for those charged with implementation, especially third-sector organizations whose intermediary role means they must reconcile divergent views of diverse stakeholders in participation practice. The result is a situation where pragmatic negotiations take precedence over any theoretical or normative vision for participation in determining its remit, scope and influence.

LIST OF PUBLISHED PAPERS

The following journal articles and book chapter, which derive from the research carried out for this thesis, have been published:

- '"Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare', *Sociology of Health and Illness* **30**(1): 35-54
- 'Public and user participation in public-service delivery: tensions in policy and practice', *Sociology Compass* in press
- 'Public participation in state governance from a social-theoretical perspective', in G. Currie, J. Ford, N. Harding & M. Learmonth (eds) *Public services management: a critical approach*, Routledge, London
- 'Representativeness, legitimacy and power in public involvement in health-care management', *Social Science & Medicine* **67**(11): 1757-1765
- 'Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements', *Critical Public Health* in press

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	acquired immunodeficiency syndrome
CD	compact disc
CHC	community health council
CPPIH	Commission for Patient and Public Involvement in Health
DH	Department of Health
EBM	evidence-based medicine
GP	general practitioner
HIV	human immunodeficiency virus
IT	information technology
LINk	Local Involvement Network
MR1 - MR5	Macmillan respondents 1-5
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NPM	new public management
NURG	National User Reference Group
OSC	Overview and Scrutiny Committee
PCG	Primary Care Group
PCT	Primary Care Trust
PPI	Patient and Public Involvement
STS	science and technology studies
UK	United Kingdom

INTRODUCTION

The involvement of the public, on both an individual level and, especially, a collective level, in the planning, delivery and accountability of public services is a growing trend in public-service governance across the economically developed world. In the United Kingdom (UK), public involvement of one form or another can be discerned throughout the history of the welfare state, but it has had particular prominence in the politics and policies of Labour governments in power since 1997, forming an important part of the party's communitarian and 'Third Way' political philosophy, and of the policies of public-service modernization following its election. Alongside calls for increased choice, policy documents (Prime Minister & Minister for the Cabinet Office, 1999; Office of Public Services Reform, 2002) stress the need for greater participation of citizens, service users and communities in the public-service reforms in train. Such calls have had varied aims, from democratic renewal and capacity building among the public, to driving the improvements of services themselves, through both 'choice' and 'voice'.

Health care has been one of the fields most affected by reforms aimed at promoting participation, and indeed by Labour's modernization efforts more generally.

Specific eventualities—such as the inquiry into the mismanagement of paediatric cardiac surgery at Bristol Royal Infirmary among other prominent medical scandals—combined with more general concerns about professional regulation, demographic transition and the efficiency of third-party payment to inform the ‘modernization’ of the National Health Service (NHS), as encapsulated in *The NHS Plan* (Secretary of State for Health, 2000b). The reforms that followed, and their development into more wholesale changes in the governance of the NHS during Labour’s second and third terms, were wideranging, but on a rhetorical level at least, patient and public involvement has been central among them. The report of the Bristol inquiry itself called specifically for the direct involvement of wideranging groups of patients and the public to be “embedded in the structures of the NHS” and to “permeate all aspects of healthcare” (Bristol Royal Infirmary Inquiry, 2001: 409), and there followed a series of white papers and acts of parliament aimed at raising the profile of involvement, by creating new bodies responsible for patient and public involvement in NHS organizations, and by introducing a legal obligation for NHS organizations to involve and consult the public in planning new services or making significant changes to existing ones. Further legislative change followed, and in common with much of the rest of the NHS, organizational change, led by central-government policy, has seemed an almost constant feature of patient and public involvement over the last five years.

As might be expected, much research endeavour has followed the increasing status of involvement in health care. It is often commented that despite this effort, there remains relatively little firm evidence about whether or not involvement has any tangible effect on health-service delivery and organization, let alone sustained, positive influence (Crawford *et al.*, 2002; Department of Health, 2004). This thesis does not seek to answer such questions. Rather, it seeks, through critical review of policy and an in-depth, longitudinal study of one particular example of involvement in health care, to consider questions about the objectives and process of participation initiatives. Various recent studies of different forms of public participation in the governance of contemporary public services demonstrate that these remain important areas for social-scientific research (e.g. Newman, 2005a; Davies *et al.*, 2006; Barnes *et al.*, 2007), as they reflect the more general contemporary relationship between the individual, society and the state (Clarke *et al.*, 2007). The aims enshrined in policy for such initiatives are multiple and often ambiguous; furthermore, in examining the implementation of public involvement, these studies and others illustrate the complications that emerge from the realization of involvement policy in complex, power-infused organizations such as the NHS. Straightforward rhetorical statements about public involvement mask the plethora of arrangements that emerge during the process of implementation, and the different publics, roles for involvement and implied relationships with public servants, such as clinicians, that are constituted through this process. More fundamentally, contemporary involvement policy and practice, and wider reforms aimed at 'modernizing' public services to make them fit for the expectations of contemporary citizens and consumers, might also be understood in a wider socio-historical context. Various writers have commented on the changing nature of Western society and the transformations in the relationships between lay citizens, professional experts and the state which have accompanied this. How are such transitions played out in the policy and practice of public involvement, and what does this suggest about how far such transitions have occurred 'on the ground', if at all?

This thesis aims to produce some cautious answers to these questions, considering theoretical and policy rationales put forward for public involvement, and then grounding these in empirical, longitudinal, qualitative research carried out over three years on an attempt to put involvement into practice. This took place in a programme of seven pilot cancer-genetics services, themselves introduced in pursuit of the modernization of NHS provision in this field, cofunded by the Department of Health (DH) and the cancer charity, Macmillan Cancer Support, following the publication of the genetics white paper (Secretary of State for Health, 2003). The pilots aimed to implement a new model of provision for people potentially at greater-than-average risk of cancer due to their genetic inheritance, integrating services in primary, secondary and tertiary care, and across the specialities of oncology and clinical genetics. In orchestrating these major service reconfigurations, the staff of the pilots—following some prompting by Macmillan—followed the spirit of recent legislation in involving the publics and patients affected in the process. However, the forms taken by involvement in the seven pilots were mixed, and the realization of involvement saw considerable divergences from policies and plans.

By considering this process—and the interaction of various levels of governance within it—as it developed through time, I seek to add to existing evidence about the practice of involvement. Drawing on the particularities of the case, and its commonalities with other contemporary attempts at involving various publics in public-service governance, I attempt to make a theoretical contribution to our understanding of the enactment of involvement, the interaction between different levels of policy and practice in the place of involvement in contemporary public-service governance, and the relationships between the public, public servants and the state that derive from current policy and practice.

The thesis is structured as follows:

- **Chapter 1, 'A brief history of public involvement'**, locates current concerns with patient and public participation in the NHS in the history of the organization and previous efforts at involving the public towards various ends. It introduces two theoretical perspectives on the nature of contemporary society—the idea of 'reflexive modernity' associated with Beck and Giddens, and the Foucaultian notion of 'governmentality'—to attempt to account for both the importance ascribed to involvement, and the role it might fulfil in contemporary governance. This theoretical overview provides the backdrop for the more substantive, empirically driven review of the literature that follows in the next two chapters.

- **Chapter 2, 'Who and how? Democratic and technocratic rationales'**, considers arguments about the need for representativeness and other, more knowledge-based, qualities in those involved in participatory initiatives. Considering the deliberative-democracy, science-studies and involvement literatures, it argues that there is often considerable overlap in practice between seemingly opposed democratic and technocratic rationales for involvement. It analyses contemporary documents relating to the NHS to illustrate the compound, multifaceted roles put forward for public and patient involvement by policymakers.
- **Chapter 3, 'The involvement process'**, grounds the issues highlighted in the previous two chapters in the specific literature on how involvement actually happens. It highlights the way in which the role of power within and beyond the encounter, and the potential for the transformation of users' roles, expectations and identities through involvement, affect involvement in practice. It then poses a set of research questions that inform the fieldwork that follows.
- **Chapter 4, 'The empirical field'**, provides some background information on the area in which the study took place: pilot cancer-genetics services introduced to reconfigure care pathways for those with suspected family histories of cancer. It sets out the role of various actors in the field, and the place prescribed for user involvement in implementing these new services.
- **Chapter 5, 'Methods'**, describes the qualitative approach taken to the empirical research, encompassing interviews, participant observation and documentary analysis. It also gives details about how these were put into practice, and of the

analysis process that followed.

- **Chapter 6, 'Getting involvement going: motivations, rationales and recruitment'**, describes the way in which user involvement was understood and put into practice by the various parties involved (involved users, employees of Macmillan, and staff on the seven pilot services). It shows how the combination of a loose rationale for user involvement, the heterogeneity of those selected as users, and the uncertainties of staff about how to put involvement into practice led, initially, to something of an 'implementation gap', whereby both users and staff struggled to find a coherent set of aims and tasks for user involvement.
- **Chapter 7, 'Developing an involved-user identity'**, looks at the national-level group meetings convened by Macmillan for the users involved in the pilot programme. It analyses the balance between the role of this group as a forum for users to determine for themselves their purpose and identity, and the need faced by Macmillan staff to orient the group towards certain managerial goals. While it finds that, on account of a degree of congruence between Macmillan and the users, there was little sense in which users were co-opted to the managerial agenda, it also indicates certain subtle ways in which a collective notion of the 'proper' involved user served to normalize the attributes and attitudes embodied by some users whilst excluding those of others.
- **Chapter 8, 'Conflicting visions of user involvement'**, considers the contrast between the ideas about involvement constructed by users and Macmillan in Chapter 7, and those of staff in the pilot projects in which the users were involved. Where involved users saw their role as a wideranging one in which their particularity and skills were an important asset in the governance of the health service, staff tended to construct the role of involved users in much more constrained, consumerist terms, seeing its principal contributions as evaluatory input on service

provision and assistance with making patient communication more 'user-friendly'. The two conceptions seemed to imply not only different constructions of the specific role of involvement, but also of the more general relationship between public knowledge and professional expertise in decisions about service provision.

- **Chapter 9, 'Negotiating the role for involvement: users, pilot staff and Macmillan'**, begins by looking in a little more detail at the role negotiated for user involvement in each site, bringing out details and contrasts that risked elision in the programme-level analysis of the previous chapters. It then returns to the programme level, noting how the national user group, concerned by the local divergences in user-involvement practice, started to press for a more directive approach to user involvement from Macmillan. Macmillan staff did indeed seek in various subtle ways to encourage the spread of best practice, but their eagerness not to impose ways of working, and Macmillan's stake in valuing all forms of involvement equally rather than generating a normative vision that might cast the efforts of some of its pilots as 'substandard', meant that their efforts were somewhat ambivalent. Rather than making structural interventions to encourage involvement, they focused instead on the need for intrinsic motivation on the part of staff to make user involvement work, a strategy which seemed, paradoxically, to encourage a 'box-ticking' approach, rather than to overcome it.
- **Chapter 10, 'Congruences, compromises, contradictions: user involvement achieved'**, considers some of the organizational characteristics that tended to militate against a more 'partnership'-based approach, of the kind advocated by Macmillan in Chapter 9, from developing in most sites. Micro-level factors seemed to combine with institutional forces to deter integration of involved users into local teams, and to construct roles for them at a national level which were out of kilter with what they envisaged. In the one site where a more partnership-based user

involvement was realized, the development of the project through time seemed to produce an increasingly professionalized role for users, which whilst productive and valued by those involved, seemed to stray from the original rationale for user involvement in national policy and the programme. Meanwhile, a similar professionalization was occurring in the personal development of some involved users at a national level, but this represented an ambivalent development for Macmillan staff, who sensed political and practical problems with the establishment of a particular group of users in this role.

- **Chapter 11, 'Discussion'**, brings together the analyses of the empirical chapters to summarize and discuss the implications of the findings in relation to the research questions set out in Chapter 3. At the level of practice, it notes the importance of the involvement process itself as constitutive of the identities of involved users, the forms that develop, and the relationships these imply between publics, the state and professionals. At the level of policy, it notes some consequences of the rather loose connection between policymakers' declared intentions and practice on the ground, and suggests some of the implications for involvement of the increasingly complex governance scene, where third-sector organizations seen as 'giving voice' to publics are drawn into the planning, management and delivery of public services. On a social-theoretical level, it notes several areas of congruence with some of the social-theoretical perspectives set out in Chapter 1, but also the limitations of their explanatory power in relation to empirical phenomena.
- Finally, the **Conclusion** summarizes the study and its findings, notes limitations, and makes suggestions about areas for future study.

1.

PUBLIC INVOLVEMENT IN HISTORICAL PERSPECTIVE[1]

Across the public services, public participation has become an increasingly prominent area of policy in recent years. The priority placed on a patient-focused NHS, for example, in high-level policy documents (e.g. Secretary of State for Health, 2000b), and now embodied in a statutory duty to involve patients and the public, has been clear under the Labour governments in power since 1997. Patients and the public are to be involved at every level of NHS provision, from being offered choice over treatment in the individual consultation to holding influence as members of foundation hospital trusts, and this reflects wider Labour policy attempting to harness the public's agency in public-service delivery in general (Gilliatt *et al.*, 2000; Clarke *et al.*, 2007). However, involvement in health services and efforts to enlist the 'active citizen' in welfare provision have earlier origins than this. My aim in this chapter is to situate current efforts to promote public and user involvement in the NHS and the wider

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[1] Much of this chapter is published as 'Public participation in state governance from a social-theoretical perspective', in G. Currie *et al.* (eds) *Public services management: a critical approach* (London: Routledge) (Martin, 2009b).

public sector in relation to the ways it has been pursued in the recent past, and in particular in relation to the disparate, changing rationales embodied in such initiatives. My main focus will be on the approach to involving users and the public taken by the preceding Conservative administrations, particularly from the early 1990s when such initiatives were pursued vigorously in the introduction of internal markets and efforts to nurture consumerism in health- and social-care provision. The ideological legacy of the Thatcher and Major years is widely accepted to have had a profound effect on the political philosophy of the following Labour governments. With regard to welfare, Labour has simultaneously attempted to break away from neoliberal policies on some fronts, whilst accepting new-Right thinking on the nature of contemporary social reality and the best ways to govern and administer it on others (Rhodes, 2000; cf. Blair, 1998). This tension, we shall see, is reflected in Labour's policies on involvement, in relation both to the underlying rationales for promoting it and the ways in which the government has sought to achieve it. Firstly, however, it is worth considering some of the theoretical rationales offered for participation, before examining how these have been drawn upon in various combinations by successive governments and policymakers.

The rationales for involvement

Public involvement in public-service delivery can be related to wider rationales for involving the lay citizenry in government and administration at a number of levels, from the overarching philosophy of policymaking down to individual-level practice. Abelson *et al.* (2003) offer numerous explanations for this view of participation as a 'good thing'. It may improve accountability, allow for better representation of the public's needs, and thereby increase the legitimacy of rule and administration. More generally, they suggest, the current attractiveness of participatory governance reflects recognition among policymakers of a more sophisticated, sceptical public, with involvement providing a means of harnessing popular rejection of a trust-based, paternalistic model of government to produce policies which match better the public's expectations. Other writers have also sought to highlight how this model of participation, drawing on the productive synergy to be gained from engaging with a demanding public on equal terms, also serves to build capacity for self-government among communities (Schofield, 2002) and promote autonomy among individuals (Truman & Raine, 2002).

Related to this vision of a mature, critical public is the more general notion that representative democracy—broadly, the election of representatives and an executive, and the implementation of democratically mandated policies through unelected, professionally accountable public-sector managers and practitioners—falls short of democratic ideals (e.g. Gutmann & Thompson, 1996; Bishop & Davis, 2002; Catt & Murphy, 2003). More direct involvement of the citizenry, it is argued, helps to plug this 'democratic deficit' (Pratchett, 1999), firstly by removing some of the inherent limitations of electoral representation, and secondly by ensuring that the technocratic elite entrusted with implementing policy is accountable to the wider public (Milewa *et al.*, 1999; Williams-Jones & Burgess, 2004). This, then, is a matter not only of improving accountability, but also of addressing power imbalances by ensuring that powerful professional groups are oriented towards the needs and wishes of the public—in the case of the NHS, long a policy concern for governments of the Left and Right alike—or of particular, marginal groups within that public (Harrison & Mort, 1998; Macdonald, 2003).

Issues of democratic legitimacy quickly come to overlap issues of appropriateness of provision in this literature, then, via questions of social justice, levelling professional power or facilitating a more relational, joined-up model of governance (Simmons & Birchall, 2005). These accounts are both input- and output-oriented (Montpetit, 2003), with democratic and technocratic rationales. We revisit this distinction later; for now we note that the two are not mutually exclusive, and may even be mutually reinforcing (Lomas, 1997; Mullen, 1999). By looking at the way in which public and user involvement has been embodied in policy and practice over the last 20 years in particular, in the next section we see how these aims overlap, interrelate and conflict as governments of different political philosophies have emphasised them differentially.

Involvement in the NHS from 1948 to the present

The inception of the NHS, as a national organization directly accountable to the Secretary of State for Health, created a centrally controlled health service subject to little local democratic influence (Toth, 1996). Local authorities retained control over community health services until 1974; when these too were transferred to NHS control, community health councils (CHCs) were set up in England and Wales to ensure continued local involvement in community-health matters—"representing the interests of the local community"—with half their membership taken from local authorities, a third elected by voluntary organizations and the remainder appointed by regional health authorities (Hogg, 1999: 88). For the following two decades, CHCs were the principal mechanism for involvement in the NHS, with mixed outcomes (see Hogg, 1996). However, even before they were eventually abolished, the role of CHCs was marginalized by NHS reorganization: the creation of an internal market, with purchasing and providing responsibilities split between health authorities and hospital trusts. This consumerist model of provision, heralded by the 1990 NHS and Community Care Act, saw health authorities cast as 'consumers-by-proxy' acting on behalf of the public, and created a very specific role for public involvement and consultation.

Competition and (proxy-)consumerism: involvement in the 1990s

The 1990 NHS and Community Care Act was emblematic of the kinds of reforms to public-service provision prescribed by new-Right thinking. Through quasi-markets and the new public management (NPM), public services were to be made more efficient, effective and consumer oriented, moving power away from professionals and towards their clients, and reducing the paternalism and inflexibility of monopolistic state provision (Le Grand, 1997; Martin *et al.*, 2004). On this basis, then, as Hogg (1999) has it, purchasers were to become 'champions of the people', and CHCs became somewhat redundant as consumer orientation was to result in responsiveness, satisfaction and the services that the people wanted (see Department of Health, 1992).

Whatever the reality of this vision and whatever the shortcomings of the internal market as a means of achieving it, the purchaser-provider split in the NHS required a new function of the involved user: that of the consumer representative, who could elucidate for the purchasing health authority exactly what it was that patients and the public wanted from services commissioned (Milewa *et al.*, 1998), ensuring that the decisions of health-authority managers as proxy consumers were in line with the views of the public. This, however, would be one among many factors influencing managers' behaviour, not least limited resources (Milewa *et al.*, 1998; 1999), and as Anderson and Gillam (2001: 15) put it, the task of assessing and acting on local populations' health needs

> heightened another tension for local decision-makers who were supposed to work with more than simply measures of demand (that is, what patients want and currently use). The internal market helped to extend a new managerialism to all corners of the NHS bureaucracy. One manifestation of this was an emphasis on evidence of cost effectiveness as the key criterion to underpin purchasing decisions. This brought Health Authorities into conflict with individual patients and their advocates in areas […] where demand is significant but evidence for their effectiveness is scant.

In some ways, then, precisely the aspects of the internal market aimed at promoting consumerist involvement in the NHS served in practice to negate its effectiveness. This reflects a tension between 'popular will' as symbolised in the wishes of directly involved users and the 'popular will' effected through the managerialist, efficiency-oriented reforms to NHS administration initiated by a democratically mandated government. This is a ubiquitous issue in involvement, which we consider further later on.

More generally, consumerist involvement of the sort promoted in the 1990s reforms was highly constrained in its aims and legitimate foci. Rhodes and Nocon (1998: 75-76) note conflict "between the emphasis on consumer choice, aimed at achieving improvement in efficiency, effectiveness and economy along the lines of consumer satisfaction, and the politics of empowerment or liberation, aimed at giving users greater control over their lives by giving them a direct say in agencies" (see also Croft & Beresford, 1992). Quite apart from the constraints imposed by scarce resources on these 'consumer representatives', the consumerist model itself rendered certain questions out-of-bounds, binding involvement to the imperatives of NPM (Milewa *et al.*, 1999). This was not, then, about democratization or accountability, but about giving the public its proper role in a market-based construction of the operation of society. For those who view public participation and the nature of society in more communitarian or collectivist terms, the shortcomings of such a conception are obvious. Vigoda (2002: 534) summarizes the tensions between NPM and 'proper' involvement thus:

> The term *client*, or *customer*, which is so applicable in the private sector, […] contradicts the very basic notion of belonging, altruism, contribution to society, and self-derived participation in citizenry actions. When someone is defined as a client, he or she is not actively engaged in social initiatives, but is merely a passive service (or product) consumer, dependent on the goodwill and interest of the owner.

Reducing this dependency, of course, was precisely one of the aims of breaking up the monopoly of the NHS through the introduction of the quasi-market and competition between purchasers, but the general characterization of consumerist involvement remains a legitimate one. Consumerism for many writers fosters essentially passive forms of involvement which do not engage citizens in the most important domains of provision, and fail to empower them to make important decisions. Bauman (1995: 273) sums up the logic of the consumerist version of involvement in relation to citizens' charters, such as the Patient's Charter introduced in 1991, which constitute the citizen

> not as a person eager to assume responsibility for issues larger than his private needs and desires, but as a consumer of services provided by agencies s/he has little right and no interest to examine, let alone supervise. Citizens' charters promote that image of the citizen by defining citizens' rights as first and foremost, perhaps even solely, the right of the customer to be satisfied. This includes the right to complain and to compensation. This does not include, conspicuously, the right to look into the inner workings of the agencies complained about and expected to pay the compensation—much less the right to tell them what to do and according to what principles.

The consumerist model of involvement, and the society-as-market discourse which informed it, were not hegemonic in Conservative thinking of the 1990s: as Prior *et al.* (1995) point out, they were accompanied by discourses of community and civic responsibility. Nevertheless, the neoliberal vision of a society of rational consumers was prominent during the Thatcher and Major years, and was efficacious precisely because it sought not only to reflect social reality but to mould it (Rose & Miller, 1992). The ideology and policies of the Left were profoundly influenced by this shift in the political and social landscape (Campbell *et al.*, 1989), and the Labour governments in power from

1997 had an ambivalent position on the market's role in welfare provision. On the one hand, the NHS internal market was (initially) abolished, to be replaced by collaborative networks of managers and practitioners governed by norms of co-operation. On the other hand, the incentivizing function of markets and competition and, more generally, of individual responsibility, was recognized in the Labour governments' policies (see, e.g., Field, 1995; Blair, 1998), and played a growing part in NHS reorganization—culminating in a *de facto* reintroduction of the internal market, this time including private providers as competitors. In relation to involvement, too, Labour's policies represented a mixture of an acceptance of the new orthodoxy and its individualistic, individualizing tenets, and efforts to reject these in favour of an approach based on ideas of citizenship, community and 'partnership' between service users and professionals.

Involvement from 1997: changes and continuities

The uniting theme behind these disparate drivers of new Labour policy was the *modernization* of the state to align with the contemporary realities of British society (Newman, 2001). Changes in the demography, economy and culture of Britain—and the political consequences of two decades of Conservative rule—meant, for the theorists of new Labour and 'Third Way' politics, that traditional approaches to translating left-wing values into a concrete programme of government were now inappropriate (Giddens, 1994a; 2000; see also the discussion in the next section). In practice, this has seen varied prescriptions for policy, but for the present discussion the most important dimensions of modernization are democratic renewal (and linked ideas about capacity building among citizens and communities) and the responsiveness of the public sector, particularly the welfare state.

Though these dimensions might seem quite distinct in their ambitions, and in what they imply for the practice of involvement, the two have been semantically linked in Labour's policy and rhetoric on public participation from the start (Barnes *et al.*, 2004b; 2007). Gustafsson and Driver (2005: 529) point to pamphlets authored by new-Labour luminaries (Adonis & Mulgan, 1994; Leadbeater & Mulgan, 1994), published by Demos in the mid-1990s, which viewed public participation as a means to promote

> the rights and responsibilities of the citizen and […] deepen the sense of citizenship through active participation in the governance of the public sphere. And what was good for politics, according to the Demos authors, would also be good for public and social administration. More 'people power' would widen choices, make public policy more accountable to users, and deliver better performance.

Public involvement in Labour's modernization of the delivery of public services, then, was a means of responding to the mature individual of late modernity without reducing her to a mere consumer. In line with the Third Way and communitarian ideas that informed new Labour's political philosophy, this was about a new way of connecting the state to the citizenry, cutting between 'old Left' statism and 'new Right' marketism, attempting instead to foster a dynamic relationship between state and citizen (Chandler, 2001). This approach was to draw on the agency and ingenuity of individuals and communities in ways which would both improve the effectiveness of the state and also reinvigorate the notion of citizenship itself, with mutually reinforcing rights and responsibilities (e.g. Labour Party, 1995 cited by Chandler, 2001; cf. Schofield, 2002; Marinetto, 2003). On this basis, then,

> the Conservative consumer would become a fully fledged citizen, with rights and duties in the governance of the country beyond the voting booth and the market place. This notion of the active citizen would be at the core of the government's strategy for 'democratic renewal' and the 'modernization' of public services. (Gustafsson & Driver, 2005: 530)

In practice, what this meant was the creation of new forums for interaction between managers and professionals and the publics and communities they served (Anderson & Gillam, 2001). In health and across the public sector, individuals were incorporated into governance as (representatives of) users, citizens and communities (Barnes *et al.*, 2003), in order to deal with the effectiveness and appropriateness of state provision via collaboration and partnership rather than through the competitive mechanisms of consumerism and quasi-market (Newman *et al.*, 2004). From a slightly more sombre (though complementary) perspective, Milewa *et al.* (2002) view this collaborative form of involvement as an alternative means of regulating professional behaviour, through direct accountability to citizens on citizens' terms rather than through performance management and the market. The important point, however, is this construction of involvement in terms of citizenship and social cohesion, rather than through the individualizing ethos of (proxy-)consumerism.

For communitarians such as Prior *et al.* (1995), this kind of approach to the relationship between the state and the individual is a satisfactory one: citizenship can be understood and fulfilled "only in the context of social networks bound together by the ties of membership" (Prior *et al.*, 1995: 17). For others, though, communitarianism and the Third Way represent fundamentally individualistic political philosophies. Delanty (2000: 30) thinks of communitarianism as "almost entirely a theory of citizenship as a self-empowering force," because its focus on voluntarism absolves the state of duty to its citizens. In common with the ideology of consumerism, then, communitarianism relies on the agency of individuals, and their ability to behave appropriately in response to social circumstance (Bauman, 1996). For Higgs (1998: 181), "communitarianism is an attempt to create a 'natural community' that can resolve the inherent contradictions of modern life, but which is constructed in the private sphere rather than through the state and based on the dictum 'choose, but choose wisely'." In these terms, community-oriented involvement represents for Milewa (2004: 245) a reconfiguration of the notion of citizenship and the duties and rights it entails, which in the long run may signal a sea-change in the relationship between state and citizen:

> If the government really believes that people 'must' make an effort to become involved in matters of planning or governance, this might have significant longer-term implications in a system of health care to which access has traditionally been unconditional.

What we see here, perhaps, is a semantic and practical slippage in what is meant in Labour's 'modernization' project. From a self-proclaimed ambition to overhaul the state's relationship to a changed society, made up of active and demanding citizens and communities, it becomes an attempt to imbue those citizens and communities with the agency necessary to provide the inputs that the responsive state needs. As Clarke (2005: 450) points out, although 'active citizenship' is about choice and voice, about "independent agents, rather than dependent subjects waiting on the state's whims," it is also about making responsible citizens who can make the 'right' choices, and 'market-ready' citizens who will make good labourers and consumers. To some extent at least in this brave new world, then, it is society as much as the state which is to be modernized.

From this perspective, new Labour's approach to social policy retains the fundamentally individualizing ethos of consumerism, recast in a communitarian and Third-Way light. Alongside this, of course, Labour's practice of the Third Way had always included elements of neoliberalism, even before its reconciliation with the quasi-market, as heralded in Blair's second term by the fully fledged return of the purchaser-provider split in the NHS. Thus in addition to the community- and citizen-oriented approaches to public and user involvement, an overtly consumerist inheritance was there to be found all along. If for some commentators, then, the Labour government's approach to community and citizenship was implicitly individualistic, then the consumerist tendencies it inherited from its Conservative predecessor were explicitly so

(Leach & Wingfield, 1999; Rowe & Shepherd, 2002). Moreover, many writers find that the NPM approach to involvement, largely retained by Labour, generally gave it a highly constrained role. Competing pressures of top-down management and directive targets have meant that concerns about citizenship become marginal, and empowerment even more so (Cook, 2002; Rowe & Shepherd, 2002; Tritter *et al.*, 2003). Managerial discretion over the methods for involvement has meant varied practices that may include deliberative models aimed at promoting dialogue and development, but often in practice follow fundamentally consumerist approaches, such as feedback forms (Martin & Boaz, 2000; Cook, 2002). So Rowe and Shepherd (2002: 284) conclude that "managers have accepted the [NPM] approach that regards public involvement as a tool for gathering information on patient views to increase the responsiveness of services rather than as a process of empowerment by involving users in decision making."

Despite a rhetorical shift in discourse on the philosophy and purpose of public involvement since 1997, then, the literature emphasises continuities from the forms that were introduced under the NHS reforms of the 1990s and based on an ideology of consumerism. Many writers have also noted the individualizing aspects of Labour's versions of communitarianism and citizenship, with their focus on agency over structure and the low profile they give to the role of the state. What I have not done in the course of this brief overview of the recent history of participation policy is look at the evidence for how involvement as put into practice embodies these individualizing tendencies, or whether in fact its democratic and empowering aspects can coexist with the consumerist approach. These are questions considered in the following two chapters, in relation to the more general issue of the tension between the technocratic and democratic aspects of involvement. First, however, we need to take a step back and consider the phenomenon of involvement in the context of modern British society. Why, in more general terms, is it that consulting and actively involving service users in the delivery of public services, whether as consumers, citizens or communities, has become so appealing to governments of all political hues over the last few decades?

Involvement in a socio-historical context

That society has been transformed since the formation of the welfare state following the second world war, and particularly since the mid-1970s, is a pregiven of contemporary sociological analysis. The form of these economic, social and cultural changes is more-or-less agreed upon; there is less consensus about their origin. Accounts of 'post-Fordism', 'high modernity', 'late modernity' and 'postmodernity' largely describe the same social phenomena, but differ on the question of causation—if indeed they find it reasonable to posit a final cause at all. What is agreed is that the certainties of the Fordist economic order (and the welfare state it underpinned), which were reasonably stable for 30 or so years, no longer apply to contemporary society in Britain and the economically developed world. Concurrently, fundamental changes in the institutions of modernity, from the family to the nation state, have occurred, such that traditional assumptions about welfare provision no longer hold.

This is the social world which the welfare reforms of the Conservative and Labour governments of the last 30 years have sought to address, significantly recasting the role of the citizen and his relationship with the state. How might this backdrop to this recasting, including initiatives such as public participation, be understood? To start to answer this question, we turn to two influential accounts of the consequences of late modernity. The first is most associated with the work of Ulrich Beck and Anthony Giddens (Beck, 1991; 1998; Giddens, 1990; 1991), whose accounts of the 'risk society' and 'institutional reflexivity' depict a truly modern modernity, shorn of the traditional tendencies that underpinned earlier modernity, and replete with both risks and opportunities. This narrative has, of course, been influential in the reformulation of the

Labour Party's political philosophy. The second is the account of the present developed by those taking up the idea of 'governmentality' sketched by Michel Foucault (e.g. 1991) in his last few years, which considers late modernity less in terms of a progressive narrative of the modernization of attitudes and institutions, and more in terms of the changing structures and channels of power which characterize contemporary relationships between human subjects.

Reflexive modernization, individuation and the state

Beck and Giddens write from different starting premises and intellectual backgrounds, and about somewhat different societies, but the pictures of modernity they sketch have much in common. The underlying thesis in each author's work is that modernity has reached a crisis point. Scientific progress has resulted not in certainty but in plurality; institutions of civil society which have underpinned economic and social development since industrialization have lost integrity and popular faith; industrial society has given rise to new risks threatening the very existence of humanity, from nuclear weapons to global warming: "society has become a laboratory where there is absolutely nobody in charge" (Beck, 1998: 9). The promises of the Enlightenment have not been fulfilled by modernization. But these outcomes are not the result of a failure of modernity, but to a large extent arise from its successes. Late modernity brings not only new risks, but also new opportunities, openings and chances for self-fulfilment that the individual of earlier modernity could not have contemplated.

In the sphere of work and the lifecourse, prior certainties of traditional societies and industrial modernity have gone, and the individual faces risks and life-altering decisions which she must make for herself (Beck & Beck-Gernsheim, 2001). Beck (1991: 128) writes of a simultaneous 'liberation' from and 'disenchantment' with the institutions on which earlier modernity rested, with "disembedding, *removal* from historically prescribed social forms and commitments in the sense of traditional contexts of dominance and support" accompanied by "the *loss of traditional security* with respect to practical knowledge, faith and guiding norms." In a modernity where no definitive answers are to be found, the individual must embrace risk and all it implies:

> To accept risk as risk, an orientation which is more or less forced on us by the abstract systems of modernity, is to acknowledge that no aspects of our activity follow a predestined course. […] Living in the 'risk society' means living with a calculative attitude to the open possibilities of action, positive and negative, with which, as individuals and globally, we are confronted in a continuous way in our contemporary social existence. (Giddens, 1991: 28)

What Beck and Giddens describe, then, is a modernity in which opportunities for self-realization are omnipresent. Marx's adage, that "men make their own history […] but under circumstances existing already,"[2] still applies, but those circumstances are more open and enabling than ever before. Of course, not everyone is equally able to take advantage of this openness. Giddens argues that the situation applies even to those at the bottom end of the socio-economic scale—indeed, the need to make hard decisions is all the more pressing—but acknowledges that the choices faced here are more restricted, such that they may be "a source of despair rather than self-enrichment" (Giddens, 1991: 86). Beck (1991: 135) notes that "even where the word 'decisions' is too grandiose, because neither consciousness nor alternatives are present, the individual will have to 'pay for' the consequences of decisions not taken" (cf. Beck & Beck-Gernsheim, 2001).

To use Ellison's (1997) words, then, there are in this schema reflexivity 'winners' and 'losers', and if willingness and ability to take advantage in late modernity are

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[2] Karl Marx, *The Eighteenth Brumaire of Louis Bonaparte* (1852). This translation is taken from http://www.marxists.org/archive/marx/works/1852/18th-brumaire/ch01.htm, accessed 22 November 2005.

unequally distributed, there are important consequences. There is an uneasy tension in the work of Giddens and Beck between their *description* of the active, reflexive citizen as a product of modernity achieved, and their parallel deployment of reflexivity as a *prescription* which the contemporary citizen should—indeed, must—follow to stand a chance of self-fulfilment. Increased opportunity for self-actualization is not an unambiguously positive societal trait for all. Moreover, as Nettleton and Burrows (2003) note, the description of reflexive modernity put forward in the work of Giddens and Beck has in some respects become a blueprint for Labour's modernization programme, and the creation of a welfare state built around risk and opportunity. The transformation of welfare policy in this way rests on the purported characteristics of the contemporary citizen, or, as noted in the previous section, on the possibility of moulding such reflexive citizens through social-policy interventions. The line between *description of* and *prescription for* the modern individual and society in reflexive-modernization discourse, then, is a blurred one, and (as Chapter 2 discusses) this generates some interesting peculiarities in the theory and practice of involvement.

Uncertainty and plurality affect not only the individual in the post-traditional order described by Beck and Giddens, but also characterize the very foundations of modernity itself: ideals of the Enlightenment such as objective knowledge and scientific truth. Once again, though, this crisis results not from modernity's failure, but from its realization. For Beck, in earlier modernity science was one institution among many which was not truly modern, since "the claims of scientific rationality to knowledge and enlightenment [were] still spared from the application of scientific skepticism to themselves" (Beck, 1991: 155). For Giddens (1994b: 87), "science was in effect not very different from tradition—a monolithic source of 'authority' in the generic sense." What characterizes the relationship of the emergent risk society to science is recognition of the contingencies of scientific knowledge and a demand that science be subjected to its own, rigorously modern, standards of testability. So once again,

> the consequences for the lay individual, as for the culture as a whole, are both liberating and disturbing. Liberating, since obeisance to a single source of authority is oppressive; anxiety-provoking, since the ground is pulled from beneath the individual's feet. (Giddens, 1994b: 87)

Again, a variety of responses on the part of the modern individual is possible, from nihilistic withdrawal to positive embracing. At a collective level, what Beck in particular calls for is democratization of science and technology, as part of a wider project he calls 'modernity as a learning process'. The fruits of modernity are to be safeguarded by ensuring that scientific progress is subjected to a critically modern framework of regulation. The key, then, is reflexivity in modernity's institutions:

> A detraditionalized *and self*-critical society also comes into being along with the risk society, at least potentially. The concept of risk is like a probe which permits us over and over again to investigate the entire construction plan, as well as every individual speck of cement in the structure of civilization." (Beck, 1991: 176)

Scientific progress and modernization, then, must be subjected to democratic accountability—of some kind. This requires what Beck (1991: 209) calls a "sub-politics of progress," acting directly on scientific activity as it occurs, in contrast to the macro-politics of national government, and which requires a democratization of what have traditionally been the autonomous spheres of professional experts: scientists, clinicians, engineers and so on. In relation to medical research, then, Beck (1991: 209) calls for an end to the existing institutional set-up, based on "the model of an undifferentiated authority to act, which does not yet know the separation of powers." Beck's focus here is on accountability, on breaking up professional monopolies for whom "the belief in progress becomes a *tradition* of progress that subverts modernity" (Beck, 1991: 214).

This requires 'politics unbound': democracy and critical inquiry drawn from their traditional place in representative democracy and extended into institutions where instrumental rationality and a progressive orientation mean that these other values of the Enlightenment have been marginalized. Beck and Lau (2005: 545) find some progress in this opening of scientific knowledge, but with this the ongoing redrawing of boundaries to exclude critique from outside scientific institutions:

> Experiential knowledge is no longer regarded as a subordinate form of knowledge, but is instead acknowledged as being irreplaceable and indispensible—albeit only if it can be objectified, that is, if it is compatible with scientific procedures and forms of representation. Thus, the integration of such knowledge occurs selectively, according to scientific criteria. Concurrently with this, new boundaries are drawn to exclude that variety of experiential knowledge that cannot be objectified using scientific methods.

In large part Giddens shares with Beck these democratizing ideals, though his focus is the consequences for the individual of high modernity. As such, he applauds the fall of what we might call 'blind faith' in scientific progress, but stresses the need for more active trust in the abstract systems of modernity, including scientific knowledge but also other modern institutions such as the market and technological infrastructure, which are simply too complicated for a layperson to apprehend alone. For Giddens, then, the key consequence of the detraditionalization of the relationship between the lay individual and expert knowledge is the opportunity for the individual to engage with a plurality of expertises and make an informed decision about which to trust.

On individual and collective levels respectively, then, Giddens and Beck both describe and argue for a greater role for lay people in the governance of risks of various kinds, and an end to the paternalistic relationship between the public and expertise. As

Lash (1994) and Pellizzoni (1999) point out, however, both accounts nevertheless reserve a special place for expertise: Beck and Giddens remain essentially modernistic or even scientistic in their approach to scientific rationality and lay knowledge, and refuse the much more radically social-constructivist perspective of some sociologists of science. What Giddens (1991; 1994b) argues for is informed decision making based on competing sources of expertise, not a challenge to that expertise from the inferior level of knowledge of the lay individual. Beck's argument for 'politics unbound' includes the lay population, but demands a particular role for dissenting *experts*:

> Only when medicine opposes medicine […] can the future that is being brewed up in the test tube become intelligible and evaluable for the outside world. Enabling self-criticism in all its forms is not some sort of danger, but probably the *only way* that the mistakes that would sooner or later destroy our world can be detected in advance. (Beck, 1991: 234)

While the lay population is the final arbiter of these questions, either on an individual basis or through some democratic mechanism, Beck and Giddens maintain a relatively conventional separation between the expert and the lay in their notions of reflexivity within science and other abstract systems. As Lash (1994: 201) puts it, "for Beck and Giddens here reflexivity involves as it were 'representative democracy' inside the new institutions with the lay public 'voting' on competing forms of expertise. There is little room in this for the 'participatory democracy' of informal everyday lay politics."

Nevertheless, there is for both Beck and Giddens another sense in which democracy is becoming 'unbound', as Beck has it. Late modernity, as we have seen, brings with it new challenges and opportunities for the individual in living a life of self-realization and self-fulfilment. Giddens (1991) thus argues that 'emancipatory politics' is being supplemented and increasingly superseded by 'life politics': that the struggles for freedom from material inequality, oppression and dependency defined by class, gender, race and other cleavages have largely been won, and so the key political questions facing the individuals of late modernity centre around what to do in the wake of these emancipations. In similar fashion, Beck (1991: 193) plays down the role of class politics in arguing that modern Western states have achieved "*established* democracy, in which the citizens are aware of their rights and fill them with life, [which] requires a different understanding of politics and different institutions" (cf. Beck, 1998). The question of the governance of science and other abstract systems, then, is not the only one in which the conventional political institutions of earlier modernity are no longer adequate. Life politics, encompassing the self-identity and lifecourse of the emancipated modern individual, draws politics out of the central-government institutions of modernity into the lifeworld of the individual and community. There is more to it than this, though. In redrawing the boundaries of politics and valid political issues, Giddens argues that life politics feeds back into the question of the legitimating rationality of modernity itself:

> Life-political issues place a question mark against the internally referential systems of modernity. Produced by the emancipatory impact of modern institutions, the life-political agenda exposes the limits of decision-making governed purely by internal criteria. […] Life political issues […] call for a remoralising of social life and they demand a renewed sensitivity to questions that the institutions of modernity systematically dissolve. (Giddens, 1991: 223-224)

So, Giddens argues, late modernity bears a new politics, whose concern with issues of self-identity over material distribution brings with it questions which go straight to the heart of modernity's instrumental reason. To this extent, the critiques of Lash (1994) and Pellizzoni (1999), characterizing Beck and Giddens as overly rationalistic or scientistic, seem perhaps misdirected. Their prescriptions for the governance of science may rely on an early-modern or traditional division between lay and expert knowledge, but Giddens also entertains the possibility of a life-political challenge to the reason of modern institutions, though he does little more than outline this idea. Of particular interest in this context is Giddens' (1991) notion of the 'fateful moment', a point in the lifecourse at which crucial, often unexpected, decisions must be made, perhaps following the realization of a risk. At these points, normality is disrupted for the individual, as he confronts fundamental questions of existence and self-identity of the kind usually sequestered by modernity. Such ideas seem particularly relevant to the empirical field described in later chapters of this thesis, the involvement of users of cancer-genetics services who are faced with fundamental questions about risk, fate and mortality at the individual and familial levels. Perhaps it is at times like these that there is a place for a more equal engagement between the reflexive individual and abstract systems, in place of the choice of competing expertises posited in more scientistic readings of Beck and Giddens.

Involvement in reflexive modernity

Whatever the exact relation between expertise and democracy in the ideas of Beck and Giddens, the key component of their arguments is that high modernity demands and creates a more fully modernistic mindset and set of relationships in society. As already noted, this analysis has contributed greatly to the Labour Party's social policy, and so it should not be surprising that many writers consider involvement and other policies, especially since 1997, in terms of a recasting of the relationship between expert authority and an active citizenry (e.g. Chandler, 2001; Clarke, 2005).

It is also, though, an analysis of a modernity which for Beck and Giddens is already emerging regardless of the political programme of any one particular government. Thus some conceive of this individual and institutional reflexivity as something that develops on account of the nature of contemporary modernity, while others see it more as being engineered through social-policy interventions. Combining both perspectives, Hess (2003) describes how the doctor-patient relationship has been 'modernized' in the Beck-Giddens mould, Tovey *et al.* (2001) track the ability of increasingly well informed and organized patient collectives to influence an increasingly receptive and democratically oriented NHS, and Newman *et al.* (2004) analyse direct involvement in the work of local authorities in terms of a shift from government towards collaborative governance, a means of harnessing the capacity and reflexive self-knowledge of the lay population to improve service effectiveness.

More sceptically, others view active-citizen-oriented social policy as a means of displacing the state's responsibilities onto the individual (Gilliatt *et al.*, 2000; Clarke, 2005). By means of involvement initiatives and the like, the citizen is enlisted as co-producer of state provision rather than empowered in the governance of services. Chandler (2001) is more cynical still, taking the view that some approaches to involvement replace democratic accountability with a therapeutic relationship between state and citizen, affording the chance for self-expression but doing nothing to transfer control of public services to the public. In these accounts, involvement seems to be less about empowerment and more about the transfer of responsibility. And for some commentators, this is partly what discourses of 'modernization', the 'active citizen' and 'risk' are all about. In Foucaultian terms, risk, for example, can be viewed as a 'technology of government' which inclines the individual towards particular dispositions and courses of action (Turner, 1997; Petersen, 1997; Higgs, 1998), as part of a complex of strategies aimed at enjoining all sorts of agents, from government bodies to individuals, in the modernist project of progress. Higgs (1998: 193) takes the example of health promotion as one such technology:

> Health promotion steps into the public domain as a virtuous activity not only promoting health but also the person. While this seems to accord with the modern conception of the agentic individual who can mould himself or

> herself, it also provides the basis for the new relationship between state and citizen—one concerned with demonstrating the appropriate 'technologies of the self'. The new citizen learns to engage with risks constructively because if he or she doesn't there is no collective security net.

In Foucaultian terms, then, 'reflexivity', 'active citizenship', 'risk' and related discourses drawn from the diagnosis of reflexive modernity and deployed by policymakers and others in seeking to modernize the state, modernize society, or towards any number of other progressive ends, are best viewed as a new incarnation of a governmental rationality—or 'governmentality' (*gouvernementalité*) in the neologism coined by Foucault—which has taken various forms over several centuries.

Governmentality in advanced-liberal society

In contrast to the risk-society and reflexive-modernity theses—which locate individuation and the changing relationship between society and state in a largely progressive metanarrative of the 'modernization of modernity'—what is distinctive about governmentality, as framed historically by Foucault and developed and applied by numerous subsequent scholars, is its focus on the role of intersubjective power in these changes. Governmental power is a constant across all kinds of more-or-less modern societies; it is its application that varies.

This approach has its origin in some of Foucault's later writings and lectures, many published only posthumously. In the first volume of *The History of Sexuality* Foucault (1981: 89) complains that the conventional notion of state power, deriving from a legalistic understanding of absolute monarchical power, is "incongruous with the new methods of power whose operation is not ensured by right but by technique, not by law but by normalization, not by punishment but by control, methods that are employed on all levels and in forms that go beyond the state and its apparatus." Governmental power is thus not the absolute domination subjects by a sovereign, but rather the 'conduct of conduct': influence on the free will of others. Power "incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their actions" (Foucault, 1982: 220). The idea of a more-or-less *freely* acting subject, then, is crucial to this understanding of governmental power.

Foucault traces his history of governmentality from the sixteenth to eighteenth centuries, where he finds a change in the nature of the relationship between governmental authority and the individual and population. The nature of government is transformed from a matter of sovereign rule over *territory* to a more general question of the governing of a *living population*. With the decline of feudalism and the expansion of colonial territory, the question of 'economy'—sound *management* of a population in pursuit of the common good—became the central concern of government. A purely juridical relationship between sovereign and subject consequently became inadequate, and so "the instruments of government, instead of being laws, now come to be a range of multiform tactics" (Foucault, 1991: 95). Principal among these in this early governmentality was the institution of the police, which in the societies of the eighteenth century was concerned less with law enforcement than with the sound administration of the growing urban areas, ensuring the upkeep of the systems which underpinned social life, from sewerage to the market. For Foucault, this signalled a crucial shift in the concern of government to the *care and command* of both *the individual and the population* together:

> What the police are concerned with is men's coexistence in a territory, their relationships to property, what they produce, what is exchanged in the market, and so on. It also considers how they live, the diseases and accidents which can befall them. In a word, what the police see to is a live, active and productive man. […] With this new police state the government

> begins to deal with individuals, not only according to their juridical status but as men, as working, trading, living beings (Foucault, 1988: 155-156)

By dealing in the life, health and wealth of its subjects individually and collectively, the governmental nation-state of the eighteenth century thus contributed to its own strength, survival and development.

Through the nineteenth century Foucault traces some shifts in governmentality. Most important is the ascent and transformation of liberalism, from a critique of the state to a programmatic political philosophy concerned with delimiting the boundaries of legitimate governmental power *vis-à-vis* the autonomous individual. "At that very moment," declares Foucault (1989: 261),

> it became apparent that if one governed too much, one did not govern at all—that one provoked results contrary to those one desired. What was discovered at that time […] was the idea of society, […] a complex and independent reality that has its own laws and mechanisms of disturbance.

Nineteenth-century liberalism, then, represented not a retrenchment from government, but its reconfiguration. Liberal governmentality was about ruling *through* society, about aligning, via a range of direct, and increasingly indirect, means, the needs and wishes of the individual with the needs and wishes of the collective (and *vice versa*). There was as much continuity in the ambitions of liberal government as there was change in the means of accomplishing those ambitions. So it is that Foucault (1988: 161-162) outlines a unified, unitary analysis of liberal and interventionist governmentalities, arguing that

> the main characteristic of our modern rationality [...] is neither the constitution of the state, the coldest of all cold monsters, nor the rise of bourgeois individualism. I won't even say that it is a constant effort to integrate individuals into the political totality. I think that the main characteristic of our political rationality is the fact that this integration of the

> individuals in a community or in a totality results from a constant correlation between an increasing individualization and the reinforcement of this totality.

Liberal and statist approaches to government are thus best understood as complementary, interrelated modes of rule which both in their ways seek to orient the individual and the collective towards modernistic ambitions of progress, efficiency and common good.

A not-dissimilar narrative is sketched by 'governmentality school' writers of the transition between welfare statism and neoliberalism in the post-war West (Rose *et al.*, 2006), something which Foucault himself also touched on in his lectures on governmentality (Lemke, 2001). Twentieth-century welfarism saw the re-emergence of a state which sought to programme society, but only through society, via the empowerment of professionals invested with "authority to act as experts in the devices of social rule" (Rose, 1996: 40). On this basis, even the fully formed post-war British welfare state did not represent the rise of state interventionism so much as a new way of administering the agency of organizations and professions whose role is one of 'governing'—i.e. dealing in the wellbeing of individuals and collectives—in relation to the state (Rose & Miller, 1992; Jessop, 2007). It follows that the rise of Thatcherite neoliberalism in the UK from the 1970s cannot be understood simply as an individualistic reaction to interventionism. For Rose and Miller (1992: 199), it should rather "be seen as a re-organization of political rationalities that brings them into a kind of alignment with contemporary technologies of government." This seems to me rather an extreme reversal of causality, deterministically positing political philosophy as purely or primarily a response to changes in the constitution of society. Leaving aside, though, this view of neoliberalism as foremost a means of harnessing contemporary technologies of government rather than an autonomous political philosophy, what we can agree upon is that the consumerism and liberalism of neoliberalism do not simply allow individuals to get on with their lives as they wish, unfettered by the state, but rather exemplify strategies of governmentality which strive towards particular outcomes. The neoliberal mode of governmentality is distinct both from welfarism and from nineteenth-century liberalism because in advanced-liberal societies it must govern not through society, "but through the regulated choices of individual citizens, now constructed as subjects of choices and aspirations to self-actualization and self-fulfilment" (Rose, 1996: 41).[3] Foucault's own analysis of neoliberalism (as delineated by Lemke, 2001) is similar. Neoliberal governmentality sees the logic of the market applied to all spheres of life, and

> encourages individuals to give their lives a specific entrepreneurial form. It responds to stronger 'demand' for individual scope for self-determination and desired autonomy by 'supplying' individuals and collectives with the possibility of actively participating in the solution of specific matters and problems which had hitherto been the domain of state agencies specifically empowered to undertake such tasks. (Lemke, 2001: 202)

So a strict dichotomy between statism and (neo)liberalism is not a hugely helpful one in understanding the exercise of political power. Governmentality in general, and neoliberal governmentality in particular, act on individuals and collectives in all sorts of ways besides direct state intervention. What Foucault's idea of governmentality offers, then, is a theory of government which focuses not on the state but on the diverse, dispersed conduits of power which instil particular forms of rationality.

Within this general schema, what seems distinctive about the operation of neoliberal governmentality within late-modern, advanced-liberal societies is the way in

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[3] In this section I follow Rose's (1996: 14) distinction between 'advanced liberalism' as the distinguishing characteristic of late-modern society and 'neoliberalism' as a particular political philosophy.

which it enlists state and non-state authorities in engaging the individual subject as an autonomous rational actor (Lemke, 2001), particularly a consumer. Professions such as medicine become the intermediaries between governmental rationality and the individual, so that, as Rose and Miller (1992: 188-189) elaborate,

> on the one hand, they would ally themselves with political authorities, focusing upon their problems and problematizing new issues, translating political concerns about economic productivity, innovation, industrial unrest, social stability, law and order, normality and pathology into the vocabulary of management, accounting, medicine, social science and psychology. On the other hand, they would seek to form alliances with individuals themselves, translating their daily worries and decisions about investment, child rearing, factory organization or diet into a language claiming power of truth. [...] By means of expertise, self regulatory techniques can be installed in citizens that will align their personal choices with the ends of government. The freedom and subjectivity of citizens can in such ways become an ally, and not a threat, to the orderly government of a polity and a society.

In this way, the individuals that make up society are moulded into appropriately rational subjects, not through direct state intervention, let alone through coercive legal arrangements, but by enlisting networks of actors with greater or lesser connections to the state. So, as Barry *et al.* (1996) point out, while neoliberalism may involve some form of degovernmentalization of the state, it certainly does not mean degovernmentalization *per se.* All sorts of new mechanisms of governance spring up which further the aims of governmentality—the most obvious in the context of Thatcherite Conservatism being the creation of quasi-markets and welfare consumerism: "it becomes the ambition of neoliberalism to implicate the individual citizen, as player and partner, into this market game" (Gordon, 1991: 36).

Governmentality, then, represents a distinctive means of understanding political rationality, and the state's decentred place in it, and of considering neoliberalism in particular. Where political-economic approaches to neoliberalism would construct it as an ideology, a false consciousness clouding the true class relations of production governing social reality, governmentality sees a discourse which produces reality as much as responding to it. In all sorts of fields, argues Rose (1993; 1996), new configurations of governmental rationality take shape, from the bottom-up regulation produced by quasi-markets to the 'extra-democratic' forms of authority to be found in quasi-autonomous non-governmental organizations. Private organizations too have a place in this distribution of power, as Rabinow and Rose (2003) note in relation to the biotech industry's role in determining the 'proper conduct' of patients in the field of health.

For the individual, advanced-liberal governmentality creates all sorts of new roles, casting her as consumer, rational agent, responsible citizen: imbuing the individual with the various competencies required for the effectiveness of this dispersed, co-optive form of rule. In this light, the active citizen of high modernity simultaneously celebrated and anticipated by Beck and Giddens can be contemplated from certain perspectives only hinted at in the previous section (Nettleton, 1997; Petersen, 1997; Higgs, 1998). Where Beck and Giddens tend to view a certain loosening of agency from structure thanks to late-modern reflexivity, from a governmentality perspective the boundary between structure and agency is less clear cut. Discourses of risk, self-fulfilment and the like are therefore best viewed as instruments of governmentality rather than in terms of individual agency (Petersen, 1997). The transformation of the role of the individual subject is arguably particularly profound in health care, with its traditionally paternalistic relationship between professionals—medics in particular—and patients. As Rose and Miller (1992: 195) put it,

> the health consumer was transformed, partly by developments in medical thought itself, from a passive patient, gratefully receiving the ministrations of the medics, to a person who was to be actively engaged in the administration of health if the treatment was to be effective and prevention assured. The patient was now to voice his or her experiences in the consulting room if diagnosis was to be accurate.

More generally, Petersen and Lupton's (1996) analysis of the new public health, which engages citizens and patients in the project of producing collective healthiness, sees its success in terms of the acculturation of the late-modern individual to "privilege the notion of autonomous individuality, not simply through health-related discourses and institutions but also through such institutions as the family, the mass media, and the education and legal systems" (Petersen & Lupton, 1996: 176).

We must be careful, however, not to characterize the Foucaultian approach to governmental power and modern subjecthood as wholly or even predominantly negative. As we have seen, power is not an inherent evil in a Foucaultian analysis—rather an intersubjective reality with immanent potentials as well as dangers—and Foucault's own reluctance to offer pronouncements on society extended to his sketches of governmental rationality as a particular enactment of power, not coercive but persuasive and even enabling (cf. Stenson, 1998). Following this ambivalence, some 'governmentality-school' writers have been keen to describe the positive ramifications for the individual of advanced-liberal society (e.g. Novas & Rose, 2000; Rose & Novas, 2005; Rabinow & Rose, 2006). Novas and Rose (2000) refer to 'somatic communities' of individuals drawn together by a common genetic condition and body of knowledge, and describe how in this process genetic knowledge is used positively by individuals in the construction of self, the creation of new communities and commonalities, and the planning of one's lifecourse. As such, it becomes a social project which involves the individual, his kin, and 'knowledgeable others' including not only clinicians and counsellors but also others with the same genetic mutations. In these kinds of writings, we begin to see a certain convergence of Foucaultian approaches and the understanding of late modernity and life politics put forward by the likes of Giddens and Beck, especially Beck's (2000; 2008) more recent writing on 'cosmopolitan solidarity' between strangers bound together by risks of various kinds.

Governmentality and involvement

From the above survey of governmentality literature, it is fairly clear how involvement might be understood from this perspective. Much of the writing in this tradition has tended to focus on the way in which the political philosophy of the new Right embodies a form of governmentality despite, indeed through, its anti-statist approach to government. Rose (1996: 61) anticipates how the political Left might "articulate an alternative ethics and pedagogy of subjectivity that is as compelling as that inherent in the rationality of the market and the 'valorization' of choice," but there is also much of relevance to new Labour's approach to involvement to be learnt from the existing literature. In part this is due to the continuity of consumerist discourse in post-1997 social policy as discussed above (cf. Clarke *et al.*, 2007); it is also because governmentalist tendencies are starkly evident in approaches to involvement that emphasise (active) citizenship, community and other key Third Way signifiers.

Thus Nettleton (1997) points out that any policy of involving users or the public is based on the presupposition that people are willing, able and competent to assist in the processes of government. As Hasselbladh and Bejerot (2007) insist, however, any such involvement relies less on the inherent, untapped agency of these individuals than on a process of 'agencification': imbuing agency through a host of measures, from making available information on managerial practices, through training the participant about appropriate conduct in the course of participation, to fostering a professional culture which engages with and is receptive to the input of non-professionals. Involvement of the public in the delivery of public services, though, may be as much about governing the public as the governance of services. As Gilliatt *et al.*'s (2000) research shows, empowerment of the public may serve to regulate services, but it may also create expectations of a public which uses scarce collective resources 'responsibly'.

> We suggest that service-users are gradually being enlisted as *responsible partners* in delivering the services they receive. Within a climate of resource constraints, consumers are increasingly expected to collude in this process. (Gilliatt *et al.*, 2000: 334)

In a similar vein, Gustafsson and Driver (2005) argue that while the service-regulating impulses of parental involvement in the Sure Start schemes they evaluate failed, the subjectifying tendencies of involvement, which engaged with parents "in order to create and reproduce the subjects necessary for governance arrangements to operate effectively" (Gustafsson & Driver, 2005: 531), achieved more success.

Alongside this relation to the individual subject, some writers have identified an emerging mode of governmentality relating to the community. Marinetto (2003) records how the regeneration initiatives of Conservative urban policy, which sought to foster the agency of communities in renewing disadvantaged areas, have been expanded since 1997 under Labour's communitarian ethos. The state is seen as too distant and bureaucratic to effect positive change, and so the opportunities and burdens of regeneration fall on the 'community', bestowed with financial clout and new-found agency. As Schofield (2002: 675) explains, then,

> community is presented as one explicit solution to some of the many problems of government. Its insertion into government relations with local people in the form of a managerial technology called community

> development enables the otherwise separate institutional worlds of local and national government to be aligned with the particular interests and needs of specific locales. [...] It is at this point, when the theoretical messages of community development become inscribed into a form of administrative technology that the discourse of community becomes overtly governmental.

This notion of 'community' is problematic, then. Just as the subjectification of the modern individual is not simply a matter of drawing on his inherent characteristics, but rather involves a reshaping of the individual into the advanced-liberal mould, so the community is not some pregiven entity just waiting to be deployed. Green (2005), for example, argues that community is more often a construction of policymakers than a coherent, pre-existing collective: 'hard-to-reach', socially deficient groups who defy mainstream policy interventions and thus require 'targeting', based on a closer understanding of their needs, priorities and mentality. Consequently the involvement of particular members of these communities in the development or implementation of policy constitutes particular individuals as intermediaries between policymakers and 'communities'—communities which have no particular prior shared identity, but which they are somehow deemed to represent. As an empirical example of governmentality, then, user, public and community involvement presents various intriguing and problematic questions about who is involved and how, and more generally, what this suggests about the relationships between the state, society and the individual and about the play of governmental power in contemporary modes of governance. In the two following chapters, we will consider the involvement literature more closely as we concentrate on these kinds of questions.

Key issues arising from a social-theoretical approach to involvement

In their descriptions of contemporary social reality, both the reflexive-modernization and governmentality approaches indicate how changing relationships between the individual, society and the state precipitate new institutional forms in the governance of the population, the state and its services. Public and user involvement in these new forms reflects the changing role of a more reflexive and active—or governmentalized and subjectified—individual in late modernity. However, the broad sketches of both approaches seem to produce as many questions as answers about the dynamics of power and the relationships of state, society and individual in late modernity. In particular, while it is evident in each approach that new roles and subjectivities emerge differentially, the practical consequences of this for the operation of involvement and other interfaces between the state and society are unclear. Clarke (2005) delineates the way in which the contemporary citizen is variously 'activated', 'empowered' as a consumer, 'responsibilized' as a subject oriented towards restraint, efficiency and progress, and 'abandoned' to the licentious free market. If, as Clarke (2005: 459) asks, these alternative 'strategies of citizenship' are a means of managing a plural contemporary society, "are they also applied or implemented differentially? That is, are the different strategies applied to different 'target' groups?" Specifically, "as participation initiatives proliferate, are we seeing the emergence of new forms of mediation between the state and its citizens" (Barnes *et al.*, 2003: 397)?

Differential approaches to citizenship might be evident in these varied new forms of mediation, as we discuss in more detail in the following chapters. Participants might, for example, be selected for their typicality of some target constituency (Green, 2005), they might be enlisted as 'responsible partners' in service delivery (Gustafsson & Driver, 2005), or they might be chosen for the knowledge they have to offer service providers (Tovey *et al.*, 2001). These roles posit rather different relationships between the state and the public, though they are not mutually exclusive. Participation initiatives aimed at improving the state's knowledge about the vagaries of the population in order to improve service provision and targeting may coexist alongside efforts to involve the public in the regulation of state-mandated actors, such as service providers and professionals. Just as, for Rose (1996), regimes of accountancy, audit and the internal market represent new techniques for the exercise of critical scrutiny over authority in neoliberal governmentality, so involvement too may have its own regulatory role. As we have seen, several writers certainly suggest that this is at least the aim, if not the effect, of some forms involvement (e.g. Milewa *et al.*, 2002; Gustafsson & Driver, 2005). If so, this would to some degree represent an intriguing complication of the conventional flow of governmental rationality, engaging the participant in the governance of the professional 'expert'.

These various and multifaceted roles might all be understood in terms of the reflexive-modernization and governmentality frameworks, but neither has much to say about the detail of policy and practice, the planning and operationalization of involvement processes. In analysing the academic literature, policy pronouncements, and one example of the empirical realization of public involvement, I hope in this thesis to fill in a little of this detail, seeking to bridge the gap between these theoretical frameworks and empirical practice, and understand each in terms of the other. Whilst informed by the ideas contained in these two social-theoretical approaches to the matter, however, it is important to remain cognisant of the risk of 'theoretical tunnel vision'. The gap between social-theoretical pronouncements and empirical reality in the work of Beck and Giddens, for example, has previously been noted (Dingwall, 1999), and more generally, there is the risk of fitting, *post hoc*, any empirical data into a predetermined model in a way that glosses over the contingencies, exceptions and peculiarities of social reality. Given the difficulty of empirical substantiation of macro-theoretical accounts such as these (Mythen, 2007), the task may be more one of noting points of alignment and points of dissonance between theory and practice, rather than expecting an empirical case study to 'corroborate' or 'disprove' the claims of social theory in any categorical sense. In this light, the key challenge is to remain critically agnostic about the claims made by such theories, highlighting rather than eliding empirical particularities that do not fit with theory, and taking theoretical insights as heuristic and suggestive rather than as claims to be put to empirical test. With Clarke *et al.* (2007: 25), then, I am keen to take a vantage point informed by these theoretical framings, but conscious of "the way in which the move between the general and the particular seems to over-simplify, reduce or essentialise the particular." Whilst seeking to draw on the explanatory power of the perspectives described in this chapter, then, I will be just as keen to note the limits to this power, and to highlight the contingencies, ambiguities and contradictions of practice which defy easy social-theoretical framing.

This thesis thus aims to consider the example of public involvement in the light of the theories discussed above, developing an understanding informed by these of the operation of public participation in the contemporary governance of public services. In general terms, it asks: what is the nature of the contemporary relationship between the individual, the state and public-service professionals, as exemplified in user involvement? Before pinning this guiding question down into more answerable research questions, however, the following two chapters look, in turn, at theory and policy relating to participation, and then at literature on its practice. Following this, at the end of Chapter 3, I present three sets of research questions, which guide the empirical research that follows in relation to three levels of inquiry: from questions of the nature and purpose for user involvement envisaged by the different parties involved in the process, through questions of the degree to which practice relates to policy and theoretical rationales for involvement, to questions about the relationship between involvement policy and practice and the social-theoretical perspectives discussed in this chapter.

Summary

Much of this chapter has been taken up with a necessarily descriptive overview of the history of involvement, and with exploring some of the key theoretical perspectives which will inform subsequent chapters. Already, though, this has highlighted some of the tensions and contradictions in the philosophy and practice of public and user involvement. Reviewing the recent history of involvement has illustrated both the competing philosophies of public involvement of the Left and Right, and also their convergences and the continuities of form through the 1990s into the new century. I have also discussed in some detail two social-theoretical approaches to the distinguishing characteristics of contemporary society, in terms of the detraditionalization of modern institutions and the relationships between individual and state, and in terms of the way in which governmental rationality spreads and operates in advanced-liberal society. In considering how these theories might relate to the prevalence and characteristics of involvement initiatives, I have uncovered some of the ambiguities and complications they suggest, but do little to examine or explain, in these relationships.

The next chapter looks in more detail at two key dimensions in involvement which have been raised briefly here—the notions of representation and lay knowledge—as we start to unpack some of the components in the rationale and practice of involvement, before focusing more closely on exactly how these are constructed in contemporary policy.

2.

WHO AND HOW? TECHNOCRATIC AND DEMOCRATIC RATIONALES[1]

In Chapter 1, I argued that social-theoretical perspectives on contemporary society suggest several rationales—to some extent overlapping, to some extent mutually reinforcing, to some extent conflicting—for involving the public in the development of policies and management of public services. The reflexive-modernization and governmentality theses both find a society in which authority is dispersed, and in which effective government relies on engaging society and individuals in the process. In both understandings, it is easy to make sense of the growing importance of involvement initiatives in public-service governance, as exemplary of wider social trends which extend throughout the post-Fordist economy, post-traditional society and advanced-liberal culture. But these theories merely provide a backdrop, saying little about how mechanisms such as involvement operate: who is to be enrolled, how their contribution is to be harnessed, and what is to be achieved.

One of the key questions here is about the selection of the involved user or

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[1] Much of this chapter is published as '"Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare', *Sociology of Health and Illness* **30**(1): 35-54 (Martin, 2008a).

member of the public, as this relates to the role she is to play. In this chapter, I explore this issue in more detail. I consider first the fashionable idea of 'deliberative democracy' which has of late created much exchange in the political-theory literature, before relating this to more general questions of how democracy, representation and representativeness might operate through involvement initiatives. I then consider a contrasting rationale for involvement under the banner of 'lay expertise', considering especially the merits and flaws of some recent contributions from the field of science and technology studies (STS) to the issue. The usefulness of this dichotomy between democratic and technocratic approaches, I find, is limited: there are overlaps and interfaces between these rationales for involvement. These I consider before concluding the chapter by analysing key recent policy documents on public and user involvement in health. What do these suggest about the relative importance of technocratic and democratic rationales for involvement in contemporary British policy, and about its fit with the social-theoretical perspectives outlined in the first chapter?

Deliberative democracy

> Deliberation […] is distinguished from other kinds of communication in that deliberators are amenable to changing their judgements, preferences, and views during the course of their interactions, which involve persuasion rather than coercion, manipulation, or deception. The essence of democracy itself is now widely taken to be deliberation, as opposed to voting, interest aggregation, constitutional rights, or even self-government. The deliberative turn represents a renewed concern with the authenticity of democracy: the degree to which democratic control is substantive rather than symbolic, and engaged by competent citizens. (Dryzek, 2000: 1)

Dryzek's introductory words on the place of deliberation within contemporary politics summarize many of the key tenets of deliberative-democracy theory. What unites the proponents of different variations on deliberative democracy is an inclination towards democracy as a *process* that cannot, at least initially, be reduced to the act of voting, but which should, by some means or another, involve all the enfranchised in reflective debate free of coercion, bartering, trade-offs and even compromise. The aim is to arrive at a consensual, mutually agreeable solution in which the opinion of each has been explored and debated in relation to those of others. In the process, original viewpoints are transformed through contact with others, illustrating the inadequacy of alternative ideas of democracy that assign primacy to the views held by actors prior to the political process (Ryfe, 2002). Most importantly, then, deliberative democracy is about the justification of decisions made (Gutmann & Thompson, 2004), which derives from collective deliberation rather than from majoritarianism and the moment of choice at the ballot box. Deliberative democracy thus chimes with critiques of conventional democratic procedure and questionnaire-based approaches as constitutive of an artificial public opinion rather than reflecting considered and negotiated viewpoints (Bourdieu, 1973; Papadopoulos, 2001)

The connection between this idea of democracy and the descriptions of contemporary society advocated by Beck and Giddens is almost self-evident, though surprisingly rarely invoked by writers on the subject (though cf. Pellizzoni, 1999; Dryzek, 2000). As Cooke (2000: 954-955) avers, one of the most convincing arguments for deliberative democracy is its conformity with ideas about the modern individual:

> For us, the inhabitants of Western modernity, certain normative conceptions of knowledge, of the self and of the good life are not simply a matter of choice but are constitutive of our self-understandings. […] The 'desacralized' view of knowledge, which goes hand in hand with a secularization of authority, […] helps to explain the value attached to

> autonomous reasoning, in particular to two of its main ingredients, rational accountability and objectivity of judgement. By 'rational accountability' I mean the individual's readiness to engage in a critically detached, informed, perceptive and flexible way with her surroundings, with other persons and with her own (self)-interpretations and life-history.

Cooke does not cite Beck or Giddens in this account of the modern individual, but the congruence between their ideas and this rationale for deliberative democracy is there to see in her commentary on the constitutive nature of understandings of knowledge and the self for contemporary Western citizens, and on the 'secularization' of knowledge and authority. In some views at least, then, deliberation represents a sound extension of democracy in responding to the crises and prospects of late modernity.

In considering what deliberative-democracy theory has to offer in our understanding of involvement in public-service delivery, there is no need to explore in depth the differences of opinion between writers on the subject. However, a few of the major divisions should be considered, in particular between those who countenance deliberative democracy as one part of a conventionally liberal-democratic system, and those more radical theorists who see deliberation as transcending liberal norms of democracy. Broadly, then, the liberal approach to deliberative democracy can be seen as part of a tradition of liberalism dating from the eighteenth and nineteenth centuries that is concerned with how the will of the majority can justifiably be imposed on the autonomous individual. Radical deliberative democracy, meanwhile, is aligned with alternative, participatory notions of democracy that reject the idea that the atomistic individual of liberalism, with inalienable rights and extant views, should form the unit of democracy. There are also important feminist and postmodernist critiques of deliberative democracy to consider.

In many conceptions, then, deliberative democracy draws its legitimacy from basically liberal-democratic principles, but with significant revisions to conventional liberal-democratic solutions. Gutmann and Thompson (1996) see deliberative democracy as a 'second-order' theory of democracy, as distinct from first-order theories such as libertarianism and egalitarianism. As such, it provides a means of making decisions when there are fundamental conflicts between the ideals put forward in these first-order theories. Deliberative democracy differs from other operationalizations of liberal-democratic principles in that it finds no foundational reason to believe that humans are necessarily rational self-interested actors holding apposite, fixed viewpoints that precede the political process. What this conception of deliberative democracy attempts to do, then, is to offer a liberal-democratic solution to situations where practical conflicts arise between differing moral and philosophical positions. In doing so it remains agnostic about the truth of these positions on matters such as human nature and the desirability of freedom or equality, but it does remain founded on certain premises which form the basis for any deliberative-democratic process. For Gutmann and Thompson (2000), these are 'basic liberty', 'basic opportunity' and 'fair opportunity', premises which are necessary to guarantee the personal integrity of the individual and his ability to participate in the political process on an equal basis with other individuals. In other words, these are not just procedural premises but also substantive, liberal-democratic, norms on which this version of deliberative democracy is to be based.

Ultimately, these foundations are not up for democratic debate: they are, so to speak, 'extra-democratic', the constitutional principles which form the basis on which democracy is to operate. This is the crucial point at which liberal deliberative democracy differs from its radical counterpart. In rejecting this kind of constitutionalism, more radical theorists such as Dryzek (2000) offer a view of deliberative democracy untethered by substantive principles, and also much more extensive in proposed scope, going beyond the domain of conventional political activity.

Dryzek's theory of deliberative democracy, then, looks beyond the institutions of liberal democracy in order to find a way of neutralizing "dominant discourses and ideologies, often intertwined with structural economic forces," which "cannot easily be counteracted through [constitutional and legal] means" (Dryzek, 2000: 21). Drawing on Habermas's (1984; 1987) *Theory of Communicative Action*, Dryzek (2000) argues that liberal writers (as well as Habermas himself in his later work) are unnecessarily constrained in their accounts of deliberative democracy as part of the liberal-democratic system. Instead, he advocates 'discursive democracy' as a means of extending democratization into fields beyond the jurisdiction of the state, a means of bringing more areas of life under democratic control by promoting "the effective participation of autonomous and competent actors" (Dryzek, 2000: 29), in a world where the power of traditional democracy is being eroded by the retrenchment of the state and the hegemony of the global economy. In Dryzek's view, then, Habermas's later (1988; 1992) construction of a state administration 'besieged' by the discursive power of deliberation in the public sphere is an inadequate one, as it accepts conventional means, such as elections, of translating deliberative power into administrative power, and says little about the impact of external power—those "dominant discourses and ideologies"—on the conduct of deliberation (see also Pellizzoni, 2001). Instead of requiring an eventual recourse to voting, then, Dryzek's (2000) idea of discursive democracy rests much more on Habermas's earlier work on the possibility of the 'ideal speech situation', in which external power is set aside and the best argument is the sole arbiter of democracy.

Some radical theorists, then, distance themselves from liberal interpretations of deliberative democracy by rejecting head-counts as the means of dispute resolution—though many radical and liberal theorists agree that in practice, any democracy should invoke both deliberative and representative mechanisms (Fitzpatrick, 2002; Saward, 2003). Nevertheless, in calling for resolutions that depart from majoritarianism, radical theorists of deliberative democracy distance themselves from liberal interpretations; in the process, of course, they create for themselves certain challenges of legitimation. If absolute consensus is not always possible, and if the will of the majority of equal, free individuals is no longer the means of arbitration, what justifies the selection of one publicly debated course of action over another? In his vision of discursive democracy, Dryzek (2001) gets round the problem by arguing that the base units of democracy need not be individuals, but the discourses which have been put forward from competing points of view and which co-exist in the public sphere. On this basis, discursive democracy is achieved "when a collective decision is consistent with the constellation of discourses present in the public sphere, in the degree to which this constellation is subject to the reflective control of competent actors" (Dryzek, 2001: 660). Consequently, the liberal concern with freedom to participate and political equality of individuals is bypassed, as is the inherent practical difficulty of incorporating large numbers of people into a deliberative process. Since discourses are to be governed through popular contestation rather than through the agenda set by political elites, elected or otherwise, it does not in principle matter who is involved.

Whilst taking into account the structuring power of external discourses on deliberation, though, Dryzek's radical version of deliberative democracy does not have a great deal to say on how such power can be neutralized in practice, other than through aspiring to the Habermasian 'ideal speech situation'. The debate on deliberative democracy has, however, seen instructive feminist and postmodernist interventions highlighting the rather naïve ways in which the literature has dealt with notions of power, rational communication and participation. Fraser (1992) argues that any effort to 'insulate' political processes from wider societal inequalities of gender and class are bound to fail, and that the notion of a unified public sphere in which deliberation is to take place tends to reproduce the marginality of certain groups within that sphere. The idea that power inequalities can be removed from deliberative encounters to assure that solutions prevail due to the power of the argument alone is problematic: feminist standpoint theorists have long argued that apparently objective criteria of judgement rest on dominant versions of rationality to the exclusion of others (Harding, 1991); as Pellizzoni (2001: 82) puts it, "the myth of the best argument probably does a disservice to deliberative democracy, because it reinforces elitist solutions," especially in areas where there is a powerful, dominant and apparently value-neutral rationality to defer to. Even if not, the forms taken by deliberative democracy can impose unnecessarily constraining terms of 'appropriate conduct' on individuals which may negate the mutually transformational meeting of difference that such forums are supposed to involve (Thompson & Hoggett, 2001; Davies *et al.*, 2006). This can result in "imposing identities on traditionally disengaged citizens before they even begin. As a result, we reinforce discrimination and ultimately perpetuate the assumptions and stereotypes that the act of inclusive participation attempts to rectify" (Campbell, 2005: 698).

There are, then, numerous tensions in the deliberative-democracy literature. The issue of external power is not easily resolved; the interface between public deliberation and the action of state remains unclear; the means of including those not directly involved in deliberation is not straightforward; and the relationship between electoral democracy and participatory deliberation is a tense one. These issues remain the subject of debate. Of particular note for our current concern is the attention which has been given recently in the literature to the realization of deliberative democracy in practice, which might contribute to the construction of a sound basis for further deliberative theory, whilst also illustrating some of the challenges that emerge in application.

Some of this work takes its impetus from Habermas's (1996) recent repositioning on the operation of deliberative democracy, in which he adjusted his previous account which opposed the instrumentally rational state to the lifeworlds of the public sphere.

Habermas withdraws from this dichotomy of systems theory, ceding that the administrative apparatus of the state does not draw solely on instrumental justification, and in the process comes to ponder the possibility of new democratic formations at the points where the state and the public sphere meet each other, through "the interplay of institutional imagination and cautious experimentation" (Habermas, 1996: 440-441). Others have considered the possibilities for such arrangements in some depth. Kelly (2004) suggests that one crucial juncture is at the point of policy *implementation* as well as formulation, allowing the involvement in democratic deliberation of directly affected groups on concrete issues, and precipitating "decisions based on justifications that are sincerely acceptable to those affected by administrative decision making" (Kelly, 2004: 56). In a similar vein, Gutmann and Thompson (2002: 146) argue for deliberative democracy at the level of health-care delivery involving "representatives of the people whose health care is in the hands of the institution." For Pellizzoni (2001), this kind of approach can help to get round the tendency of consensual models of deliberative democracy, which assume the unity of reason, towards expert-rational solutions. "Reason can operate at a lower level, that of the comparison of contextual knowledge, the search for concrete solutions to situations described in different ways but recognized as problematic" (Pellizzoni, 2001: 80). 'Local' deliberative democracy might draw more easily on situated knowledge and alternative rationalities. However, as we will discuss in more detail in Chapter 3, efforts to put deliberative democracy into practice face numerous difficulties that relate to and go beyond the theoretical debates outlined in this chapter (Thompson & Hoggett, 2001; Davies *et al.*, 2006).

Meanwhile, the questions of who is involved, and of the relationship between this form of democracy and others, remain. Delanty (2000: 135) argues that "participation is more suitable to local and regional democracy than to national and transnational levels of governance." But what about when the decisions reached through these different layers and forms of democracy conflict? How easily can a group 'affected' by the implementation of policy be delimited, and therefore selected for special deliberative involvement? And if not every member of that group can be involved deliberatively, how should delegates from these groups be selected? For all it has to say about the principles of deliberation, many of the tensions that deliberative democracy raises return us to familiar questions about the practice of involvement such as those posed at the end of the last chapter. In particular, these are questions of representation and representativeness: whether conventional liberal-democratic or demographic representativeness is a viable aim in involvement initiatives, or whether there are alternatives which are more appropriate and desirable.

Representation and representativeness

Because deliberative-democratic processes cannot include everyone, the question of representation becomes a fairly central one. In liberal conceptions, some form of election of representatives or random selection to attain statistical representativeness tends to be the offered solution (Gutmann & Thompson, 1996). Radical deliberative democrats argue that representation can be secured through empathetic deliberation or in the nature of the discourses debated (Dryzek, 2000; 2001).

Rationales for public involvement are not, as noted in the previous chapter, necessarily drawn from democratic ideals, and so need not necessarily share this concern with representing those not present. Nevertheless, much of the literature on involvement does focus on the question of representation and democratic representativeness, and indeed offers much criticism of the representational failings of involvement as put into practice. Church *et al.* (2002: 17) echo much of the literature when they bemoan the reliance of Canadian policymakers on "the same traditional middle-class cross-section of citizenry to represent the interests of all members of the community." Similar points are made in various national contexts by others (DeSario, 1987; Macdonald, 2003; Gollust *et al.*, 2005; see also Crawford *et al.*, 2003). Through a combination of self-selection by those wishing to be involved and selection of the 'right' kind of people by those managing the process, public-involvement initiatives are seen to represent some subgroups of the public better than others.

Two proposed responses to this state of affairs are random selection, in order to involve a statistically representative sample of the target population, and an electoral model, so that those being represented decide on who is to represent them. But apart from the various practical problems associated with these approaches (time, cost, administrative complexity etc.), there is no necessary guarantee that such approaches offer more accurate representation in the first place (Bourdieu, 1981; Parkinson, 2003). The rationale for random selection is that it should result in a proportionally accurate representation of a wider population in terms of various characteristics, for example class, gender or ethnicity. Selection may be stratified to ensure the representation of particular minority groups. But there is no fundamental reason why demographic characteristics shared between a population and a random sample should translate into accurate representation on the level of views expressed. Where efforts are made to ensure the representation of, say, ethnic minorities, there is an assumption that this particular common characteristic is more important than others in ensuring correspondence between representative and represented. Consciousness of difference is necessary, as Barnes *et al.* (2003) point out, to ensure that different groups are recognized and included in participation processes, but can easily slip into a fetishization of particular characteristics, which may be less relevant as sources of social differentiation in some situations than in others. It can also lead to other points of commonality and difference between groups, less prominent in social consciousness, being ignored. Random selection, and especially stratification, thus prioritize various assumed bonds of social unity and difference over an active relationship in which the representative is selected or elected by the represented, which is why Parkinson (2003) prefers an electoral model of deliberative democracy to alternative versions involving random selection, such as citizens' juries. But there are plenty of problems with these kinds of mandated relationships between population and representative, too. Bourdieu (1981; 1984), for example, argues that any delegation to a representative involves usurpation, since the political process will introduce unanticipated situations and questions, and thus require the representative to speak for the represented without reference to them. Similarly if, as deliberative-democratic theorists suggest, proper democracy and true deliberation require those taking part to be open to transformation of their views, outlook and even identity, what becomes of the original representational relationship mandated by those being represented (Abelson *et al.*, 2003; Saward, 2005)?

Representativeness, then, is not easily secured by these two apparent solutions, even if the technical obstacles are overcome. Various writers on involvement have sought to circumvent this difficulty by advocating 'experiential representation' (Prior *et al.*, 1995) as a more auspicious alternative. Eyles and Litva (1998), Frankish *et al.* (2002) and Thurston *et al.* (2005) variously argue for what Frankish *et al.* (2002: 1476) call

> a new kind of active (as opposed to passive) representation based on an experiential relationship. There are limits to other types of representation, such as electoral representation, because there is no guarantee that such representatives share similar constituent gender, ethnic or socioeconomic status, let alone understand their needs or experiences. Needs are best identified and appreciated by sharing in the lives of others. Representation, based on shared experiences where needs are actively and subjectively assessed, enhances the legitimacy of representation when economy of time and problems of scale restrict participation by all.

The idea here, then, is that

> representation requires understanding and understanding is difficult where experience is limited. [...] Needs are best appreciated when they are shared. If those who represent citizens have no understanding of their needs drawn from experience, then can they be regarded as capable of acting as representatives? (Prior *et al.*, 1995: 73)

In this conception, representation becomes a matter of common experience in the situation of the group represented. Socially defined signifiers of commonality cannot be assumed relevant. The question of how 'common experience' is to be defined and judged is not answered in any detail by these authors, though it seems to be about an active, dialogical connection between representer and represented and, more than this, direct personal experience too. The notion of experiential representation does at least, though, offer an interesting alternative to approaches which rely on electoral mechanisms or the demographic-statistical representation of commonality.

Which representation when? Democratic and other rationales

The notion of active, experiential representation moves away from conventional notions of representation associated with democracy, and liberal democracy especially. In common with some of the theories of deliberative democracy explored earlier, the ambition of this idea is to represent a group in its richness of character and particularity of experience. But it is distinct too from deliberative democracy, at least the abstract theoretical notion of deliberative democracy. Deliberative democracy is primarily a theory of democracy: its overriding aim is to arrive at collectively binding decisions through a mechanism that involves in the fullest way possible the entire (enfranchised) population. Critiques of the authenticity of representation, and suggestions about how to improve it, may similarly contribute to improving the way in which democracy is put into practice. However, attempts to achieve representativeness, such as this notion of 'experiential representation', are not always oriented towards democracy, in the narrow sense of government by '*the people*'.

It is important to make this distinction clearly, because ideas like 'experiential representation' clearly have their place in refining democratic practices based on the rather cruder, electoral mechanisms of liberal democracy, and in fulfilling the promise of more deliberative approaches. But they also point towards the importance of other forms of contact between the state and its publics, ones which involve particular groups in their particularity, in complementing (though not replacing) electoral mechanisms. What this means is a breaking down of this unitary 'the people' of liberal and social democracy into various constituent groups, as defined by experience, identity, or whatever else, in pursuit of a wider *democratization* rather than the improvement of *narrowly defined*, large-scale electoral democracy. These groups are likely to be involved not in order to improve the practice of democracy narrowly defined, but because they are disproportionately affected by these policies, or because by virtue of their experience or expertise they have a particularly important view that needs to be heard.

Thus discussions about the virtues of deliberation or improved representation are not just relevant to this narrowly defined, national-scale democracy, but more widely too. Kelly's (2004) discussion of deliberative democracy at the point of policy implementation, for example, is not about democracy in this narrow sense at all, but about the involvement of affected groups in matters affecting them. The issue of representativeness in involvement initiatives, then, should not be reduced to one of *democratic* representation, especially the liberal model of democratic representation. Lack of representativeness (e.g. underrepresentation, in statistically descriptive terms, of a particular group) in an involvement initiative may or may not be a problem, then, depending on the nature of the problem and the kind of involvement it demands.

In terms of public and user involvement in health-care delivery, there are domains which may be more appropriately dealt with on a narrowly democratic basis, and those which are more amenable to involvement of particular groups, as Lomas (1997) points out. Lomas (1997) argues that there are three ways in which the public, and its various constituent publics, might be involved in health-care decision-making: as citizens, as taxpayers, and as patients (see also Charles & DeMaio, 1993). Referring specifically to questions of resource allocation, he argues that it is through (narrowly defined) *democratic* mechanisms which address the public *as citizens* that involvement should take place, either through conventional liberal-democratic ballot-box approaches, or alternatively through systems which access the opinions of citizens through deliberative rather than aggregative means. However, Lomas also identifies a particular role for the public *as patients*, whose experience bestows a more nuanced, sensitive perspective with regard to compassion, equity and the softer benefits of health care, offsetting the general public's proclivity for high-profile life-saving interventions over low-profile life-enhancing treatment. Martin *et al.* (2002) offer a slightly different distinction between the part to be played by *public representatives*, whose role in involvement initiatives should be to ensure fairness of process, and *patient representatives*, whose role is to advocate patients' needs and explain the patient's experience.

Litva *et al.* (2002) find that members of the public themselves construct the place of the public in health-care priority setting largely in terms of the roles identified for *citizens* by Lomas (1997), and for *public representatives* by Martin *et al.* (2002). The public is to be a source of 'common sense' for health-care decision makers in choices about funding priorities, improving the decisions made according to narrowly democratic principles. However, what is also clear from Litva *et al.*'s discussion is that there are certain ambiguities to this role. In performing the role of 'citizens' / 'public representatives', those involved are to use their "practical knowledge and personal experiences" (Litva *et al.*, 2002: 1834). The task of *democratically* representing the citizenry's collective views on health-care spending, then, is accompanied by an *experiential* component which sensitizes these representatives to what the patient will encounter. Thus in practice, there is something of an overlap between the roles identified by Lomas (1997) for the involved member of the public as *citizen* and as *patient*. Of course, part of the argument for the effectiveness of democracy as a political system rests on its ability to draw on the knowledge of the people, including their personal experiences, but there is nevertheless a shift here in the idea of the public as the source of *collective will* and the idea of the public as a source of *relevant knowledge* deriving from personal experience.

Arguably, those best placed to supply such an understanding are not members of the public as citizens but particular groups of patients themselves, as suggested by Lomas (1997). In other words, the narrow definition of democracy, with the forms of representativeness it demands, is not the only defensible rationale for involving the public, even in questions of resource allocation. Knowledge and experience may also have important contributions to make. Where the allocation of scarce resources is not, directly at least, the central concern of participation initiatives—as, for example, with involvement in the management and delivery of a service within a predefined budget—there may be all the more reason for forms of involvement which are based on rationales beyond narrowly democratic representation.

'Lay expertise'

These wider foundations for involvement, such as experience, affectedness and understanding, all seem to point towards rather different conceptions of the rationale for involving (particular sections of) the public in the planning and delivery of health services, ensuring more appropriate provision in one way or another. In recent years, policymakers and academics alike have recognized the utility of these 'public assets', as can be seen in various government initiatives and in the surge in the use of terms such as 'lay knowledge', 'lay expertise', and even 'lay epidemiology' in the academic literature (Prior, 2003). In explaining this rise, we might draw on the theories of governmentality and, particularly, reflexive modernization discussed in the previous chapter, and the displacement of a paternalistic relationship between medical and administrative science and the non-expert population by new forms of interaction.

The STS literature has long recognized the intricacy of some of the knowledge held by laypeople, including patients (Lambert & Rose, 1996), just as it has delineated the social foundations of the expert knowledge produced by scientific endeavour. What many critics once saw as a dangerously relativistic field of study has more recently developed a much more normative programme, culminating in a controversially agenda-setting paper by Collins and Evans (2002). They advocate the study of who 'should' be involved in the development of science, developing a distinction not between scientists and laypeople but between those possessing relevant 'expertise', whether certificated by the qualifications and regalia of (a particular esoteric field of) science, or uncertificated, and deriving from personal experience. This, then, is not a framework for the democratization of science, but for the extension of contributory rights on an explicitly technocratic basis.

The management and delivery of health services is a distant field from the kinds of laboratory sciences that Collins and Evans (2002) seem to be referring to, but the relevance of their proposal for our area of interest is nevertheless evident. Questions of the management and delivery of a particular service may be best addressed by those with the technocratic expertise or experience most relevant—including the users of that service. Collins and Evans (2002) draw on Wynne's (1992) celebrated case study of government scientists' failure to incorporate the knowledge of Cumbrian sheep farmers following the Chernobyl disaster (which suggested that the source of excess radiation in local vegetation might be the Winscale plant, much closer to home) in their risk assessments and decisions, and on Epstein's (1995; 1996) account of the uncertificated expertise of AIDS activists in San Francisco, which resulted, eventually, in the recognition of their unique contribution and the inclusion of their viewpoints in the practice of clinical trials. In the latter example, Collins and Evans (2002) find that incorporation of relevant outside knowledge resulted in the improvement of scientific practice and consent to involvement by HIV-positive patients. Does this way of thinking about involvement in the health service help, then, to make a useful distinction between the narrowly democratic inclusion of the *general* public in matters of values, such as questions of resource allocation, and of *particular* publics in technical matters, such as the efficient management and delivery of particular services?

Exactly what constitutes 'expertise' in Collins and Evans's (2002) outline is not entirely clear-cut. If we examine more closely their corroborating case studies, we start to see that the expertise they assign to the 'lay' groups involved is a somewhat more difficult entity than they suggest. For example, the nature of the expertise of Esptein's AIDS activists is rather more complex than it seems at first. These individuals accumulated vast knowledge about the HIV virus, the drugs and trial methodology to become scientifically conversant and gain such credibility that clinicians felt obliged to recognize their expertise according to medicine's own standards. Technical expertise, however, was not itself what activists brought to the table in Epstein's (1996) account. What they contributed was an understanding of human values, articulating the need for a trade-off between 'absolute scientific integrity', with its promise of sound medicine for future generations, and scientific pragmatism to help palliate suffering in the present. What was crucial was their ability to gel their axiological concerns with scientific arguments (for example around the desirability of recruiting diverse groups to trials to improve external validity of findings) in opposition to those who preferred the scientific 'purity' delivered by stricter eligibility criteria. Fundamentally, however, their contribution was ethical rather than scientific—but expertly aligned with existing sides of scientific and methodological debate. Consequently, contrary to Collins and Evans's (2002) claims, this was not a matter of a technical contribution to the effectiveness of science, so much as a value-based contribution of the kind that Lomas (1997), for example, sees as a matter for (narrowly defined) democratic resolution.

What place for 'lay expertise'?

In these terms, there seems a thin line between expertise and the kinds of sensitising experiential contributions of particular, affected groups outlined in the earlier section. The distinctiveness of the contribution of the 'uncertificated experts' identified in Collins and Evans's schema thus comes under assault from two very different epistemological positions. For the more constructivist wing of science studies, any separation of technical and political questions is unviable, as the very idea of a 'purely scientific question', unadulterated by wider social considerations, is attached umbilically to the licence of the powerful to define and delimit what science is (Wynne, 2003; cf. Irwin, 2004). For those who accept the epistemic superiority of scientific over non-scientific understandings of the world, meanwhile, the idea that 'lay experts' have a distinctive and worthwhile contribution to make, distinct from narrowly defined democratic input, is doubtful, at least in health care.

This is the argument put forward by Prior (2003). He argues that lay patients may well have 'expertise' in their own conditions, but this is not qualification for being involved in questions of service provision.

> They often have detailed knowledge of other people as well as of themselves […] and intimate knowledge about the circumstances in which they live. […] And all in all, they are experts by virtue of 'having experience'. Yet, experience on its own is rarely sufficient to understand

> the technical complexities of disease causation, its consequences or its management. This is partly because experiential knowledge is invariably limited, and idiosyncratic. (Prior, 2003: 53)

For Prior (2003: 54), a disingenuously technocratic rationale for public participation should not substitute for the inclusion of the public on a democratically representative basis: "the worthy political aim of ensuring participation and consultation of the lay public in all matters to do with medicine."

One does not have to look far for evidence of the limitations of lay understandings of medical matters, especially in relation to genetics (Parsons & Atkinson, 1992; Axworthy *et al.*, 1996; Emery, 2001; Henwood *et al.*, 2003). Even Kerr *et al.*'s (1998) exploration of the alternative forms of expertise held by patients in relation to genetics seems in some way to corroborate Prior's account: they argue for the value for the intuitive self-understandings of laypeople but accept that the greater the medical importance of the issue in hand, and "the more relevant professionals' expertise was to them, the more people felt they had to trust them" (Kerr *et al.*, 1998: 56).

In Prior's account, then, involvement of the public in health-care provision is defensible only at the level of the consultation with the individual patient, whose expertise is the intimate knowledge of her own condition and personal experience, and at the level of the political: i.e. through (narrowly) democratic means with corresponding forms of representation. 'Lay expertise', then, is left with a very marginal role, since it should not be valued as a contribution to clinical or managerial practice, and has no privileged position in relation to the democratically warranted involvement of the wider lay public. The democratic accountability of the health service and the medical profession should not be allowed to slip into the involvement of particular, supposedly 'expert', subsections of the population; neither should the involvement of particular groups of patients be allowed to interfere with questions which should properly be resolved democratically.

Yet there seems to be more to lay knowledge of medicine and health-service delivery than the merely "limited, and idiosyncratic" experiential knowledge that Prior describes. Some recent research hints at the real expertise that laypeople may derive from experience of disease and the receipt of health services. Lambert and Rose (1996) explore the nuanced, sophisticated understandings of patients with a genetic predisposition to high cholesterol, finding embodied insights distinct from clinical understandings of the condition. These patients competently assessed and assimilated "a deluge of often contradictory information from a multiplicity of sources, laden with different levels of prestige and trustworthiness" (Lambert & Rose, 1996: 69). Their accounts contained scientific inaccuracies (albeit frequently imparted by their doctors), but also incorporated an "understanding of the historically contingent and partial nature of scientific knowledge" (Lambert & Rose, 1996: 73). Similarly, Nettleton and Burrows (2003) describe information available on the internet as used by patients as "a reflexive resource that demands proactive engagement in order to obtain strategic advantage in the real world" (Nettleton & Burrows, 2003: 171; cf. Scott *et al.*, 2005). Ziebland (2004) discusses narratives of patients drawing on internet resources to gain knowledge about their treatment, preparing themselves for encounters with family physicians whose knowledge of specialist medicine was inevitably limited.

Common to these analyses (Lambert & Rose, 1996; Nettleton & Burrows, 2003; Ziebland, 2004), and to that of Epstein (1995), are accounts of how the experience of disease gave rise to a desire to acquire knowledge of aetiology, prognosis, and entitlement to service provision. The knowledge obtained was both clinical and social, but it did not conform to accounts which stress the centrality and authority of the clinician as source of expertise. In principle, there is no reason why some aspects of the scientific expertise of the lay patient might not surpass that of the expert clinician, and indeed for Ziebland's (2004) respondents this was sometimes the case when, for example, they discovered the existence and availability of new forms of treatment of which their clinician was unaware. All in all, what these accounts point towards is the way in which the fact or risk of disease brings out a willingness and ability to become expert in a way which *combines* experiential dimensions with conventional scientific knowledge, and claims for itself legitimacy in providing a valuable, sensitizing and productive input to the management and delivery of health services.

However, what this willingness and ability also seem to rest on is a certain amount of social capital. Epstein's (1995) AIDS activists were, as we have seen, the educated, articulate and mobilized middle-class mouthpiece who took it upon themselves to speak for their community of patients; Ziebland (2004) stresses how social identity was crucial both in her interviewees' searches for knowledge and in their ability to deploy it to their advantage; Nettleton and Burrows (2003) are explicit in arguing that the utility of internet information rests on the reflexive capacities of users to interpret, discern and marshal it to their advantage. These kinds of abilities are, of course, distributed unequally across the population. In arguing for a place for 'lay expertise' in user involvement initiatives, then, are we not arguing for the involvement of the particular kind of person—the 'reflexivity winner', perhaps—who is inclined to develop that kind of expertise?

Re-enter the active citizen

The notion of expertise and a technocratically useful input arrived at in the previous section suggests that it may be tied closely to social background and identity. In the examples from the literature presented, a combination of the shock of diagnosis and the realization of risk gave rise to a desire to become conversant in the medical consequences of a condition, and in the possibility of and entitlement to treatment. Yet this was not purely an individualistic and self-interested response: Epstein's (1995) patients took on the role of advocates and activists, and Ziebland (2004) similarly explores the collectivist activities of her respondents, describing how, for example, "after what she described as her 'blackest day' she [an interviewee with inflammatory breast cancer] decided to set up a website and a brochure" (Ziebland, 2004: 1788). These kinds of accounts recall the idea of 'life politics' as put forward by Giddens (1991), collective action triggered by a 'fateful moment' at which the fragility of an individual's modern existence comes into sharp relief. There is also resonance with the idea of 'biosociality' put forward by Rabinow and Rose (2006) to denote the formation of new communities, bound by biomedical status, which draw on knowledge in novel ways in pursuit of self-fulfilment and self-advocacy. Given the emphasis, explored in the previous chapter, of social policy on harnessing and enhancing the autonomous, active citizen of late modernity, perhaps it is exactly these kinds of emerging collectives and individuals, with their particular expertise borne of experience and motivation, that involvement is designed to engage—notwithstanding their potential social exclusivity.

In this conception of emergent "new forms of mediation between the state and its citizens" (Barnes *et al.*, 2003: 397), the qualities required of those involved are varied, and are not just about representativeness or expertise in their narrow senses. Rather than the descriptive representativeness that might be achieved through stratified random selection or the active representational relationship implied by an electoral mandate, the crucial initial quality might simply be 'experience', which may constitute a form of expertise or, as we saw earlier, a form of 'experiential' representation. From this starting point, however, we can see how the qualities demanded of those involved by contemporary social policy quickly extend beyond the narrow realms of 'representativeness' and 'expertise'. It may demand those with the capacity and drive to engage with social policy in the active way required (cf. Nettleton & Burrows, 2003;

Ziebland, 2004). Further, it may be seeking a particular kind of rational individual, who has a certain grasp of the disease and the health system, and of the potentials and limitations of the service professionals are striving to provide (Hogg & Williamson, 2001). There is a thin line, of course, between these kinds of criteria and the exclusion of those who lack these reflexive skills (Petersen, 1996; Ryfe, 2002; Campbell, 2005), but this is not necessarily the aim or even the effect of such an approach. If "participants have to be able to communicate insights and concerns in such a way that others understand what the issues and options are, and where the constraints lie" (Brownlea, 1987: 606), then the that ability may be a legitimate criterion for inclusion (cf. Daykin *et al.*, 2004). But this could easily slip into an exclusion of more radical publics who fail to "understand" or accept the official line about the issues, options and constraints.

There is, therefore, a need to study the extent to which, as Barnes *et al.* (2004b: 269) have it, a 'politics of presence' is compatible or incompatible with the various kinds of representativeness demanded in different circumstances, and "how 'old' institutional norms of advocacy and representation [interact] with 'new' norms of deliberation and involvement." Is enthusiasm for involvement and for putting the view of a/the public, what Campbell (2005: 689) calls "a conscious and thought-out desire to be, or to become, a certain type of person," something which enhances or impairs the representational connection, and indeed the effectiveness and utility, of the contribution that involved publics and service users can make?

This is an empirical question; undoubtedly there are potentials and dangers inherent in such approaches to the involvement of the public in health-care governance. As we saw in Chapter 1, however, late-modern social policy—especially the reforms of post-1997 Labour governments—is constructed around the view that society has fundamentally changed, that it is composed of increasingly reflexive and decreasingly deferential citizens, and that this requires a modernization of the welfare state (including its governance and modes of interaction with the public). Moreover, this modernization expects and relies upon the agency of these presumed 'active citizens'—their reflexivity, their rational action, their acquiescence—as mediators to ensure that its provision meets as effectively as possible the needs of this diverse society. Green (2005) explores one such form of mediation, the way in which policymakers involve certain individuals on the basis not of their representative mandate or expert knowledge, but of their 'typicality' of the 'hard-to-reach communities' that social-policy interventions are designed to affect. Schofield (2002) offers another example, of the way in which communities are involved in urban-regeneration initiatives as a source of local knowledge, capacity and agency which is expected to ensure the appropriateness of the state's intervention. Public involvement in health can be viewed in a similar light, as a means of assisting the effectiveness of welfare-state provision not by drawing on democratic legitimacy, nor necessarily on the expertise, narrowly defined, of the lay public, but through enlisting the agency of certain groups whose capabilities give them a special mediating function. These might be, from an optimistic or pessimistic perspective, either the 'active citizens' or the 'reflexivity winners' (Ellison, 1997) of a contemporary society where citizenship is a multiplicitous status applied differentially across the population (Clarke, 2005).

Whether positive or negative, though, what should be clear from this overview is that analyses of public participation constructed solely in terms of 'authenticity' of representation, or which set up as two opposed approaches to participation those premised on empowerment and those based on consumerist consultation (e.g. Cook, 2002), are fundamentally limited. Various authors have demonstrated the malleable nature of representation in the practice of public participation, emphasising the various (but not altogether negative) ways in which involved individuals draw on notions of 'the public' in negotiating initiatives (Contandriopoulos, 2004; Barnes *et al.*, 2007). As

Contandriopoulos (2004) points out, public-participation initiatives thus differ from conventional, narrowly-democratically conceived forms of political action in that they usually do not rely for their legitimacy on the statistically-descriptively accurate representation of the public. However, his consequent conclusion, that the viability of a given public-participation mechanism therefore rests instead on claims to represent the public as a whole through a more symbolic construction of representation, does not necessarily follow. Contandriopoulos (2004: 328) argues that "the political efficacy of public participation ultimately rests upon symbolic struggles to appropriate the intrinsic legitimacy of the public." But there is more to these roles than representational claims, whether statistically or symbolically constructed. In short, the involved member of the public is more than just a token of the lay citizenry: rather, she embodies (and her legitimacy rests on) other qualities seen as important in governing the interface between state and society. This seems truer than ever with a contemporary social policy geared towards drawing productively on the attributes of certain groups of citizens in pursuit of effectiveness and appropriateness of provision, whether those attributes are typicality, agency, reflexivity, communicative ability or whatever else.

There is some illustration of this trait of contemporary social policy in the wider literature (e.g. Schofield, 2002; Green, 2005), but as we saw above, the involvement literature largely tends to understand and judge participation in terms of more traditional notions of representativeness, empowerment and to a degree, expertise. This arises, perhaps, from the fact that these criteria seem self-evident in the rationales for public participation: in different proportions, they are almost always cited in the justification for such initiatives. Looking below the surface, though, I suggest that these different aims coalesce in forms that transcend straightforward understandings of 'democratic representation' or 'lay expertise'.

Technocracy and democracy in the policy literature

Thus there seems to be considerable overlap in the way technocratic and democratic approaches to public and user involvement are put into practice. We now take this idea a little further, in turning to discuss the kinds of features that recent British policy stipulates for public and user involvement in health. Considering the detail of policy documents, is involvement in the NHS more oriented towards democratic legitimacy, or about harnessing the expertise, of one sort or another, of those involved—or does it, as suggested above, transcend the two categories? How far does it rest on the kinds of qualities associated with the 'active citizen' of reflexive modernity and Third-Way policy, with the productive potentials and exclusivist dangers inherent in the concept?

These kinds of questions have been asked of various aspects of Labour's public involvement policies, particularly in relation to public-service reform (Gustafsson & Driver, 2005) and the 'democratic renewal' of local government (Leach & Wingfield, 1999; Chandler, 2001). In the field of involvement in health, Labour has made waves, firstly in the 2001 Health and Social Care Act by imposing on all NHS organizations a duty to involve and consult the public on the planning of service provision and the development of proposals for changes in the provision and operation of services. This was followed in the 2002 NHS Reform and Health Care Professions Act by the abolition of CHCs in England and their replacement by various bodies which took on their responsibilities, along with some supplemental responsibilities. Among these bodies were Patient and Public Involvement (PPI) Forums, one for each NHS trust and primary care trust (PCT), charged with the duty of monitoring and reviewing services provided and ensuring that the views of patients and the public were included in planning and provision, and with powers to inspect NHS premises and demand information. PPI Forums have a special place within public-involvement agenda as the trusts and PCTs they relate to are legally obliged to involve them in decision-making processes. An umbrella body, the Commission for Patient and Public Involvement in Health (CPPIH), was set up to oversee the work of the PPI Forums and appoint their members (Le May, 2003); this body, however, was wound down from 2006, and at the same time PPI Forums were merged to relate to commissioning PCTs only rather than every trust individually. Subsequently, following the 2007 Local Government and Public Involvement in Health Act, PPI Forums were also disbanded, to be replaced by Local Involvement Networks (LINks), which sought to tie various public involvement initiatives in health more closely into commissioning decisions.

When PPI Forums were first mooted (as Patients' Forums) in the NHS Plan (Secretary of State for Health, 2000b), various rationales for involvement were invoked. Forums were to be formed through the random selection of patients who had responded to the trust's annual survey, and through selection of representatives from local voluntary organisations, in equal proportions; subsequently, representation of the wider public (beyond patients) was added, and selection was replaced with application and appointment. Policy guidance offers various justifications for PPI, emphasising in particular three fundamental objectives: "strengthened accountability to local communities; a health service that responds to patients and carers; and a sense of ownership and trust" (Department of Health, 2003b: iii). There is stress on both accountability and the need to "tap into the enthusiasm and energy of … patients, the public and local communities" (Department of Health, 2003b: 2).

Technocratic and democratic rationales are similarly emphasised in parallel guidance for practitioners, but in sometimes confused or contradictory ways. At one point, for example, this guidance plays down the need for representativeness, answering the claim that "patients and members of the public who do get involved are often unrepresentative" by responding:

> Unrepresentative of who or what? Patients and members of the public

> bring their own experiences to the debate. Unless they are speaking on behalf of a patient's group or an established forum they are rarely able to represent the collective views of others. (Department of Health, 2003c: 50)

A variety of contributions beyond representational 'accuracy' is stressed, including "knowledge, experience of … using services, behaviour, wants, information needs, attitudes, and considered and informed opinions" (Department of Health, 2003c: 39). Elsewhere, however, the document specifically asks practitioners to ensure that "a representative cross-section of people, community groups and key stakeholders have been involved from an early stage" (Department of Health, 2003c: xii).

There is also a certain lack of clarity about the roles of PPI Forums and of local-government 'Overview and Scrutiny Committees' (OSCs), introduced in Labour's reforms to subject the NHS to formal local democratic influence. Exhorted to interact and co-operate by guidance (Department of Health, 2003a), their remits overlap considerably. The language used in the practitioners' guidance goes some way towards illuminating the marginal distinction between their rationales: where the role of PPI Forums is "to monitor and review NHS services of their trust from the patient's perspective" and "inspect premises used by NHS patients from the perspective of the patient's experience" (Department of Health, 2003c: 125), OSCs are to focus on "the planning, provision and operation of health services" (Department of Health, 2003c: 127), with an ability to summon, question and call to account trust chief executives. The emphasis on the place of *experience* and the view from a locatable *perspective*—that of the patient and member of the public—in the role of PPI Forums contrasts, perhaps, with the more objective concerns of the formal democratic remit of OSCs. If the function of PPI Forums is a representative one, then it is one imbued with experience, affectedness and other personal attributes rather than one where electorally or statistically accurate representation is most important.

Beyond experiential representativeness or experiential expertise, however, Forum members are expected to embody various other characteristics too. For a start, they are not there only to put their own views (representative or expert or not) to the trusts they partner; they must also seek out the experiences, needs and wishes of the wider patient and public population:

> [PPI Forums] will be made up of local people and will represent the views of communities about the quality and configuration of health services to PCTs and trusts. This representation will be actively finding out what patients, carers and families think about their health services. (Department of Health, 2003c: 125)

The handbook issued to PPI Forum members offers advice about how to go about this task, stressing the need to consider "the experiences and needs of people living across the whole of your forum area," including "differences between the health needs of one part of your area and the others," any "particular health problems in your area," and "communities whose opinions are overlooked" (CPPIH, 2004: 25). Direction about when and how to survey patients and the public follows. In terms of the commitment of time and level of competence required to carry out such activities effectively, what is needed here sounds more like the professional expertise of a public-health department than a 'lay expertise' of the kind examined above. The handbook acknowledges that Forum members will have to prioritise and be pragmatic, but even then the range of managerial, research and negotiation skills demanded is impressive. CPPIH staff are instructed to ensure that only "people with sufficient time and interest in health get the limited number of places available on the Forums" by selecting applicants on the basis of various criteria, including "understanding of the health needs of the community," being "enthusiastic about making a difference," and possessing the ability "to work as part of a team."[2] In other documents, however, the emphasis of the CPPIH is on representativeness and diversity of background, seeking to stress in a progress report that Forum members are not just a select clique:

> 10% of Forum Members were from ethnic minorities, as well as equal splits of 1/3 having never volunteered previously, 1/3 having volunteered before but not in health and the final 1/3 as having volunteered in health in the past. The Commission remains committed to help make Forums as representative of the communities they serve as possible. (CPPIH, 2004: 4)

Varied and impressive qualities are demanded, then, of Forum members and others involved in participation initiatives in health. Representativeness is required with experience and 'lay expertise', alongside various skills that one might associate with professional management—or at least with a highly developed reflexivity. Whether or not participants fulfil these criteria in practice—indeed whether or not it is possible for anyone to fulfil all these criteria simultaneously—the fact that they are sought in the first place says something about what health policy wants from participation. From amidst the confusion within the policy literature emerges the kind of multifaceted ideal-type individual sought by the state.

The publicity materials used by the CPPIH to recruit to PPI Forums are particularly illuminating here, exhibiting the tensions in the parallel searches for representatives, 'lay experts', skilled reflexive citizens, and anyone to fill the requisite number of places decreed by statute. One early leaflet praises the amazing lengths to which people go to improve health—running marathons dressed as chickens, for example—before introducing PPI Forums as a new way of making an impact. Then the

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[2] CPPIH document on recruitment and selection process, http://147.29.80.160/portal/csc/genericContentGear/download/Recruitment+and+Selection.doc?document_id=1800089, accessed 19 December 2005

rejoinder: "ordinary people only—experts and chickens need not apply."[3] Another, later, leaflet, however, explicitly suggests that "if you have knowledge or experience of a particular aspect of health or healthcare, you may wish to contact your Forum to contribute to discussions that may be taking place around that topic" (see Figure 1).[4] A passage repeated on several leaflets affirms that "you may be young or old or from *any* section of the community—most importantly you'll want to check and challenge when it comes to health."[5] Leaflets and advertisements stress the virtuous enthusiasm and local orientation of Forum members—"groups of volunteers in your local community who are enthusiastic about helping patients and members of the public influence the way that local healthcare is organised"[6]— and implore their readers to make a similar commitment: "How many of us care enough to make a difference? Care enough to give a voice to patients? Care enough to give time and energy for health?"[7]

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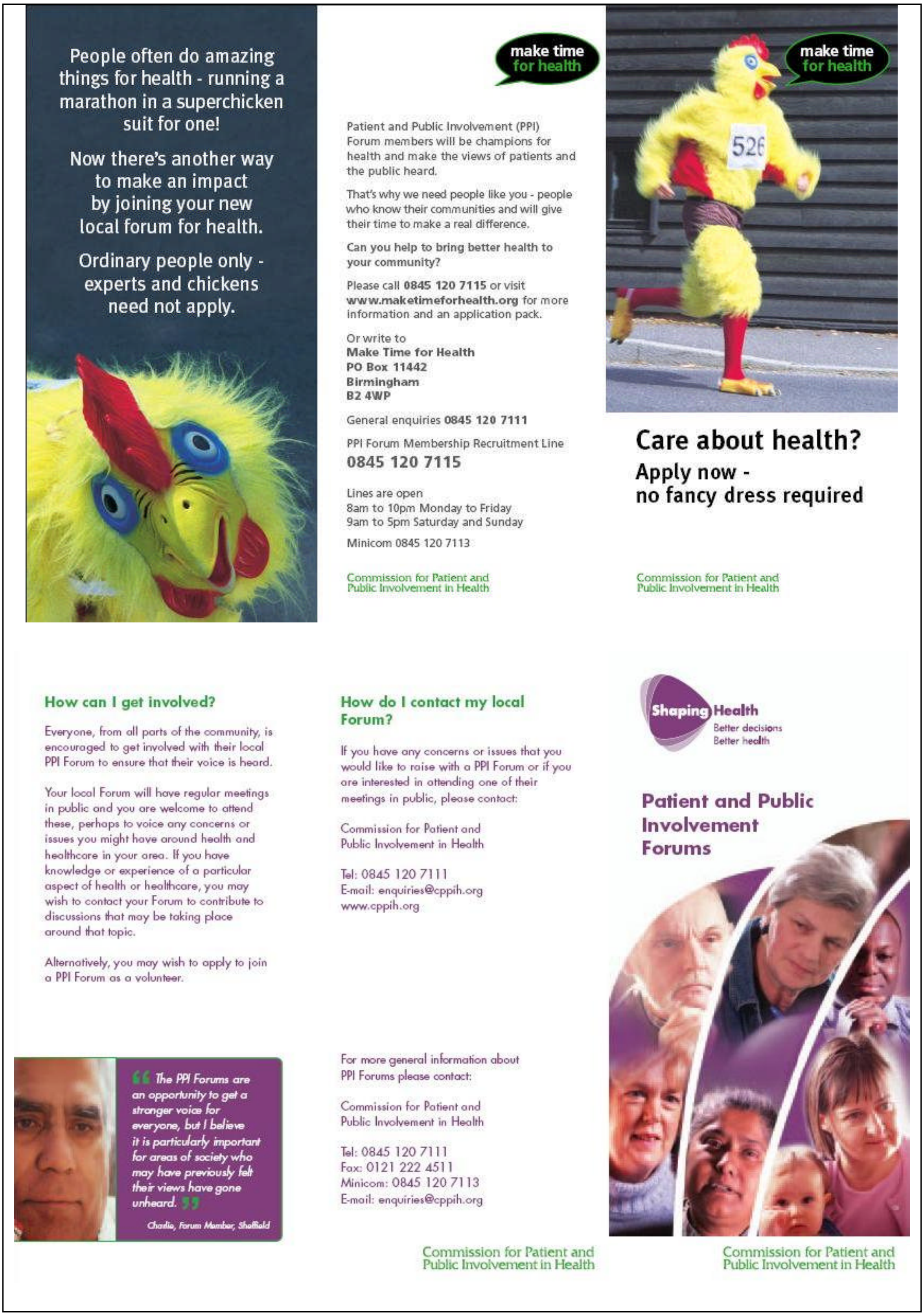
[3] CPPIH leaflet 2003, http://147.29.80.160/portal/csc/genericContentGear/download/PPI+leaflet+chicken.pdf?document_id=100001, accessed 19 December 2005

[4] CPPIH leaflet 2004, http://147.29.80.160/portal/csc/genericContentGear/download/PPI_FORUMS_6PP+FINAL.pdf?document_id=16200007, accessed 19 December 2005

[5] E.g. CPPIH leaflet 2003, http://147.29.80.160/portal/csc/genericContentGear/download/PPI+leaflet+crowd.pdf?document_id=100002, accessed 19 December 2005

[6] E.g. CPPIH leaflet 2005, http://147.29.80.160/portal/csc/genericContentGear/download/Forum+Leaflet+March+05.pdf?document_id=70100011, accessed 19 December 2005

[7] CPPIH leaflet 2003, http://147.29.80.160/portal/csc/genericContentGear/download/PPI+leaflet+crowd.pdf?document_id=100002, accessed 19 December 2005



People often do amazing things for health - running a marathon in a superchicken suit for one!

Now there's another way to make an impact by joining your new local forum for health.

Ordinary people only - experts and chickens need not apply.

make time for health

Patient and Public Involvement (PPI) Forum members will be champions for health and make the views of patients and the public heard.

That's why we need people like you - people who know their communities and will give their time to make a real difference.

Can you help to bring better health to your community?

Please call **0845 120 7115** or visit **www.maketimeforhealth.org** for more information and an application pack.

Or write to
Make Time for Health
PO Box 11442
Birmingham
B2 4WP

General enquiries **0845 120 7111**

PPI Forum Membership Recruitment Line
0845 120 7115

Lines are open
8am to 10pm Monday to Friday
9am to 5pm Saturday and Sunday

Minicom 0845 120 7113

Commission for Patient and Public Involvement in Health

make time for health

Care about health?

Apply now - no fancy dress required

Commission for Patient and Public Involvement in Health

How can I get involved?

Everyone, from all parts of the community, is encouraged to get involved with their local PPI Forum to ensure that their voice is heard.

Your local Forum will have regular meetings in public and you are welcome to attend these, perhaps to voice any concerns or issues you might have around health and healthcare in your area. If you have knowledge or experience of a particular aspect of health or healthcare, you may wish to contact your Forum to contribute to discussions that may be taking place around that topic.

Alternatively, you may wish to apply to join a PPI Forum as a volunteer.

"The PPI Forums are an opportunity to get a stronger voice for everyone, but I believe it is particularly important for areas of society who may have previously felt their views have gone unheard."

Charlie, Forum Member, Sheffield

How do I contact my local Forum?

If you have any concerns or issues that you would like to raise with a PPI Forum or if you are interested in attending one of their meetings in public, please contact:

Commission for Patient and
Public Involvement in Health

Tel: 0845 120 7111
E-mail: enquiries@cppih.org
www.cppih.org

For more general information about PPI Forums please contact:

Commission for Patient and
Public Involvement in Health

Tel: 0845 120 7111
Fax: 0121 222 4511
Minicom: 0845 120 7113
E-mail: enquiries@cppih.org

Commission for Patient and Public Involvement in Health

Shaping Health
Better decisions
Better health

Patient and Public Involvement Forums

Commission for Patient and Public Involvement in Health

Figure 1: Laity and expertise as qualifications for involvement in PPI Forums

Perhaps the strange mix of representativeness, diversity, ordinariness, knowledge and expertise to which these materials appeal is best summed up in a passage repeated in several CPPIH leaflets:

> Forum members will be champions for health and make the views of patients and the public heard.
>
> That's why we need people like you—people who know their communities and will give their time to make a real difference.
>
> *Can you help to bring better health to your community?*[8]

What is required, above all, is this mystical quality of knowing one's 'community'—something which people like *you* possess! You are ordinary enough, motivated enough and knowledgeable enough to take on the duties of a PPI Forum member—but of course *you* could be anyone who has picked up (and, perhaps crucially, read) a leaflet whilst attending a local health service. The materials appeal to "local people," "ordinary people", "people who know their communities," seeking to link personal concern with individual health to a common communitarian consciousness that demands collective responsibility and collective action.

'Ordinariness' and commonality with the 'wider community' have a special place in these appeals: not only do they provide particular insights unavailable through other mechanisms, but they also enhance the ability of Forum members to perform their role of accessing the local population to uncover its views and needs in ways that public-health research, apparently, cannot. The practitioners' guidance endorses as good practice an example of this kind of capacity, relating the work of one Primary Care Group (PCG) which (prior to the PPI reforms) employed older people as 'peer

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[8] E.g. CPPIH leaflet 2003, http://147.29.80.160/portal/csc/genericContentGear/download/PPI+leaflet+crowd.pdf?document_id=100002, accessed 19 December 2005

researchers' in a survey of older people:

> The PCG advertised for older people to undertake the interviews through older people's groups and the media. It trained seven volunteers who undertook the interviews in people's homes. This allowed the PCG to reach 'the hard reach' [sic] people in the borough, use the skills of older people to build a comprehensive picture of the needs of the local people, and obtain a frank and realistic view of the issues. (Department of Health, 2003c: 61)

Commonality, experience and various talents, including drive and enthusiasm, come together in this kind of mediating role that makes the population knowable to the health service in ways not achievable through the state's traditional means.

Discussion

While the new system of PPI in England draws on discourses of both expertise and representation, then, the way in which it does so transcends democratic and technocratic rationales. The identity of the individuals to be involved has clearly been a major concern for policymakers and the CPPIH. Elsewhere, similar 'person specifications' are evident in other regulatory mechanisms in health, such as the National Institute for Health and Clinical Excellence (NICE), which requires lay members of its committees and working groups to have "experience of health services and the issues that are important to people with the condition(s) or subject area(s) covered," including, in the case of its public-health committees, experience that "could include active work in the community to promote public health or to prevent illness."[9] The Medical Research Council's advisory group on public involvement is composed of "members drawn from

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[9] Source: http://www.nice.org.uk/page.aspx?o=242614, accessed 2 October 2006

all walks of life, [who] share an interest in health and research";[10] an expert advisory committee to the DH on new and emerging infections calls for lay members who "have an understanding of the issues associated with public health and communicable disease" and who "have experience of committee work."[11]

As argued earlier in the chapter, then, any discussion of public participation which limits its analysis to the extent of empowerment, the accuracy of representation or the expertise of those involved neglects the most crucial dimensions of contemporary public-participation policy. Although the contradictions and overlaps might simply be seen as exemplifying confusion and ambiguity in policy discourse and implementation, what I hope I have demonstrated is that a coherent, if multifaceted, picture emerges from these official documents of who this involved public should be and how they should operate, which brings together varied discourses of involvement—empowerment, consumerism, stakeholding, responsibilizing—identified by Barnes *et al.* (2007: 8-27) as co-existing in contemporary policy. Contrary, then, to Baggott's (2005: 547) argument that "the relationship between PPI forums and their constituencies appears weak and this is partly because little thought has been given to the nature of their representative function," PPI must be considered in terms of the range of pragmatic and productive connections it engenders. The ideal involved members of the public, as demanded by PPI, are hugely multifaceted individuals, but what seems to be asked above all is that they know and can make knowable their constituencies. Partly, this is by virtue of their typicality and commonality. But it is also to be achieved through their labour, their efforts to understand better the views of local populations, something which is aided by the combination of their ordinariness—their very laity—

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[10] Source: http://www.mrc.ac.uk/index/public-interest/public-advisory_group_public_involvement.htm, accessed 2 October 2006

[11] Source: *Guardian*, 5 July 2006

and their extraordinary enthusiasm and armoury of reflexive skills.

What emerges is a conception of the involved member of the public as filling a mediating role of the kind identified in certain other areas of contemporary social policy in economically developed countries (Petersen, 1997; Schofield, 2002; Green, 2005): lay individuals whose disposition and social location provide particularly acute insights to government. Such insights make knowable the vagaries of the wider population which involved individuals articulate through typicality, commonality or communicative skill, and help to ensure the appropriateness and efficacy of public services for that population. They are almost, perhaps, 'experts in laity'.

This mediating role echoes some of the ideas put forward in the Foucaultian accounts of advanced-liberal governmentality discussed in the previous chapter, with their emphasis on how contemporary government rests not on 'top-down' regulation, compulsion and direction by the state and its agencies, but on the rational actions and choices of the subjects of government. Even in this contemporary order of 'bottom-up' regulation-through-autonomy, however, there are certain loci of power through which the aims of the individual subject are aligned with those of government and through which governmental authority comes to know and understand its subjects, thereby achieving more effective techniques of government: notably the intermediary professions described by Rose and Miller (1992) (alluded to in Chapter 1 on p.36). What this analysis of public involvement seems to suggest is a curious development in this mode of governmentality. Particular members of the public—archetypically 'active' citizens, with productive subjective qualities varying from willingness to rationality to knowledge of their peers—seem to be cast in new interpretations of these crucial, mediating roles in governmentality. They bring together experience, representativeness and knowledge in new configurations which help to make knowable the wills and whims of the governed to governmental power: the crucial input upon which a modernized welfare state, fashioned around the idea of a fundamentally changed, reflexive society, rests for its success. What we see, moreover, in these policy texts, is the way in which it is not just the backgrounds and characteristics of these individuals, but their *labour*, too, which is crucial in this process of illumination. Their position is seen as offering a privileged vantage point for making understandable all sorts of peculiarities throughout society to the health service: for them, the needs and views of 'hard-to-reach groups', for example, are less hard to reach. The knowledge gained from such exercises is then to feed into the priority-setting processes of the health service.

What seems especially interesting about this mediating role, then, is that it seems to be about the governance of the health service and its agents—including some of the traditional professional experts of governmentality—rather than the governance of society at large. As noted in the previous chapter, much of the governmentality-studies literature focuses on the mechanisms of new-Right, neoliberal government. While, as we saw, much of this remains relevant to current policy, and especially the consumerist inheritance of new Labour from the Conservative administrations that preceded it, the example of these very recent developments in PPI policy discourse in England (tied, as we have seen, closely to wider Third Way policy in the NHS and beyond) suggests, perhaps, some of the ways in which advanced-liberal technologies of government have evolved in a policy context which also emphasises the merits of partnership, integration and networks between communities, private organizations and the state, alongside quasi-marketization and top-down accountability.

Summary

This chapter has considered the various forms of representation and expertise that might provide rationales for involvement, and their implications for how involved service users might be selected and constituted. Bringing these sets of justifications together, I have argued that there are considerable overlaps, with both sets resting implicitly or explicitly on the characteristics associated with the 'active, reflexive citizen', characteristics which are distributed unevenly across the population. By examining in some detail aspects of the government's health-policy reforms relating to patient and public involvement, we have seen also how various competing justifications for involvement are brought together in more or less complementary ways in the search for 'typical', 'representative', knowledgeable and willing individuals to fulfil these intriguing intermediary roles in health-service governance. This policy analysis suggests some of the ways in which advanced-liberal governmentality seems to be realized in practice, and developing under the politics of new Labour, with its emphasis on the importance of other modes, alongside the market, in the governance of the contemporary welfare state.

Of course, this analysis has remained in the realm of policy, rather than the practice of involvement, and cannot illuminate how far such policy discourses are practically efficacious. In the next chapter, we look at issues raised in the literature relating to the conduct of involvement, before bringing together the themes explored over these first three chapters in posing the research questions that inform the empirical work that follows.

3.

THE INVOLVEMENT PROCESS[1]

We turn now to the literature on the practice of involvement. Much has been written on the dynamics and tensions that arise at the interface between laypeople and professionals or managers in various settings, from the individual-level consultation to collective encounters such as public- and user-involvement forums. In this chapter I concentrate on some core findings of this literature of particular relevance to the issues raised in previous chapters and which inform the empirical work. The aim is to flag these issues and to relate them back to those raised earlier in the literature review, rather than offer extended analysis. In particular, I consider the effects of interpersonal relationships and power within and beyond the encounter: how do these work to include, exclude and transform those involved and their contributions? How do processes of inclusion, exclusion and transformation relate to the rationales for involvement considered in Chapter 2, such as representation and expertise? After discussing these issues in relation to the practice of involvement, the way in which its products are used by decision-making managers, and the place of involvement in wider

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[1] Much of this chapter is published as 'Public and user participation in public-service delivery: tensions in policy and practice', *Sociology Compass* in press (Martin, 2009a).

contemporary governance arrangements, I conclude by proposing some research questions arising from the literature-review chapters for empirical investigation.

The encounter

There is a long history of study of the interactions between doctors and patients in individual-level consultations (Gothill & Armstrong, 1999), and the lessons of this literature on the role of power and identity in communication present a useful backdrop to work on the dynamics of groups where laypeople and professionals or managers interact. While findings from individual- and group-level interactions are occasionally conflated (e.g. Evans *et al.*, 2003), the interactions of groups add further dynamics to such encounters, with the performance of inclusion and marginalization and the potentially transformative effect of participation of particular note.

Whereas certain government-mandated involvement initiatives, such as CHCs, PPI Forums and LINks, are able to determine their own agenda and even have powers over the NHS bodies to which they relate, if involvement is led by the public-sector organizations themselves, there tends to be an immediate power imbalance in favour of managers and professionals. In many cases presented in the literature, managers and professionals possess ultimate control over such key questions as who is involved, how they are involved, what constitutes a legitimate issue for involvement, and, as considered in the next section, how knowledge produced through involvement is translated into action. A fundamental question relating to the encounter for authors seeking normative criteria by which to evaluate involvement processes, then, is the extent to which users and their viewpoints are given equal weight in the process (Charles & DeMaio, 1993; Barnes, 1999a). There are numerous examples in the literature of how staff ignore, belittle or gloss over contributions which conflict with their own preconceived frameworks of legitimacy and competence (e.g. Petersen, 1996; Milewa, 1997; Williams, 2004; Hodge, 2005). As Beresford and Campbell (1994) point out, there is no necessary integrity to these frameworks: views of service users may be discredited by providers as 'unrepresentative' even though forums are often set up only to include the lone voice of a single willing user who therefore can be little other than a token.

Even where more democratic approaches to setting agenda and the validity of divergent frames of rationality are adopted, however, power inequalities are not easily 'bracketed'. Various authors have proposed and tried to locate a form of Habermasian discourse ethics in involvement practice (e.g. Porter, 1997; Gregory & Romm, 2001; Gregory, 2003; Montpetit, 2003), but others are sceptical about how far it is possible to bypass the insidious effects of power simply by instating rules and norms of conduct in debate. Barnes *et al.* (2004a; 2007) follow feminist critiques of Habermas in arguing that the affective, non-rational components of communication are integral to successful deliberation, and as such can contribute to or detract from inclusiveness and equality, but cannot simply be removed from debate leaving nothing but pure communicative rationality. In their case study of a women's group which contributed to the policies of a local authority, they describe how personal relationships were crucial in advancing deliberation and neutralizing power relationships (cf. Davies & Burgess, 2004). As Scott (2000: 263) puts it, "individuals do not move toward consensus solely as a result of the force of a better argument but additionally—I would say primarily—through the building of communicative relationship."[2]

Rules aimed at ensuring that all involved can contribute to reasoned debate may, therefore, have perverse consequences if the definition of 'reasoned debate' excludes certain groups by intent or accident. But there are difficulties, too, with the role of emotions in such processes, and with alternative modes of self-expression such as story-

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[2] It should be noted that others make the opposite criticism of Habermas's discourse ethics: for example Chandler (2001) finds that Habermas focuses on self-expression to the detriment of rational debate.

telling, greeting and rhetoric, of the kind emphasised by Young (2000). While Barnes (2004: 131) notes the need to for deliberation processes to value "diverse experiences and styles" of conduct to avoid excluding alternative contributions, Thompson and Hoggett (2001) and Stokkom (2005) note the more insidious role that emotional dynamics may play. Such dynamics may be especially challenging where social difference comes into play. Ryfe (2002: 365) finds that more socially differentiated groups are more likely to have rules of conduct to ensure the flow of deliberation; this, of course, may result in the favouring of "certain kinds of identities or the expression of particular issues or conversational styles." Davies *et al.* (2006: 146) similarly find that minority-ethnic and disabled members of the citizen-involvement group they studied were sometimes marginalized because the distaste of the group for overt conflict—"rather than crude attempts to seize the agenda and repress other voices"—resulted in the uncritical acceptance of hegemonic discourses. They thus suggest that some ground rules are needed in any deliberative forum, to ensure inclusion of those who would otherwise be marginalized. Clearly any social practice involves power relations of some kind, including practices designed to bracket power. Given this, the key questions are empirical: how power operates in practice through the encounters of involvement, and what effects conduct—in the form of rules, norms, discursive strategies, and the interaction between participants—has on the process, by marginalizing or prioritizing particular participants and their contributions (cf. Fung & Wright, 2003). Davies *et al.*'s more general findings about the conduct of involvement are pertinent here. In contrast to the deliberative-democratic model of the process by which collective opinions are reached—through the stepwise exchange of opinions resulting in rationalistic resolution of differences and emergent consensus—they find that meaning is produced more collaboratively in the first place, with understandings co-produced continually through interaction. Thus, they argue, "the deliberative ideal as *procedure*, in the shape of a quest to reproduce the ideal speech situation, is in question" (Davies *et al.*, 2006: 207)—though this is not an inherently negative finding. Rather, it implies, involvement initiatives need to work "'with the grain of how citizens behave', recognizing that 'to work against the grain is to reproduce the passive citizen'" (Davies *et al.*, 2006: 198; quoting Prior *et al.*, 1995: 88). What, then, are the practical consequences of the rules and norms of involvement for the kinds of contributions—and participants—that are produced?

There is a useful literature to draw on here focusing on the micro-politics of involvement processes, and particularly on how actors influence the course of involvement, both through explicit rules of conduct and frameworks of legitimate domains, and in more subtle ways. Hodge (2005), for example, examines the 'boundaries of discourse' in a mental-health user forum, in which users were allowed and even encouraged to raise their own issues, but where professionals still determined which points could be actioned and which would not.

> The forum exists to bring the system into dialogue with the 'authentic' voice of service users. In order to be seen to be doing that, the system's representatives on the forum must be open and empathetic to the frustrations of service users' subjective experience of the system. However, what it is not there to do is to expose the system to fundamental normative challenge that would undermine its authority. (Hodge, 2005: 176-177)

In effect, the consequence of the expectation that users share their experiences in this forum, with no corresponding expectation of action, was that the power relationship between professionals (as detached, 'objective' representatives of the system who were not expected to talk subjectively about personal experience) and users was reinforced. Other writers point towards the ways in which the agenda of involved publics are denigrated by managers and professionals. Williams (2004) identifies five discursive strategies deployed to ensure that difficult issues are accommodated without necessitating action, such as switching agendas, deferring action, deploying superior knowledge and so on. Studying another mental-health user group over a period of two years, Milewa (1997) finds that of 57 issues raised by users with management, 22 resulted in satisfactory outcomes, one was formally rejected and some 29 received no formal response at all (the remainder being deferred beyond the duration of the study). As others are keen to point out, though, this is not a matter of absolute discursive power held by professionals: involved users, too, dynamically shape the norms of inclusion and exclusion through the involvement process (Barnes *et al.*, 2004b), though professional power is often dominant—often less because of overt attempts to control the encounter than because of their external, structural power as service gatekeepers.

In apprehending the findings of these studies, of course, the key issue for us is not the legitimacy or otherwise of the power of professionals and managers to determine the agenda of these forums. Often the implication of these studies and the wider literature is that service users should be given more control rather than merely being consulted or placated (see, e.g., Charles & DeMaio, 1993; but cf. Litva *et al.*, 2002; Contandriopoulos, 2004 for alternative views). The question of service-user empowerment is an important one but is not central to our concern here. Rather, what is of interest is the issue of what the mediating process of the encounter itself implies for the knowledge produced and for the actors involved and not involved. Which discourses are discarded and which are taken up? In which domains do involved users, managers and professionals believe that service users have a legitimate and valuable contribution to make? How does the process of involvement affect the content of the knowledge produced and the actors themselves?

Transformation through involvement

An interesting corollary issue which flows from these kinds of questions centres on how the process of involvement itself affects the views and even self-identity of the actors involved. Contrary to Milewa's (1997: 166) claim that "public participation is premised on the implicit—*often unexplored*—assumptions that the individuals concerned already hold apposite opinions, that they view such opinions as legitimate and reasonable, and that they are willing to make known their true thoughts," many recent writers have emphasised how the relationships engendered by the encounter itself are crucial to the discourse produced. A prerequisite for successful communication according to Habermas and theorists of deliberative democracy is that those involved must be open to changing their opinions through dialogue. An interesting finding from this empirical literature, however, is that the transformation of those involved may sometimes take a more profound form.

Barnes *et al.* (2004a: 95) discuss the transformational effects of a number of forums of public involvement, comparing 'bottom-up' groups initiated by service users or members of the public themselves with "spaces in which collective identities not articulated previously might be constructed," often with some success. In relation to a group focusing on women's services, for example, they identify "deliberate attempts to make connections across lines of difference among women [which interviews suggested] had a transformative impact—not simply on women's opinions, but a deeper transformation of their sense of self" (Barnes *et al.*, 2004a: 97). Ryfe (2002) similarly finds dialogues which create bonds across difference and a reflexive reappraisal of actors' own positions, the resulting relationships forming a crucial foundation for further action. Simmons and Birchall (2005) suggest that motivations for participation change through involvement, with individualistic rationales replaced by more collective impulses. For Campbell (2005), then, involvement shapes those involved as citizens and individuals, creating self-consciously active citizens with a practical orientation towards the state and governance.

These are intriguing ideas, and point towards the positive effects that the involvement process itself might have on the capacities of those involved and therefore the potential of involvement as discussed in Chapter 2. There are also, though, some inherent ambiguities in the consequences of such transformations (Barnes *et al.*, 2003; 2004b). In one sense, transformation suggests the possibility of transcending some of the limitations of the kinds of notions of representation discussed in the previous chapter, premised on accepted and assumed boundaries of commonality and difference:

> The concept of representation depends on a simple and static notion of identity. It is based on a set of characteristics considered to define the individual (race, age, gender, disability, and so on). This fails to acknowledge either the differentiated nature of identity or the significance of the process of identity construction that may take place within the process of deliberation itself. (Barnes *et al.*, 2004b: 273)

On the other hand, there is a sense in which such a transformation may imply a distancing from the wider public:

> Processes of establishing legitimate identities are based on a range of different, and conflicting, notions of representation. These may be unsustainable in practice—as some of our data suggest, notions of representation may become rather amorphous and fluid after the initial process of group formation. (Barnes *et al.*, 2003: 396)

There is a question, then, around the relationship between the rationale for involvement and the process by which it takes place and identities of participants are formed. Is the transformation of the encounter something which assists participants in fully realizing their role, or does it have a distorting influence?

Beresford and Campbell (1994: 317) argue that this is a positive dynamic which enables a more thorough and competent representation to take place:

> Getting involved may not only lead to change, but also change *us*. We become different. We become 'unrepresentative' in ways some service providers do not want. We become confident, experienced, informed and effective. At the same time, because getting involved is not something that most people are encouraged or have the chance to do, the mere fact of being involved may be seen as making us 'unrepresentative'.

For others, though, the issue is more difficult. Campbell (2005) sees willingness to be transformed through involvement as a very particular, reflexive quality, specific to certain subgroups: the kind of attribute largely confined to 'reflexivity winners', as discussed in Chapter 2. The question, then, is how the relationships and identities built through the encounter feed back on the democratic and technocratic roles assigned to involved members of the public. In a plural society in which citizenship is increasingly constructed in terms of mutual obligations and an active relationship to state and society (Lund, 1999), is it the case, as Barnes *et al.* (2004b: 277) argue, that

> the question of how far public participation can contribute to political renewal […] must focus on how far processes of participation foster social networks and enable the development of collective identities, as well as enabling the construction of new discourses within which public policies can be debated[?]

Or alternatively, as Bourdieu (1981) intimates, does transformation represent distancing and professionalization, with political activity reified as a matter for specialist input, and the original rationales for involvement, whether premised on representativeness or 'lay expertise', consequently eroded?

Power beyond the encounter

Beyond the realms of the encounter itself, much has also been written about the power of state organizations over what is done with the fruits of involvement. A lack of directiveness in guidance about how involvement should be conducted, along with conflicts between accountability to public forums and conventional vertical managerial accountability, are often blamed for inconsistencies in how knowledge produced by involvement is used.

In this context, many authors have characterized discretion over the way in which the outputs are used as a matter of 'self-legitimation' (Harrison & Mort, 1998) by managers playing 'the user card' (Mort *et al.*, 1996). Various authors have found evidence of involvement being used to justify *faits accomplis* (Crawford *et al.*, 2002), and of the views of those involved being ignored where they do not correspond with the plans of management (Glasner & Dunkerley, 1999). In such processes, the ambiguities and arguments of the involvement process are 'black boxed' into a single moment of agreement with managerial plans (Williams, 2004), such that much of the beneficial labour of deliberation—working through the issues, highlighting tensions and areas of uncertainty, and so on—is lost to the organization. For Harrison and Mort (1998), then, involvement, designed to improve the decision-making process, actually serves as a resource of self-legitimation for particular managers within the system.

> Networks produce implicit bargains and work for the benefit of insiders, implying they are difficult to legitimate; there is no obvious justification other than self-interest for favouring insiders rather than outsiders. An ostensible extension of the network, in the case under discussion to the 'public' and to users, is an obvious means of seeking to enhance its legitimacy. As we have seen, however, the ways in which our studies show this to have been done have left local managers very much in control, at least in the sense of 'holding the ring' between a multiplicity of stakeholders. (Harrison & Mort, 1998: 68)

Others point to the variety of constraints, particularly the expectations of 'vertical' management and institutional context (Wistow & Barnes, 1993; Lowndes *et al.*, 2001a; Orr & McAteer, 2004; Reddel & Woolcock, 2004; Barnes *et al.*, 2007), which often give rise to this marginal role for involvement. Consequently Milewa *et al.* (1998; 1999) suggest that the characterization of managers as self-legitimating is unfair: rather it is the system which limits involvement's role to one of disempowered consultancy and which casts "local communities as advisers to health authorities within the parameters of these ideological perceptions of reality" (Milewa *et al.*, 1999: 460). What the system demands is an 'active management' that implies judiciousness in selecting issues for public involvement, choosing the publics to be involved, and deciding whether and how to use the outputs (Milewa *et al.*, 1998). In this context, involvement may not be about empowerment or democracy, but may nevertheless provide useful inputs to effective service delivery (Rowe & Shepherd, 2002). Public involvement can only operate within the policy framework set up for it. Nevertheless, organizational culture may play a part in whether and how involvement is valued (Brown, 2001), and there may be opportunities for professionals and managers to use their 'constrained discretion' to their advantage: Newman *et al.* (2004: 213) highlight how "tensions between national policy priorities and local views and priorities […] may be replicated in public service organisations themselves as they seek to create a 'strategic/local' boundary that limits the structure of participation opportunities."

Involvement and contemporary governance

An important empirical concern emerges, then, around the role of managers and professionals in structuring involvement and using its outputs. In particular, there are questions about how different tiers of management within organizations may construct and value involvement differently—and how some professional groups, too, might see more value and opportunity in involvement than others (Daykin *et al.*, 2004).

These different organizations, tiers of management and professional groups—and the relationships between them—become all the more important given the multiplicity of interconnections between proliferating agencies that characterizes contemporary public-service governance (Newman, 2005b). Without being drawn uncritically into a 'governance narrative' (Newman, 2001), there is nevertheless a sense in which governance—broadly, "the arrangements by which authority and function are allocated and rights and obligations established and regulated and through which policies and practices are effected" (Gray, 2004: 4)—has shifted in recent years. The rise of the 'appointed state' (Skelcher, 1998) at the level of policy and regulation since the 1980s has continued under Labour, and has been complemented by the proliferation of locally based agencies and calls for partnership, collaborative working and integration, in pursuit of 'network governance' (Newman, 2001). Within such arrangements, involvement is often given a prominent place—rhetorically at least—as "communities and citizens, [and] public sector managers and front-line workers, [are] all constituted as active agents in a process of co-governance," as Newman (2001: 52) puts it from a governmentality-tinged perspective.

The consequences for the realization of involvement are ambivalent. In theory, partnership and participation seem complementary (Lowndes & Sullivan, 2004; Sterling, 2005): 'lateral' governance may complement pushes from policy and from the public for more-expansive involvement processes (Milewa *et al.*, 2002). In practice, involvement may remain marginal, as the concerns of more powerful organizational partners come to dominate the agenda of joined-up governance networks (Rummery, 2006), or as previously autonomous user groups are co-opted into the nexus of governance (Barnes *et al.*, 2007). As Newman (2005a: 206) notes, then, participation in governance processes may present a means of managerializing the political—"securing a more consensual form of politics, […] a settlement more attuned to the modernisation of welfare states"—but it may also present opportunities for those involved to open up new sites for political negotiation. Once again, the question of what actually happens—and how and why—is an empirical one.

As we shall see, this is an area of particular interest in relation to the empirical field of this thesis, where the involvement of a third-sector organization—Macmillan Cancer Support—at the level of both policy and implementation adds an extra set of managerial actors to the governance scene. In some examples in the literature, differences between professional and managerial groups resulted in novel strategic alliances between involved publics and (particular groups of) professionals (Barnes *et al.*, 2003; Montpetit, 2003; Rutter *et al.*, 2004). Involved users and members of the public rely on professionals to make their voices heard, and professionals may depend on users to aid them in improving responsiveness and for legitimation (Newman *et al.*, 2004). Sometimes, this co-dependency results in frustration and ineffectiveness (Lachman, 2000); in other cases, though, the result may be tension for the professional between involvement and conventional vertical accountability, and thus the potential for such new alliances:

> Conflicting regimes of power and different norms and practices flowing from these multiple and overlaid models of governance [...] open up potential lines of conflict between actors, for example between those at the 'strategic centre' of organisations and those involved in 'local' forums. [...] As well as producing conflict *between* different actors, such tensions may also produce conflicting allegiances and identifications *within* individual actors. This was evident in interviews with many officials who, as forum members, were caught between their accountability to the organisation that employed them and their growing commitment to the lay members with whom they were interacting. (Newman *et al.*, 2004: 218)

What this suggests is that the kinds of transformation through involvement discussed above need not be limited to involved publics: changes in views and even identity may extend to professionals, too. Again, there is certainly a sense in which this may be desirable, though there are evident dangers in this notion as well. For one thing, it is difficult in practice to distinguish between principled loyalty to 'the cause' and the instrumental use of involvement to bolster managerial legitimation or professional hierarchies (Mort *et al.*, 1996; Tritter *et al.*, 2003). Moreover, there is a tension here between this new role as advocate of involvement and the more traditional function of the professional and manager identified by Contandriopoulos (2004) and Milewa *et al.* (1998), as arbiter between the competing claims of diverse stakeholders. Given the constructed nature of the publics that are engaged through involvement, as underlined in the previous chapter, such tensions are all the more noteworthy, with alliances of professionals and publics potentially coming to champion very particular causes which other professionals and other publics may contest given limits of resources. We are led back, once more, to empirical questions. To what use do managers and professionals put the outputs of user involvement? What do they consider to be the value of these outputs (aids to responsiveness, sources of untapped expertise, the representative view of the public?) and, accordingly, how do they balance them with competing priorities? What do professionals and managers want to achieve through involvement?

<u>Some research questions</u>

The foregoing review brings into focus a number of connected areas of inquiry which offer a departure point for the empirical work that follows. At the most abstract level, what interests me is the contemporary relationship between individuals, society and the state, and more specifically what light the theory and practice of involvement in the governance and management of health can shed upon this relationship. In slightly more concrete terms, I am concerned with how this relationship configures notions of democracy, knowledge and authority, and what kind of reconfiguration (if any) of these domains is embodied in processes of involvement. Empirically, a crucial aspect of these questions seems to relate to those involved: who they are, how they are selected, what the system demands of them, what they offer. As we have seen, though, such questions cannot be answered by focusing solely on involved members of the public as if their perspectives and identities were fixed and static. Various components of the process are implicated too, not just recruitment, the encounter and the transformations it may produce, but also the discourses and networks of actors that give involvement its place in health-care practice, and the managers and professionals who co-produce the outputs of involvement processes and seek to endow them with a certain degree of legitimacy. Studying involvement in these terms allows us to connect the question of how those involved construct themselves, and are constructed by the system, to the question of what 'the system' (and various actors within it) see involvement as offering.

In overarching terms, a number of interconnected research questions present themselves for investigation, moving back out from the most directly empirical to the more abstractly theoretical. My primary research questions centre on the following:

- Who are involved users? How do they construct themselves, how are they constructed by (various actors within) the system, how do these constructions change and develop? (These questions are addressed especially in Chapters 6, 7 and 10.)
- What do the different actors consider that involved users contribute (for example some form of expertise, democratic input, the views of typical patients, etc.) to the management and delivery of services? How does this contribution develop through the process of involvement? What does the system demand of involved users *vis-à-vis* what they try to provide? (These questions are addressed especially in Chapters

7-10.)

- What are the views of different actors in the user-involvement process about the legitimacy and utility of the knowledge produced? (This question is addressed especially in Chapters 8 and 9.)

From these derive some secondary questions:

- How does user-involvement policy relate to practice, and how does involvement function within the organizational parameters and governance structures of the pilot programme studied and the wider NHS? (This question is addressed especially in Chapters 7, 9 and 10.)
- How is the input of user involvement put into practice? (This question is addressed especially in Chapters 9 and 10.)
- How far does the contribution find its legitimacy in democratic, technocratic or other rationales? (This question is addressed especially in Chapters 7 and 8.)

The more theoretically oriented questions are likely to be answerable only speculatively, but are nevertheless posed now to give direction to the empirical work:

- What does the practice of user involvement have to say about the relationship between the individual, the state, society and knowledge in late modernity?
- Who or what is being governed through user involvement?
- How far do theories of reflexive modernization and governmentality provide a useful lens through which to understand changing processes ‘on the ground’?

In the next chapter, I give an overview of the specific empirical field—a programme of pilot cancer-genetics services—in which the fieldwork was located. In Chapter 5, I detail my approach and methods. There follow five chapters focusing on various aspects of the findings, then in Chapter 11 I discuss these in relation to the research questions set out above.

4.

THE EMPIRICAL FIELD

The remainder of this thesis presents empirical research conducted between 2005 and 2008 on user involvement in a pilot programme of cancer-genetics services, funded by the DH and Macmillan Cancer Support to implement a new care pathway for patients at possible risk of inherited cancer. This formed one stream of a wider pilot programme of services funded following the genetics white paper, *Our Inheritance, Our Future* (Secretary of State for Health, 2003). I was employed to work as a researcher on an external evaluation of this programme, and used this opportunity to study user involvement in the programme alongside the evaluation work. My research on user involvement also contributed to the findings of the evaluation.

This chapter sets the scene for this work, looking first at the organization of cancer-genetics services in the NHS, then at the 2003 white paper and the pilot programme it heralded. Following this, I devote attention to Macmillan's role as a charitable organization seeking both to facilitate organizational change in the planning and delivery of cancer services and to involve 'people affected by cancer' in that process. Finally, I give some details of the place of involvement in the programme, and of the seven cancer-genetics pilots that were ultimately funded.

Cancer and cancer-genetics services in the NHS: recent developments

Since the NHS's inception, cancer provision has gradually gained in importance, reflecting the more general shift in the burden of illness away from epidemics towards chronic disease that has followed increasingly effective measures for managing infectious diseases, increases in life expectancy, and changes in lifestyle common to the economically developed world. Rising incidence of cancer, however, did not result in a coherent clinical or organizational response from the NHS. Bungay (2005) documents various contingencies in British cancer provision that have resulted in relatively poor NHS performance and patient outcomes. Conflict between medical specialities in Britain over jurisdictional responsibility for the diagnosis and treatment of cancer, for example, meant that oncology remained unrecognized as a clinical speciality for a long time, and while most European countries took on the World Health Organization's recommendation that cancer treatment be delivered by specialist multidisciplinary teams, the UK did not. Meanwhile, new treatments such as chemotherapy were left for cancer charities to fund through academic medicine concentrated in university hospitals. The result was relatively low *per capita* numbers of cancer-related medical and surgical consultants, and disparate levels of provision (and concordantly disparate outcomes) across the country (Bungay, 2005).

Things came to a head in the early 1990s, when various government documents, reports from professional bodies and pressure from charities pushed cancer provision up the political agenda. The result was *A Policy Framework for Commissioning Cancer Services* (Department of Health, 1995)—also known as the Calman-Hine Report, after its two principal authors, the then chief medical officers of England and Wales—which recommended a significant reconfiguration of cancer services to ensure that provision was better matched to need. It recommended new structures "based on a network of expertise in cancer care reaching from primary care through Cancer Units in district hospitals to Cancer Centres" (Department of Health, 1995). These recommendations were accepted by the Conservative government of the time, but with no funding allocated for implementation, and it was not until the NHS Cancer Plan (Secretary of State for Health, 2000a) that there was a policy-led drive to put recommendations into practice (Munro, 2001).

The success of the networks in realizing the idea of shared expertise and co-ordinated care was mixed, with inter-organizational disputes over service rationalization, and an overriding concern for meeting centrally determined targets, more characteristic of some cancer networks than this harmonious vision (Addicott *et al.*, 2007; Martin *et al.*, 2009a). However, the clinical-network approach advocated by Calman and Hine did provide the starting point for further reforms, including in relation to cancer genetics. Family history of certain cancers had been well established as a risk factor for the development of those diseases for some time, and consequently family-history clinics were a common, if unevenly developed, feature of cancer care in many hospitals, led by oncologists and cancer-care nurses. However, only a few, rare cancers were known to be caused by Mendelian genetic disorders, i.e. those where a specific mutation in an identified single gene was responsible, and it was only in these cases that clinical-genetics services tended to be involved (Gray & Harper, 2004). In the early 1990s, a number of Mendelian syndromes were discovered that related to small subsets of more common cancers, notably breast, ovarian and colon cancer. This led to a growth in clinics located in clinical-genetics centres for patients at risk of inherited cancer, and by the late 1990s, cancer genetics was the major reason for referral to these centres—though coverage was highly variable (Wonderling *et al.*, 2001).

The government responded by setting up a working group on cancer-genetics services. The Harper Report (Department of Health, 1996), as its recommendations were known, called for a reorganization of cancer-genetics provision following the

Calman-Hine model for general cancer services, with primary care responsible for identification of potentially at-risk patients (representing a more proactive approach to ascertainment than the reactive risk assessment of symptomatic cancer patients in hospitals that had previously predominated), cancer units responsible for risk assessment and screening of those referred by primary care, and specialist genetics services, integrated with specialist cancer centres, offering services for high-risk patients and disseminating expertise across the area. As with the Calman-Hine model, then, the Harper Report was about networked knowledge management, service rationalization and matching expertise to need. The Harper recommendations, too, were accepted but not funded, and in the few years following publication, the degree to which provision in England corresponded to the model varied markedly (Wonderling *et al.*, 2001).

The Kenilworth model

Besides seeking to implement the recommendations of the Calman-Hine Report, the Cancer Plan (Secretary of State for Health, 2000a: 90) also promised the development of services that followed Harper's recommendations, and committed the DH to "work in partnership with Macmillan to develop new services to improve cancer genetic risk assessment." Macmillan, and clinicians associated with the organization, had been closely involved in the implementation of a structure of provision following the Harper model in Wales. Following the Cancer Plan, in 2001 Macmillan and the DH jointly convened a working group, in Kenilworth, Warwickshire, to devise "a national model for service delivery, building on existing good practice and lessons learned from cancer genetics services already established" (Macmillan, 2001: para.1.2), for England. Comprising policymakers including the cancer 'tsar', various health professionals, Macmillan service-development officers and a service-user representative, the aim was to develop a coherent model care pathway and division of labour that was somewhat more exacting than the Harper recommendations. The resultant 'Kenilworth model' included clear guidance about issues such as levels of knowledge required of practitioners in different parts of the network (from level one—"short, baseline training […] available to everyone working in primary care [… that] should cover awareness of cancer genetics and an overview of the organisation of local services"—to level four, equivalent to that of a genetic counsellor) (Macmillan, 2001: paras 6.7-6.10). It also mentioned the need for user involvement in service provision (paras 5.25-5.27), though this, as we will see, was developed in more detail when it came to piloting the Kenilworth model.

The new genetics, NHS policy and the 'Mainstreaming genetics' programme

Cancer was not the only clinical field in which knowledge of genetic aetiology was coming on apace at this time. Developments such as the mapping of the human genome were resulting in new, clinically applicable knowledge, including not only Mendelian gene mutations with specific clinical results, but also associations between multiple variations in genes relating to risk of numerous diseases. The white paper *Our Inheritance, Our Future* represented the government's response to this unfolding "revolution in health care," as the prime minister put it in his foreword to the document (Secretary of State for Health, 2003: 1). It heralded new investment in clinical-genetics research, and in the staff and equipment of specialist services. It also announced funding for a programme of pilots aimed at "spreading knowledge" and "building genetics into mainstream services" (Secretary of State for Health, 2003: 3). With the potentially exponential expansion in knowledge of the role of genetics in health—not only specific gene mutations but also wider genetic makeup, and its interaction with environmental factors—it was important to ensure that those outside genetics centres were able to apply knowledge for the benefit of patients. With this in mind, the aim of the pilot funding announced in the white paper was to "spur the take-up of genetics by other specialties by supporting new initiatives in genetics based care—in the hospital sector, primary care and in screening programmes" (Secretary of State for Health, 2003: 36).

The programme of pilots encompassed four streams: five projects set up to identify and treat people with a relatively common genetic disorder known as familial hypercholesterolaemia; 10 service-development projects aimed at integrating genetics knowledge with other clinical specialities; 10 general practitioner (GP) with a special interest in genetics projects, involving GPs taking one or two days a week to acquire genetics knowledge and then work to spread awareness through primary care, provide leadership on genetics issues and provide clinical services; and six (later increased to seven) cancer-genetics projects, cofunded by Macmillan, which were to implement the Kenilworth model in their local areas. Invitations to bid for the £8 million of pilot funding were issued in early 2004, and money was allocated to the familial hypercholesterolaemia, service-development and four cancer-genetics sites in the second half of 2004. The GP with a special interest sites and the other three cancer-genetics projects followed early in 2005.[1] The cancer-genetics projects which were funded were intended to last for between two-and-a-half and three years, though in all seven cases, varying amounts of extra (unfunded) time were allocated to the projects. Each pilot was required to include plans for evaluating its work, and alongside these internal evaluations, the DH also funded an external, programme-level evaluation of the pilots,

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[1] The staggering of the award of the cancer-genetics funding arose because of a lack of interest from primary-care-led projects in the initial invitation to bid from Macmillan and the DH. It was predominantly hospital-based genetics and cancer departments that applied for the money. Four of these bids were funded, and the invitation to tender was then reissued with a specific appeal for primary-care-led applications. Following this, a further three projects were funded, all hosted by PCTs, with the requisite involvement from colleagues in cancer units and specialist centres.

to address the organizational issues arising from the pilots' efforts at service reconfiguration. I was employed on this project from its start, in November 2004.

User involvement

The pilot programme as a whole was evidently in tune with wider NHS 'modernization' policy, in its efforts to shift knowledge, power and provision towards primary care, and to promote the sharing of knowledge between different 'silos' of the health service and create joined-up, patient-centred provision. Accordingly, the invitations to tender for pilot funding all required bidders to address patient and public involvement in their applications. All of the funded bids conformed to this requirement, but it became apparent from initial visits to the pilots that my colleagues and I undertook during 2005 that in practice, in the majority of sites, user involvement was minimal. There was marked doubt among pilot staff about who such users might be, how they might be involved, and to what ends. While in some sites there were plans for consultation with local PPI Forums or disease-specific groups, or even for initial surveys or focus groups, in most, user involvement seemed to have been quietly sidelined.

The exception to this was the seven cancer-genetics projects. As we shall see in the empirical chapters, this was not because their staff, on the whole, were more enthusiastic or knowledgeable about user involvement. Rather it was because Macmillan was proactive in encouraging, contributing to and monitoring user involvement in the seven sites it was cosponsoring. A traditionally professionally led, and to some extent medically dominated, charity, Macmillan was in the midst of considerable change at the time of the pilots. Previously its most visible work was the sponsoring of cancer-related NHS posts, which it would 'pump-prime' for three years on condition that the NHS would commit to ongoing funding, and the Macmillan name would be attached to the post in perpetuity—the well known 'Macmillan nurses' and more recent 'Macmillan GPs'. Now, though, it was seeking to reorient its work

Figure 2: Macmillan's rebranding

somewhat, acting as a force for wider, organizational change in the 'new NHS' (and beyond), through activities including this partnership with the DH. This was the increasing focus of its efforts as "a development organisation that tries to secure innovation, change, and improvement" (Brown, 2002: 188). The aim, then, was to improve the experiences of those affected by cancer throughout the care pathway by initiating, spreading and consolidating change—as signalled by the organization's rebranding from Macmillan Cancer *Relief* to Macmillan Cancer *Support*, which took place midway through the pilot programme (see Figure 2).

In pursuing this reorientation, a particular concern was to include the views of patients and carers in the influence Macmillan was attempting to wield. It had recently taken over another charity, Cancer Voices, and this, among other user-involvement activities, was to provide this perspective, as expressed on the organization's website:

> We use our experience to improve cancer care. People who live with cancer are experts by experience. Together we use this knowledge to make a positive difference to the lives of people affected by cancer.[2]

The invitation to tender for the Kenilworth funding was short on detail about user involvement, merely stating that bids "will need to include a clear statement of the intended approach for involving users in the operation of the pilot project," though it did also offer a contact number for further support on this issue. It was really only after

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[2] http://www.macmillan.org.uk/About_Us/Force_for_change/Cancer_Voices.aspx, accessed 16 May 2008

funding that the rather more proactive approach that Macmillan would take to user involvement became clear. Involvement was to take the form of a 'partnership' between pilot staff and users. In contrast to the pilots in the other streams of the programme, where the DH took a rather hands-off approach, Macmillan required three-monthly reports from the projects it had cofunded, convened biannual 'Pilots Together' events at which it brought its projects together to provide strategic input and attempt to encourage 'cross-learning' between them, and offered various other inputs relating to user involvement among other issues. The three-monthly reports were to be submitted according to a structure which included a section on user involvement, while the Pilots Together events always included at least one session pertaining to involvement. A Macmillan representative attended each pilot's steering-group meetings, and made it clear that Macmillan expected involved users to be present at these meetings, too. Furthermore, Macmillan convened a 'National User Reference Group' (NURG), at which it brought together involved users from the seven sites, Macmillan managers and user-involvement facilitators, and two, more experienced, involved users from previous projects, with a view to supporting user involvement, sharing ideas and increasing users' site-level influence. All in all, after funding was committed, it was clear that there was going to be much more impetus to user involvement in the cancer-genetics sites than the others. It was for this reason that my study took these seven projects, and their associated national-level groups and meetings, as its empirical field.

The cancer-genetics sites and national arrangements

The seven pilots were located across England. While their common aim was to implement the Kenilworth model locally, there were notable contrasts in the way they went about doing this: for example, in terms of the particular populations targeted by the pilot work (the entire local population in some pilots; particular at-risk or underserved subsets such as minority-ethnic or economically deprived groups in others), in terms of the skill-mix of staff, and in terms of the division of labour between primary, secondary and tertiary care. Their arrangements for user involvement were also varied, as we shall see in Chapters 6-10. Macmillan asked each site to designate one member of staff 'user-involvement lead', with the responsibility of setting up and running user involvement. It provided two workshops for the user-involvement leads over the course of the programme. Four of the seven cancer-genetics sites were also selected as case studies in the external evaluation of the genetics pilot programme; fieldwork for this thesis covered all seven sites. Table 1 presents summary information on the sites, referred to by the letters A to G in this thesis.

On a national level, the cancer-genetics programme involved:

- Pilots Together events, held approximately biannually over the three years of the programme, plus one shortly after it ended. At these events, pilots presented to one another on their progress, and Macmillan provided input on current policy issues, its own plans and certain tasks facing the pilots, such as user involvement. Those present included staff from the pilots, involved users, Macmillan representatives, representatives from the DH, and other health-service professionals and managers interested in the pilots' progress. I attended five of these meetings (all but one).
- Programme steering-group meetings, held approximately biannually over the three years, to assess the progress of the pilots and intervene if necessary. These included Macmillan and DH staff, and two involved users who put themselves forward from the NURG. I did not attend any of these meetings.
- Evaluation-group meetings, three of which were convened midway through the programme to agree a basic set of outcome data that every pilot would collect. Present were Macmillan and DH staff, at least one representative from each pilot, and three involved users who put themselves forward from the NURG. I attended all three of these meetings.

- NURG meetings, which sought to bring together involved users from the seven pilots with two other, experienced involved users who were not tied to any specific project, to provide mutual support, share ideas and work together both on national-level user-involvement activities and to promote site-level involvement. These took place three to four times a year over the pilot period. Present were Macmillan staff, involved users, and occasionally, early on, one or two members of staff from sites where users had not yet been recruited. I attended 10 of these meetings (all but the first one).
- Two meetings for user-involvement leads, led by a Macmillan user-involvement facilitator, which sought to provide a basic understanding of the principles of involvement, and allow leads to develop their own ideas about how to put it into practice. Present were Macmillan staff, a number of involved users who put themselves forward from the NURG, and user-involvement leads. I was not present at either of these meetings.

At both the national and local level, then, the programme was structured by Macmillan to ensure plenty of scope for user involvement, and support for those involved. By virtue of my employment on the programme's external evaluation, I was fortunate enough to have the opportunity to engage with both the national-level and local-level activities fairly soon after they had begun, and observe how they unfolded through to the end. My research would contribute to the understanding of the wider evaluation, and could also benefit from my involvement in this, which provided insights into the wider organizational set-up and issues in four of the cancer-genetics pilots (and seven further cases from outside the cancer-genetics stream). The next chapter considers my approach to this study.

Site	Host	Brief description	Referral route	Professional background of service lead	Professional background of user-involvement lead	Case-study site in evaluation?
A	Acute hospital	Hospital-based service providing for a large population, principally focused on rationalizing cancer-genetics provision and care pathways within the acute sector	Referrals from health professionals	Clinical geneticist	Nurse	Y
B	Genetics centre	Hospital-based service with community-based clinics providing for a moderately sized, ethnically diverse and economically deprived area, with a focus on improving access to provision for underserved groups	Self-referrals and referrals from health professionals	GP	Administrator	
C	Genetics centre	Hospital-based service with community-based clinics providing for a moderately sized, ethnically diverse and economically deprived area, with a focus on improving access to provision for underserved groups	Referrals from health and social care professionals	Clinical geneticist	Nurse	
D	Genetics centre	Comparison of hospital-based service using a telephone-triaging system to take possible cancer-genetic referrals from GPs, with community-based clinics aimed at ethnic-minority groups, each serving a moderately sized population	Self-referrals and referrals from health professionals	Cancer geneticist	Genetic counsellor	Y
E	PCT	Pilot incorporated into the work of an existing community-based team of cancer nurses, serving a fairly small area, with a focus on improving access to cancer-genetics provision from primary care	Referrals from health professionals	Nurse	Nurse	Y
F	PCT	Community-based service provided across a large but sparsely populated area, with a focus on improving awareness of risk of inherited risk of cancer and access to services	Referrals from health professionals	Nurse	Nurse	
G	PCT	Community-based service provided in a fairly small area, with a focus and on improving knowledge of cancer risk in general and access to cancer-genetics services	Self-referrals and referrals from health professionals	Nurse/ Manager	Nurse	Y

Table 1: Characteristics of the seven cancer-genetics sites

5.

METHODS

This chapter describes the empirical research I conducted, from early 2005 to early 2008, in the field described in Chapter 4, the data from which form the basis of the analysis presented in Chapters 6-10. With its focus on the process of user involvement, the research was qualitative in nature, seeking to understand and explain the practice of user involvement as it took place. This chapter covers the entirety of the research journey, from the study's background, through methodological considerations, research design, practice in the field, interpretation and analysis, to presentation in this document. But I also acknowledge that research in practice is messier than this linear representation suggests, and so attempt to do justice to the emergent nature of design, empirical work and analysis as they unfolded. My particular concern is to give a fair description of the *practice* of the research, and how this relates to the validity of my findings. Quality in qualitative research—i.e. the robustness of methods in reaching valid and reliable findings—is currently a vexed question, and in health-related qualitative research in particular, there have been recent moves to establish more-or-less standardized means of assessing quality (e.g. Spencer *et al.*, 2003; Dixon-Woods *et al.*, 2007). Whilst not wishing to dismiss such efforts altogether, I have concerns over how far quality in qualitative research can be appropriately measured. I fear that attempts at uniform approaches to evaluating quality are overly influenced by the quantitative paradigm, and specifically the need to 'measure' the quality of qualitative work for incorporation into meta-syntheses and systematic reviews. My own view is that the particular contingencies of qualitative research are what gives it validity: a study's limitations (particularity, choice of method, uniqueness of context) are also its virtues (for more detail, see Martin, 2008c). In this understanding, a clear description of research process is crucial to assessing its validity, and the scope of the insights it might bring. Such a description can be made only qualitatively, and judged only subjectively.

'Markers' of validity and reliability suggested in guidance on judging research quality, such as use of primary data in presentation of findings, seem to me of only limited utility. However many primary data are included in qualitative reportage, belief in their validity rests on the reader's trust in the researcher (most fundamentally, that the researcher hasn't fabricated them, or at least that s/he hasn't been over-selective in choosing what to present). A clear and honest description of the research process is therefore for me a more important means of evaluating the (inseparable) strengths and weaknesses of a study—albeit one that is understandably neglected in the presentation of much qualitative work, given constraints such as word limits, resulting in somewhat ritualistic, 'checklist'-style methods sections. Ultimately a comprehensive 'audit trail' of the research process, through design, fieldwork, analysis and findings, is unrealizable given the quantity of data it would require and the demands it would place on the reader. Trust between reader and writer therefore remains of importance, and must rest on honesty and reflectiveness in the researcher's account.

The chapter runs as follows. First, I explain the background to the project, and its origin in certain conveniences of time and place that may be somewhat elided by the narrative progression of the thesis as a whole. I then present my methodological approach, relating this to the ontological perspective that informs my understanding of social reality and the means I see as fit for apprehending it. I spend more time considering how this approach translated into practice, in terms of my conduct in the field and the way in which I interpreted the products of my three principal modes of data collection. I then discuss the analysis process—trying not to divorce this artificially from work in the field—and the way I seek to rationalize my findings in the pages that follow without losing sight of the empirical specifics that produced them.

Background

As Chapter 4 relates, I first encountered the field as a result of my employment on the external evaluation of the genetics pilot programme that followed the 2003 white paper. It will probably come as no surprise that this was more the result of instrumental engineering on my part than happy coincidence. In the summer of 2004, I saw an advertisement for this research fellowship, which was unusual in two respects: firstly, it invited applications from those with a doctorate *or equivalent experience*, and secondly, it offered employment for four years. I contacted one of the lead investigators to see if it would be possible to register for doctoral study alongside the work, and on receiving a positive reply, I applied for the post, and was successful at interview.

The idea of the doctorate, then, came before any idea about its substance. It was agreed that I would take a theme from the evaluation to make 'my own' for doctoral study, but which? The first few months were spent making this decision, through contact with the field and perusal of the literature. I found the area of user involvement compelling, and it seemed from the pilots' bids that it was a major part of the programme (though, as noted in Chapter 4, these bids were somewhat misleading!). Furthermore, it seemed somewhat distinct from the rest of the evaluation, with its primarily organization-and-management perspective on the field. There is little in this literature on involvement, which remains the domain primarily of social policy, health-services research and sociology. User involvement thus represented a discrete field in which my colleagues had relatively little interest. This meant that I could focus on it without worrying about overlap between our interests that might compromise the necessarily individualistic nature of doctoral study, and that I could develop my own discrete programme of research activities in accordance with this focus, rather than relying solely on the evaluation's methodological approach and fieldwork.

My doctoral work on user involvement in the seven cancer-genetics sites therefore proceeded alongside the 'day job' on the evaluation of the programme, which involved 11 cases from across its four streams, including four cancer-genetics sites (see Table 1 in Chapter 4). This gave rise to some useful practical and substantive synergies. Access to the field—both informal (getting to know key stakeholders and gatekeepers) and formal (negotiating the NHS's sometimes challenging ethical and research-governance procedures)—was secured through the evaluation, for which I led an application for ethical approval to the Trent Multi-centre Research Ethics Committee which was approved in September 2005. Interviews I carried out for the evaluation provided me with a grounding in the dominant concerns of staff as they established their pilots in cancer genetics and other fields, and in some cases also provided valuable data specific to user involvement (discussed in more detail below). Meanwhile, my doctoral research involved a much greater amount of observational work than the evaluation, and this 'immersion' afforded a more nuanced understanding of the field that would otherwise have been difficult to acquire. And despite the marginality of user involvement to the predominant concern of the evaluation, my dual approach did allow me to draw out certain parallels and contrasts between the operation of inter-professional and inter-organizational teams within the health service and attempts to involve users as partners in these (see especially Chapter 10).

Research design and methodological approach

Where the wider evaluation deployed a comparative-case approach to study the development of services cutting across entrenched NHS boundaries (see Currie *et al.*, 2007; 2008; 2009; Martin *et al.*, 2007; 2009a; 2009b), my work on user involvement took a slightly different approach. My interest was less in comparison between the sites, and more in the discourse and practice of user involvement in the programme as a whole, as it related to the research questions put forward in Chapter 3. From my first encounters with the field early in 2005, it was apparent that user involvement in individual sites was largely a matter of one or two individual users and their relationships with a service. If each of these was treated as a case in a comparative study, the focus would become the individual and her/his relationships with pilot staff, rather than the organizational unit of analysis intended in comparative-case research. It therefore seemed more propitious to consider user involvement in the cancer-genetics projects as a whole, with occasional inter-site comparison, as presented in Chapter 9, for example.

To address the research questions, with their focus on rationale, process and the constitution of users and their contributions, it was self-evident that a qualitative approach was required. My interest was in a variety of issues, including both questions of motivation and intention, and questions of practice, and as such three complementary methods seemed appropriate.

- I saw *in-depth interviews* as an important foundation for my research, for practical, empirical and epistemological reasons. Practically, the bulk of my previous qualitative work had used interventional approaches such as interviews and focus groups, and my relative paucity of experience of collecting naturally occurring data through observation meant that I did not wish to risk relying on my observations alone. At any rate, empirically, events at which involved users interacted (with each other, with pilot staff and with Macmillan staff) were relatively few and far between.

It would therefore not be possible to engage in prolonged ethnographic work, and besides, questions of motivation and intention could not be addressed this way. Epistemologically, whilst accepting Silverman's (2001) argument, that interview data have perhaps been overused at the expense of observation of unfolding events, I maintain—in line with the general position I set out at the beginning of this chapter and elsewhere (Martin, 2008c)—that there is a particular value to interviews that derives from their very 'artificiality'. Silverman (2001: 286) describes the methodological difficulty associated with researchers' tendency to "move relatively easily between observational data and data that are an artifact of a research setting, usually an interview," and clearly caution is required in any attempt to use different qualitative methods as means of triangulation in search of the 'truth' of the matter. Nevertheless, interviews do provide an intensive means of getting at the views of research participants: understanding their accounts of their motivations, exploring the nature of their experiences and knowledge and how these relate to their work in user involvement, and accessing their interpretations of incidents which occurred in the course of the fieldwork. The status of interview data as purposive 'accounts' of events (Murphy & Dingwall, 2003), then, may be seen as a source of some utility, not just a limit on their validity. Similarly, the researcher's conduct of the in-depth interview should not, as some argue (Babbie, 1992), be governed by an effort to remove all traces of the interviewer's personality from the conversation, but should instead accept the fact that interview data are co-produced by both parties, viewing this as an inevitable characteristic of the interview. This is not to suggest that an overtly leading interview style is appropriate or acceptable, but it is to recognize that an individual's identity is unfixed and relational, and so an account of interview practice that posits replicability as the measure of quality is unviable. Contingency, then, should be acknowledged as a constraint on validity, but it should also be embraced as a necessary condition of that validity. I planned to interview various stakeholders in user involvement nationally and locally—involved users, user-involvement leads within pilots, Macmillan staff responsible for planning and facilitating involvement—and to re-interview involved users themselves towards the end of the pilot period, to gather their reflections on the process.

- The national and local-level meetings described in the last chapter provided crucial opportunities for *observation* of the unfolding of user involvement as it happened. Early on, I was able to attend meetings at both levels as I got to know the field and actors, and it quickly became apparent what an important source of data these could be, both in their own right, and as a means of sensitization to the concerns of the actors ahead of interviewing them. Observation, then, was important in helping to ground my research questions in empirical realities, not just as a source of data on my preconceived agenda (cf. Silverman, 2001). My observational work started while I was still getting to grips with the literature early in 2005, and continued through to the end of the programme in early 2008. As a member of the external-evaluation team, my presence in these meetings was largely taken for granted, but this also meant that at some meetings I was as much an active participant (offering input, for example, on evaluation strategies) as an observer. This, along with the fact that I did not use recording equipment at these meetings (which, at the national level, were usually whole-day events totalling five or six hours each), meant that I had to be judicious in my observational work. Primarily, therefore, I concentrated on noting the conversations and deliberations of the meeting, plotting the flows of interaction between participants and capturing occasional snatches of verbatim speech.[1] I did not seek to record more subtle aspects, such as body language, in detail, not because

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[1] In the empirical chapters, excerpts from my observation notes are given in italic type. Direct quotations are presented in double quotation marks.

these are unimportant, but because I did not feel I could do them justice in my notes or analysis. Nevertheless, the mere fact of 'being there' was enough to transmit a sense of the way these meetings were ordered, and while I noted my observations on the atmosphere of such meetings, this sense of order was difficult to reduce to field notes. As I consider below, this understanding derived from presence was consequently something which tacitly informed my analysis, rather than being an explicit subject of analysis in its own right. On the national level, I attended three sets of meetings relevant to user involvement, and I was present at at least one local-level meeting in all but one of the seven pilots.

- Finally, the pilots and programme produced a wealth of written material which invited *documentary analysis*. Murphy and Dingwall (2003: 54) locate official documents "somewhere between the worlds of observation and of interviewing," since whilst pregiven rather than a product of the research process, they are "artful reconstructions of the events that they describe, although […] they also form part of these events." As such, I treated these as illustrations of the way in which organizations or groupings sought to construct reality rather than as necessarily 'authentic' accounts of that reality. Indeed, they probably exemplified this considered, instrumental rehearsal of events to a greater extent than interview data, since the latter were the unpreconceived product of a particular interaction at a particular moment. Documents also provided another means of tracking the development of involvement, on this discursive level, through time—from initial bids, through quarterly reports, to final internal-evaluation reports.

I adopted this combination of approaches, then, to answer the breadth of the research questions set out in Chapter 3. The complementarity of the methods also provided a way of enhancing my interpretation of what I witnessed, but less as a means of triangulation (in the sense of confirming the accuracy of my analyses) than of pluralization: a way of incorporating the breadth of understandings of the phenomena in question and to avoid reifying any one perspective as definitive—including my own.

Empirical work

As noted above, my exposure to the field began at the same time as my initial review of the literature. Consequently I was already forming an emergent understanding of the empirical field before formulating my research questions, and so the former, along with the literature, informed the latter. Figure 3 details the timing of my empirical work. From start to finish, it took place over almost three years, though as the figure illustrates, the most intensive work was done between mid-2006 and mid-2007. I attended national-level meetings from early 2005; interviews and attendance at local-level meetings started around a year later, as I wished to complete my literature review and preparations, and also due to the need for site-level research-governance clearance.

In all, I conducted 28 interviews on user involvement (12 with involved users, five with representatives of Macmillan, four with user-involvement leads, and seven follow-up interviews with users still engaged with the programme at the end) and attended 39 meetings (21 at pilot level,18 at programme level). Table 2 gives some more details on this empirical work. Additionally, from the four cancer-genetics case-study sites selected for the external evaluation, a further 28 interviews with pilot staff (20 of which I conducted) also contained material pertaining to user involvement. Interviews with involved users lasted between 35 minutes and over three hours; interviews with Macmillan and pilot staff were from 50 minutes to two hours.

The sample did not quite conform to my plans. Notable, for example, is the fact that in three sites, I did not carry out an interview devoted solely to user involvement with the user-involvement lead. This was because in sites which were also case studies for the external evaluation, it seemed too much of a burden to demand an extra interview of user-involvement leads, who were also interviewed between one and three times for the evaluation. (The exception to this was Site D, where the user-involvement lead's sole work on the pilot was organizing user involvement.) The breadth of perspectives, deriving from sections of interviews relating to user involvement from various different practitioners in these sites, did not fulfil the same function as an in-depth interview with one individual, but did at least offer an interesting alternative.

More problematically, I was not able to interview every involved user in all of the projects. Some had had only very brief involvement with their pilot, and our paths never overlapped at local meetings. Others (Chunna and Fred) I met at local or national meetings, but did not manage to interview. This resulted from the way I went about obtaining interviews, which with hindsight was perhaps overcautious. With a view to making them as useful as possible, I did not request interviews with involved users until I had got to know them reasonably well from local or national meetings. This enabled me to ground our conversations in the events of such meetings, and also meant that rapport was more-or-less achieved even before the interview began. I found that this resulted in productive, insightful interviews, often emotionally involved, and frequently quite lengthy, as Table 2 illustrates. This helped to bring out the complicated ways in which, for example, motivation tied into personal biography. The downside was that I missed the opportunity to interview Chunna and Fred, both of whom had agreed in principle to interview, but subsequently ended their involvement with the programme before we could fix a date (subsequent contact seemed inappropriate in the case of Chunna, who had withdrawn for unspecified personal reasons, and did not succeed in obtaining an interview with Fred, who had returned to full-time employment).

The great variation in length of interviews, between and within the three groups of respondents, related partly to the degree of rapport established beforehand, but also, of course, to the substance of the interviews. It was clear that for some involved users, motivations and actions in user involvement were inextricably linked to (their narratives about) their prior biographies. Others spoke relatively briefly about their backgrounds, though even in these cases, they often related their reasons for becoming involved to specific prior events or general prior dispositions. Interviews with pilot and Macmillan staff were naturally less personal in nature, and were carried out predominantly in places of work, whereas most interviews with users took place in their own homes.

Each of the involved users I encountered is given a pseudonym (see Table 2: for the reader's convenience, these have been selected to correspond to the site labels A-G, with the 'national-level', experienced involved users who attended the NURG given names beginning with H), while Macmillan and pilot staff are referred to by a brief professional designation. Given the focus of this thesis, I considered it helpful to be able to trace certain narratives around individual users through the empirical chapters, so that the reader might see how their experiences and utterances tie together across themes. Those involved from Macmillan, on the other hand, are referred to only as Macmillan respondents 1-5 (MR1-5), since any label identifying professional role would risk undoing the anonymity of the members of such a small group. One possible risk of this approach to representation is that where we see individual particularity among the named involved users, Macmillan and its staff appear as something of a monolithic entity. This was not the case, and I hope that the heterogeneity of Macmillan's approach to involvement is evident, for example in Chapter 9. Follow-up interviews were obtained with users who were still involved at a local and/or national level towards the end of the pilot period. These interviews took place around 18 months after their initial interviews, and included reflections on the process in general, as well as discussion about specific eventualities I had observed over the course of the programme.

Interviews were all digitally audio-recorded, with the exception of the interview with Emily, where recording failed.[2] I transcribed the 28 interviews conducted specifically for this study in their entirety; interviews conducted for the evaluation were transcribed in their entirety by a third party.

From Figure 3, it may be noted that the numbers of meetings observed in the pilot sites varied significantly. This was due to a combination of factors. The amount of time taken for research-governance approval by different NHS organizations was variable, so I could attend meetings as a researcher much later in some than others. Frequency of steering-group and project-group meetings also varied: in Site G, project-group meetings were monthly, while in Site A, steering-group meetings were supposed to take place quarterly, but staffing difficulties resulted in numerous cancellations, and consequently I was able to attend only one, final, meeting. The nature of the meetings which formed the principal outlet for user involvement was divergent, too. In Sites C and G, involvement was incorporated into project-group meetings, which involved core staff associated with the management and delivery of the pilots. In Sites A, D and E, there was user involvement in steering-group meetings, involving not only core staff but also wider stakeholders, such as strategic managers from the PCT, or representatives of other stakeholder groups (such as local GPs). In Sites B and F, there were separate meetings for involved users, facilitated by the user-involvement lead, who would be the only staff member present. However, in Site B, by the time the (very slow) research-governance process was complete, I was informed by the user-involvement lead that user involvement had been suspended, and that there would be no more meetings of the group until further notice. The descriptions of user involvement in Site B that I obtained from the user-involvement lead and the involved user, though rich, seemed no

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[2] Fortunately I realized this immediately after the interview, and was able to dictate everything I could remember into the audio recorder (totalling over half an hour of, admittedly slightly repetitious, monologue, for an interview which only lasted 55 minutes!).

substitute for witnessing these meetings firsthand.

As a member of the external-evaluation team, official documents from the programme—bids, progress reports, internal-evaluation reports, 'narratives' compiled by Macmillan from the discussions that took place at NURG meetings—were forwarded to me as a matter of course, and I also obtained official minutes of meetings I attended, where available. My reading and analysis of these took different forms according to the nature of the document in question. Quarterly progress reports and official minutes, which as might be imagined were copious in volume, I read upon receipt and then filed, but did not subject to detailed analysis. This, then, was more a part of the 'acclimatizing' process, contributing to my tacit understanding of what was taking place, rather than 'proper', canonical, analysis. Bids, reports and narratives I read upon receipt, and then reread attentively in the course of my more rigorous analysis of observation notes and interview transcripts, which I describe in the next section.

Interpretation, analysis, presentation

A number of recent commentators have highlighted the mystical tenor of much qualitative reportage. It remains a closed black box, and at best, we are told that themes 'emerged' from the data during this rigorous intellectual endeavour. In Hammersley and Atkinson's (1995: 209) words,

> the development of analytical categories and models has often been treated as a mysterious process about which little can be said and no guidance given. One must simply wait on the theoretical muse.

Correspondingly, there have been calls for a much more explicit rendering of this process, paying more attention to its practicalities, for example the iterative process of reading and rereading, identifying key concepts, finding inconsistencies, constructing better interpretations, and building a range of concrete and analytical categories or themes (Hammersley & Atkinson, 1995).

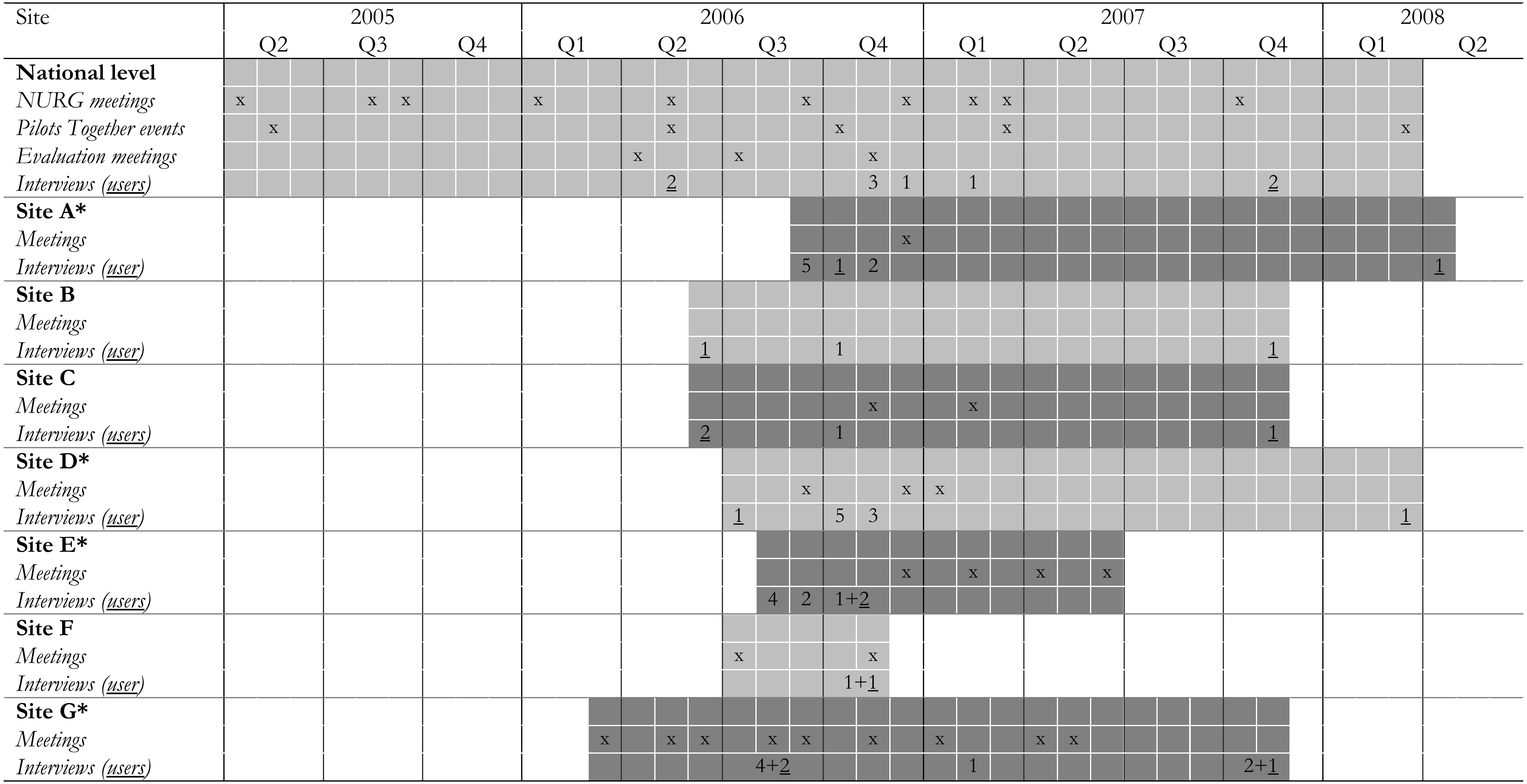
As already indicated, I fully accept the need for proper documentation of the research and analysis process, as a key means of evidencing the integrity of work and thereby fostering trust. However, I must also admit to harbouring certain doubts about how far the full, embodied experience of the analysis process can be reproduced in a step-by-step description—at least one that does it any justice. This is not because there is any magic to the analytical process, but rather because, in my experience at least, analysis is not confined to a rational, stepwise process, and cannot be rationalized as such. Even if the researcher subjects the data to an ordered, iterative analysis, this is not the only or even necessarily the primary means by which key insights develop. To relate an account of the interpretation and analysis of data that limits itself to the ordered and rational, then, is just as unhelpful and spurious as descriptions that speak in the abstract terms of 'emerging' themes. Here, then, I describe my formal approach to analysis, but highlight also the more subjective dimensions to my understanding and interpretation of the data, even as these defy any satisfactory explicit articulation.

On a formal level, my analysis took just the kind of approach described by Hammersley and Atkinson (1995) above. Using the computer-assisted qualitative data analysis programme NVivo 7 to assist me, I read and reread transcripts, meeting notes and some of the official documents (as indicated in the previous section), and coded these in categories derived from both the literature and my reading of the data. I organized transcripts and other data sources by respondent group (involved user, pilot staff, Macmillan staff) and site, in order to facilitate an understanding of differences of perspective between groups and differences of approach to involvement between sites. After some refinement and reordering of my categories ('nodes' in NVivo parlance), I ended up with 58 of these, containing between three and (exactly) 300 coded excerpts ('references') from the data sources. I then looked at these categories one by one, effectively exposing me to the data as organized on a thematic, rather than individual, group or site, basis. Following a limited amount of further revision and rationalization of categories, I wrote a summary of each, to assist my own thought processes and ensure that I had a coherent written analysis, rather than just the assemblies of loosely connected data excerpts that NVivo nodes represented. From these summaries, I subsequently worked up a structure for the thesis, deciding how categories related to one another and working out a representational strategy that would marry comprehensibility with integrity. The seven follow-up interviews with involved users, and the last two national-level meetings, were exceptions to this process. Data from the two meetings were added to the NVivo-aided analysis *post hoc*, rather than being drawn upon in the analytical development process. The follow-up interviews were subjected to a somewhat 'lighter-touch' process, involving the identification and analysis of sections relevant to the existing analysis.

That was the formal analysis process, and I should stress that it was intensive and extensive, carried out over many months. However, my understanding, interpretation and analysis of the data were not confined to this process. In practice, analysis starts in the field, and is only finalized (even then in an arguably provisional form) when the final draft is complete. Subjective immersion in the field informed my understanding of 'the data'—meaning, in Glaser's (2001: 145; quoted in Glaser, 2002: para.1) sense, "not only what is being told, how it is being told and the conditions of its being told, but also all the data surrounding what is being told." These 'meta-data' were to some extent encoded in my notes, but were also important on a more tacit level. Listening to and transcribing interviews, and typing field notes following lengthy meetings, planted analytical kernels which grew to inform my ongoing thinking. A fieldwork diary, kept intermittently during my exposure to the pilot programme, allowed me to note developing insights which were the product of particular moments of experience in the field, or came from reading, by chance, items from the literature that gave rise to a different perspective on an interview encounter. To reassure myself, and my supervisors, that my fieldwork was giving rise to a coherent set of ideas that might form the basis of a thesis, I also put together two documents on the key themes arising from my work, late in 2006 and early in 2007.

These various modes of apprehending and managing my work, then, took place ahead of and alongside my more formal engagement with the data, and inevitably influenced it. Of course, no researcher enters an analysis process from a position of complete neutrality, and arguably this would represent rather an undesirable model. It is, though, important to acknowledge the multifaceted nature of the process as it occurs, even if the full detail is elusive. In Figure 4, I try to depict how the different strands of my thinking contributed to my understanding, and how this fed into the representation of my work in this document.

Beyond the analysis process, there is also the question of what is presented in reporting the research. Clearly this is guided by the analysis, but there are also evidently other concerns: there is a need, for example, for a 'storyline' that is engaging and in some way novel, since originality is an explicit criterion used in assessing the worth of research by editors of publications and examiners of theses. Whilst not necessarily opposed to other criteria of quality—such as perceived strength of evidence, for instance—concern for originality will inevitably temper the choice of material to present. In presenting my findings here, I aim to strike a compromise, between (i) the need to foster a narrative that is compelling and comprehensible, without obscuring the 'messiness' and ambiguity of the field and the data, (ii) the need to highlight what is distinctive about the field and my findings, and (iii) the need to ensure that all I say is grounded in a robust and defensible analysis of the data. With the aim of reconciling readability, analytical robustness and coherence, the following five chapters trace something of a temporal narrative from the beginnings of involvement in the programme through to its outcomes at pilot and programme levels. Each chapter, though, also has a distinctive thematic focus, from the motivations and preconceptions about involvement in Chapter 6, through the deliberations and negotiations at different levels covered in Chapters 7 and 8, to the efforts at realizing partnership covered in Chapter 9, and the interrelationship between micro- and macro-level factors that gave rise to the outcomes described in Chapter 10. These themes are discussed in some depth at the end of each empirical chapter, and then in Chapter 11, I bring some of them together in an overall discussion of the research questions put forward at the end of Chapter 3. Finally, the Conclusion revisits and reiterates the key points made in Chapters 6-11.



Site	2005									2006												2007												2008					
	Q2			Q3			Q4			Q1			Q2			Q3			Q4			Q1			Q2			Q3			Q4			Q1			Q2		
National level																																							
NURG meetings	x				x	x				x				x				x			x		x	x							x								
Pilots Together events		x												x					x					x												x			
Evaluation meetings													x			x				x																			
Interviews (users)														2						3	1		1									2							
Site A*																																							
Meetings																					x																		
Interviews (user)																		5	1	2																	1		
Site B																																							
Meetings																																							
Interviews (user)															1				1													1							
Site C																																							
Meetings																				x			x																
Interviews (users)															2				1													1							
Site D*																																							
Meetings																		x			x	x																	
Interviews (user)																1			5	3																1			
Site E*																																							
Meetings																					x		x		x		x												
Interviews (users)																	4	2	1+2																				
Site F																																							
Meetings																x				x																			
Interviews (user)																				1+1																			
Site G*																																							
Meetings												x		x	x		x	x		x		x			x	x													
Interviews (users)																	4+2						1									2+1							

*Case-study site in the external evaluation. Figures given for interviews include those with staff carried out for the wider evaluation which included material on user involvement.

Figure 3: Fieldwork timeline

Site	Staff interviewed*	Involved users			
		Encountered	Sex	Interview date (length hrs:mins)	Follow-up interview date (length)
National level	**Macmillan respondents 1-5**	'Harry'	M	05/2006 (2:55)	11/2007 (1:20)
		'Helen'	F	05/2006 (3:40)	11/2007 (1:05)
Site A	Clinical geneticist; manager; nurse/user-involvement lead; nurse; genetic counsellor; surgeon; oncologist	'Ava'	F	10/2006 (3:10)	04/2008 (1:00)
Site B	**Administrator/user-involvement lead**	'Betty'	F	06/2006 (1:35)	11/2007 (0:45)
Site C	**Nurse/user-involvement lead**	'Chanan'	F	06/2006 (0:35)	-
		'Chris'	F	06/2006 (1:25)	11/2007 (1:00)
		'Chunna'	F	-	-
Site D	**Genetic counsellor/user-involvement lead**; two clinical geneticists; cancer geneticist; genetic counsellor; two nurses; administrator	'Dawn'	F	07/2006 (1:55)	03/2008 (0:45)
Site E	Nurse/user-involvement lead; four nurses; manager; genetic counsellor	'Emily'	F	10/2006 (0:55)	-
		'Emma'	F	10/2006 (1:00)	-
Site F	**Nurse/user-involvement lead**	'Fiona'	F	11/2006 (1:05)	-
		'Fred'	M	-	-
Site G	Nurse/user-involvement lead (two interviews); service manager (two interviews); strategic manager; data analyst; GP	'Gayle'	F	08/2006 (1:50)	11/2007 (0:45)
		'Gemma'	F	08/2006 (1:15)	-

*Interviews pertaining solely to user involvement are given in bold; those from the wider evaluation containing relevant material are in normal type.

Table 2: Summary of interviews and characteristics of interviewee by site

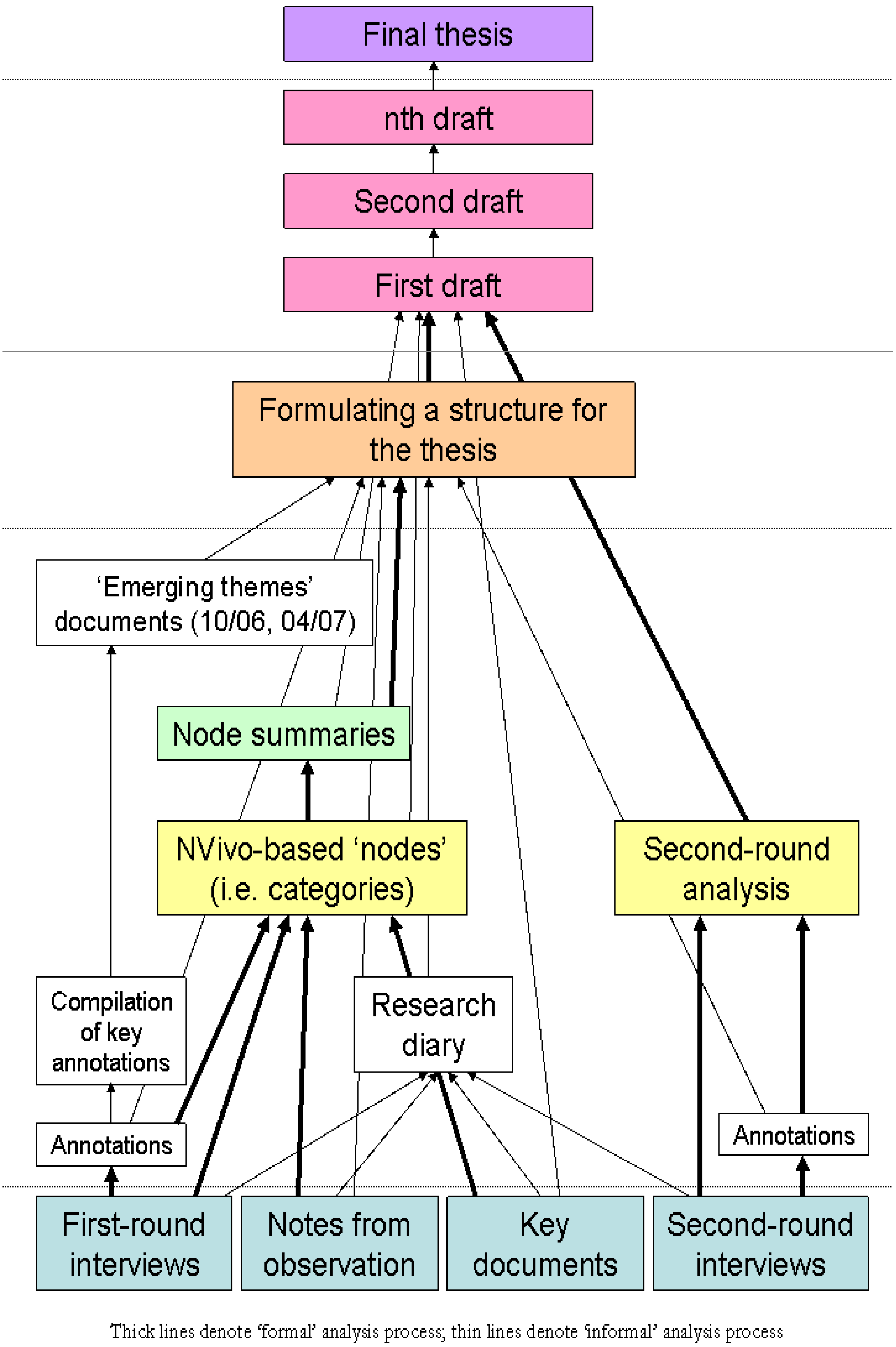


Figure 4: The analysis process

6.

GETTING INVOLVEMENT GOING: MOTIVATIONS, RATIONALES AND RECRUITMENT[1]

This chapter considers the foundations of user involvement in the cancer-genetics programme. From the perspectives of Macmillan as the organization co-ordinating the programme, the pilot staff as those charged with involving users in their projects, and the users themselves as those filling the roles, what was the purpose of involvement, and what did they want to get out of it? As seen in Chapter 4, in a very general sense, the reasons for doing user involvement appeared self-evident. User involvement is *de rigeur* in NHS service development, and NHS organizations are obliged to involve patients and the public in service reconfiguration; the Kenilworth model had at its core an ambition to make the cancer-genetic care pathway more ‘patient centred’; and Macmillan as an organization was seeking increasingly to amplify ‘the ‘voices’ of users in relation to the cancer experience. As we will see, these generalities hid a degree

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[1] Some of the data reported in this chapter are included in ‘Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements’, *Critical Public Health* (in press) (Martin, 2009c).

of ambiguity and even confusion in the detail. There was general consensus, on a rhetorical level at least, that involvement was worthwhile, but in relation to the question of exactly what it should achieve, there was a good deal of uncertainty. Hard work on the part of pilot staff to get involvement up and running, and strong motivations for participation on the part of involved users, did not translate into the early establishment of a commonly agreed aim for involvement. Rather, what was apparent, at least at first, was inertia, with both staff and users reluctant or unable to determine a productive role for user involvement. This 'implementation gap', as I call it, seemed in part to arise from the expectation that the role for involvement be determined locally. The 'good thing' of user involvement is an even better thing if it grows organically and locally, through collaborative partnership responding to local needs. But given discrepancies in the visions for involvement held by users and staff that were already becoming apparent, the agency to develop involvement from below was lacking. The overview presented here provides the underpinning for more detailed discussion of these issues—the implementation gap, the discrepancies of vision, the parameters set by normative user-involvement discourse—among others in the chapters that follow.

Rationales for user involvement

First, then, we consider the rationales for user involvement articulated by Macmillan as the 'driving force' behind involvement, and the professionals charged with implementing it. This leads into discussion of how these rationales, with other pragmatic concerns, guided pilots' recruitment processes. Following this, we consider this question from the users' perspective, in relation to their motivations for becoming involved and how these related to the rationales put forward by Macmillan and the pilots.

Macmillan's rationale for user involvement

As noted in Chapter 4, at the time of the fieldwork Macmillan was seeking to reorient itself somewhat, to become more closely aligned with the interests and views of service users. As one Macmillan respondent put it, Macmillan remained professionally led, but sought to open itself to input from patients and carers, to give their concerns voice. As the emphasis of the organization's work shifted from the funding of individual GPs and nurses towards more wholesale influence of systems of care, so this patient input was seen in Macmillan as increasingly important. A focus on "the totality of the journey, […] through primary care, secondary care, specialist care" meant that "we're interested in their whole experience of cancer" (Macmillan respondent 1). The logic, then, of Macmillan's emerging mission—to contribute to organizational development in the NHS and other agencies in pursuit of coherent, joined-up care pathways—was greater input from the user, whose experience was the ultimate arbiter of its success.

Essentially, then, the contribution of user involvement was to be the contribution of "people affected by cancer," premised on their experiential knowledge of the good and bad aspects of service provision: "today's experience influencing tomorrow's planning," as Macmillan respondent 1 had it. Though prominent, however, the utility of experiential knowledge was just one among a cluster of justifications put forward by Macmillan. The wider skills that users might contribute were also implicated in these rationales, as considered in later chapters. In particular, moreover, Macmillan was highly conscious of the political currency of user involvement, both in terms of its own standing with the public, the NHS and the government, and for the pilots themselves. By seeking to give voice to patients and carers, Macmillan could itself become that voice, at a time when the legitimacy accorded to users' perspectives was increasing. Macmillan saw a similar instrumental potential for the pilots it sponsored to 'utilize' user involvement in this way, as a means, for example, of gaining leverage with commissioners. Drawn upon in this way, user involvement could be a "powerful tactical instrument, as well as just being the right thing to do" (MR1).

With this dual utility, as a means of service improvement and a political tool in the sustainability of pilots, Macmillan sought to sell the virtues of user involvement to the pilots. From an early stage, it was made clear to pilots that they were expected to take involvement seriously, and devote as much effort as necessary to establishing user-involvement processes in their sites. As already detailed, this encompassed quarterly reports, the designation of 'user-involvement leads' among pilot staff, and the NURG meetings for users themselves. In pursuing each of these activities, however, Macmillan was keen not to impose a format for user involvement. Rather, "the ethos behind Macmillan is that we *advocate* that people do user involvement, but we don't *dictate* […] what it looks like" (Macmillan respondent 2). On the face of it, the rationale for this was straightforward: if user involvement was to be effective in relating the experience of patients and carers of the services they had encountered, then it needed to fit the local organizational set-up for service development. This was also in keeping with the emerging wider *modus operandi* of Macmillan, as an organization which saw its role as one of 'steering' service provision through influence on an increasingly fragmented NHS governance, less subject to top-down direction:

> "Areas and regions have a different set of dynamics, they have a different set of needs, they've already got things in operation. Who are we to say, 'Start again and do it all our way'? That's just not what Macmillan's about; it's this whole partnership thing. It's providing support to people, groups, to involve, develop, strengthen, in a way that's meaningful to them, and then there's some ownership." (MR2)

In this organizational context, Macmillan recognized involvement as something that was better achieved through lateral influence than didactic instruction.

Moreover, there was a sense for Macmillan respondents in which any attempt to impose a user-involvement process on pilots would undermine the very ethos that this 'partnership working' relied upon: collaboration based on mutual respect and recognition of the complementarity of each party's contribution. This reflected wider Macmillan policy on partnership working, "where patients, carers and health professionals work collaboratively to bring about tangible service improvements. […] [This] requires a clear understanding of what is meant by partnership working by all those participating in it" (Macmillan, 2005: 4). This in turn echoed academic definitions of partnership as requiring "similar status, shared power and some equality of influence over both the agenda and outcomes of shared decision making" (Chadderton, 1995; quoted by Rutter *et al.*, 2004: 1974). A collaborative, partnership-based approach to involvement thus required the active engagement of staff to succeed: an engagement premised on recognition of its potential rather than on obligation.

In short, for Macmillan the form taken by involvement was to be influenced rather than imposed. In later chapters we explore some of the tensions that arose from these normative expectations about user involvement. For now, it suffices to note that beyond the general direction that involvement should make a contribution to service provision and could provide political leverage, the detailed role of users was left to pilots to determine.

Pilots' rationales and the recruitment of involved users

In the main, staff involved with the pilots—even those designated by their colleagues as 'user-involvement leads'—had little past experience of involvement. However, they were well versed in overarching rationales, and subscribed to the principle that user input was important to ensuring appropriate provision and assisting with improvements. On this rhetorical level, the purposes envisaged by pilot staff were largely in line with the experiential rationale put forward by Macmillan, with users able to offer a contribution based on their identity and experience as 'people affected by cancer'.

Whether such generalized acceptance of user involvement as a 'good thing' would have been enough to see pilots establish user-involvement processes without the push from Macmillan is questionable. Certainly in some cases, the main impetus to recruitment of involved users was Macmillan's mandate, translated into a responsibility of the site's designated user-involvement lead:

> "It's a very important part of Macmillan's work, and something that we were expected to do was set up a user group, and that was part of my job description. Also it's a government initiative to get users more involved in everything, so it was felt it would be helpful if I did it here." (User-involvement lead, Site B)

Pilots quickly found that recruiting users could be an arduous, time-consuming process, and one which they had to accomplish alongside the many other time-consuming tasks involved in setting up new services. There was also the question of exactly who these users should be. It was in relation to their experiential knowledge that staff saw most potential for involved users, but as new pilots, the services by definition did not have past patients in the narrowest sense. Some user-involvement leads sensed a lack of direction from Macmillan on this question, too: "I've felt quite alone on that front, really" (User-involvement lead, Site F).

These three factors—the lack of direction about the 'population' from which involved users should be drawn, the protracted nature of the recruitment process in the face of other pressing priorities, and the need to set up involvement of some kind to comply with Macmillan's expectations—combined in most sites to result in recruitment that was driven more by pragmatism than by a clear rationale. Staff cast their nets wide in the hope of finding anyone willing to become involved. Variously, those recruited as involved users included past cancer-genetic patients accessed via local clinical-genetics departments, past non-genetic cancer patients accessed via oncology departments' and cancer networks' existing PPI groups, individuals who responded to advertisements in local NHS publications, individuals involved in associated voluntary activities such as local cancer charities, and laypeople known to staff as interested, willing and able to become involved.

With this heterogeneity, and ambivalence about what exactly constituted appropriate identity for a productive contribution to user involvement, specific roles became a matter of *post hoc* determination. As we see later, this resulted in conflict as users and staff negotiated the role for involvement; for the moment, though, this situation was satisfactory for staff, who had fulfilled their commitment to establishing involvement, and anticipated a loosely specified contribution from these loosely defined 'users':

> "Betty was the first user that we got on board—in fact she joined before I did—and she was involved in our group, but she has no genetic connection at all. And I know she feels a bit uncomfortable about that sometimes, because she doesn't feel that she's appropriately there. But actually, from our point of view, it's not that important—it's just having a user's perspective on the genetics service." (User-involvement lead, Site B)

There were two exceptions to this pragmatically driven recruitment process. In Site C, where a key emphasis was improving access for the underserved south Asian population, the user-involvement lead sought to supplement the first involved user, Chris (who was white and middle-class, and had become involved via her prior work with Cancerbackup, after the pilot approached the charity looking for interested parties to become involved users), with involved users from Asian backgrounds, eventually recruiting two who met this criterion. In Site G, the user-involvement lead was clear from the start about what she wanted from user involvement, and purposively approached two past patients, known to her from her previous work as a cancer nurse at a local hospital, whom she saw as having the necessary attributes for her plans. We consider both these sites in more detail later.

Just as Macmillan was staunchly non-directive about who to recruit for involvement, so it left the issues it was to cover to local determination. There were certain tasks that seemed obvious objects of user involvement, which users in all seven sites were asked to apply themselves to. These included checking information leaflets and publicity materials, and feeding back opinions on 'what patients would want' from service delivery, whether the users themselves had direct experience of service delivery or not. Beyond these, though, there was considerable mystification about exactly what involvement could achieve.

> "[We've done] very little. And that's the answer. Between me and you and the tape, I don't know: I don't know how to involve them, I don't know what to ask them to do and it's very difficult getting meetings between us."
>
> (User-involvement lead, Site C)

Staff, especially the user-involvement leads to whom responsibility had been delegated by their colleagues, relayed their concerns about the function of involvement to Macmillan. At the biannual Pilots Together events, involvement was repeatedly highlighted as a major concern by pilot staff. Macmillan agreed to hold two workshops for user-involvement leads, but once again, Macmillan staff were clear that this should be about general guidance—instilling the right attitude towards involvement—rather than about didactic instruction:

> "The discussion about how might it be useful was almost too far down the line, because they hadn't really got to grips with what it was and how it could manifest itself, and the length and breadth of it." (MR2)

User-involvement leads, however, were in the main seeking a more directive input about how to do it and what it could achieve:

> "It was very much an interactive group, and they wanted our ideas really. They didn't really give us much direction, I don't feel. They wanted the groups to run themselves, but I felt it would have been helpful to have more direction." (User-involvement lead, Site F)

Consequently, rather than acting as a knowledge-sharing event where good practice could flourish thanks to cross-pollination of ideas between sites, the workshops were more useful in demonstrating to user-involvement leads that they were not alone in their difficulties:

> "It was really helpful to talk to the leads from other pilots, and encouraging to know that we'd had the same sorts of thoughts—some of them had found it difficult to get users onboard, so I felt quite confident, I thought, 'Ooh yeah, we've done that!' But it was good to know that they struggled with the same things as me." (User-involvement lead, Site F)

In the majority of cases, then, the expectation that innovative user involvement might blossom from the local discretion granted by Macmillan was not realized in the efforts of staff—a trend exacerbated by the pragmatic, rather than principled, recruitment of users. The workshops for user-involvement leads reassured them that they were not alone in their mystification but did little to support the development of locally sensitive user involvement. For Macmillan, making involvement work seemed to be more a question of the pilot staff's agency than of providing templates or models for them to follow. The task was to create the right *mindset* among staff for accomplishing user involvement:

> "Not only is there not the understanding necessarily about how it can help, but also in some cases, there's a bit of trepidation about actually entering into a dialogue with somebody who has potentially got a terminal diagnosis,

> how you handle that. […] The dialogue needs to be person to person. That requires a change of mindset if you are a health-care professional." (MR2)

Only in this way, according to the Macmillan prescription, could involvement develop properly, with the necessary, voluntary investment from staff for it to achieve its potential. The main effort had to come from local-level practitioners; Macmillan could only support it. For those practitioners, however, this represented an abdication of responsibility with which they struggled to deal. Even some within Macmillan acknowledged that the expectations placed on pilot staff were heavy:

> "I had no previous experience of user involvement, so in a way, I can empathise with the projects, for the simple reason that they were in exactly the same boat: 'What the hell do we do with these people? OK, we gather them together, then what?' I mean, how many times can you go through a leaflet and a poster or a letter that's going out? […] That was one of the criticisms about the Kenilworth model, the fact that the whole thing about user involvement's very woolly." (Macmillan respondent 3)

In the spirit of partnership and collaboration, pilots looked instead to their newly recruited users to provide agency and direction to involvement. Despite the willingness they had shown in agreeing to become involved, however, we see in the next section that initially, these users were reluctant or unable to provide this.

Involved users' motivations

The difficulty faced by staff in finding individuals who were willing to become involved users suggests that such individuals were hard to find. Certainly, it was acknowledged by all parties—pilot staff, involved users themselves, and Macmillan—that there was something special about the individuals who agreed to become involved: they differed from the 'typical person on the street'. The consequences of this for the legitimacy of the role that users were to perform are considered in Chapter 8; for now, it suffices to acknowledge that, as Macmillan respondent 3 put it,

> "people who join the user group are there for their own, personal reasons. They want to make services better for other people, because perhaps either they've had a very good experience themselves, or they've had a very bad experience. There's nothing in between those two, really. But people join the user group because they do have their own personal agenda."

This view on the particularity and power of involved users' motivations was largely borne out in the views expressed by the users themselves. As we see in the next chapter, it was a recurrent topic of conversation at NURG meetings. And it was notable in the reasons given by users in interview for their decisions to become involved in the programme, especially those who had personal experience of inherited cancer, but also those with less direct reasons for participating.

In general terms, then, the reasons given by users for their involvement—retrospectively, of course—highlighted their agency and proactivity, and personal interests in cancer or genetics. Many related that their inclination towards involvement was something which marked them out from others: Fiona counted herself as "a certain sort of person who will do something" as opposed to the apathetic, uninterested majority, while for Chris it was "the way I've been brought up—my father was a local councillor—so I always had a feeling of being involved with the community." Simultaneously, there was acknowledgement that involvement of this kind offered a stimulating and productive way for this group to expend their energies. Gayle, for example, described involvement in the programme as giving her a "focus" of the kind that she had lost following medical retirement from the civil service, and contrasted the work to fundraising activities that might not offer the same kind of stimulation:

> "I do feel like it's something worthwhile; to me it's really worthwhile that

> I'm able to give back. […] I feel like I'm paying back, but in a way that's right for me."

Through this kind of activity, users expressed their desire to make a concrete difference to service provision. As we see below, this was often connected to a widespread dissatisfaction with the current state of cancer-genetics services.

A common theme in this motivation and disposition was the affective way in which experience of cancer or genetics had influenced users. Diagnosis with cancer was commonly constructed as a life-changing experience—a 'fateful moment' in Giddens' (1991) terms—prompting reflection and a desire to influence provision for the better. The implications of the genetic dimension to the diagnosis compounded this effect:

> "I've got family members that are affected by it and I know what it can do. So I would go out and embrace the actual project. Genetics, I've embraced because it's me, it's happened to me, and I think it's very important. And I think more and more people being aware that there is a genetic link to breast cancer and ovarian cancer, I think that people that have got a big history of cancers in their family should consider genetic testing." (Dawn)

In such accounts, the personal impact of a genetic diagnosis led into familial concerns about the implications for relatives, and from here into wider concerns still for others in similar positions. To some extent this rested on a commonality of material interests: involved users were happy to acknowledge, for example, that their motivation was in part the benefit of improved cancer-genetic services for themselves and their families. The motivation went beyond this, though, extending to an emotional commonality that could not be reduced to material interest, and which seemed most important in leading their motivation and the contribution they felt they could make through involvement:

> "I know friends who are in a similar situation, lost several members of their family, perhaps including their mother, and you want to help people to get

> the message out. It's a horrible thing to lose people young, and also the awful way—my mum had breast cancer which went to the bones, and it was hideous, it was so painful. And so if you can avoid that, this is surely the major thing that spurred me on." (Fiona)

Yet this kind of active response to such personal experiences, users recognized, was not universal: there was a difference, then, between them and others who might respond by seeking to put such experiences behind them, move on.

It was in this confluence of interest, personal experience and collective concern that involved users located their motivation, and the contribution their involvement could make. In Chapter 7 we explore how this identity and role were concretized, galvanized and normalized by users and Macmillan respondents at the regular NURG meetings. For now, we note that users were unabashed in proclaiming the personal basis of their motivation, but saw this as something that sat easily with making a contribution with a wider, collective benefit, at least for the community of interest of cancer-genetic patients, potential patients, and their families.

Users' experiences of NHS provision

An important component of the experiences that fed motivation was users' encounters with the NHS as they sought information on their condition, underwent diagnoses and received treatment. As noted in Chapter 4, it was acknowledgement of the deficiencies of the NHS's provision for cancer-genetic patients that had prompted the Harper Report, and the work of the DH and Macmillan in formulating the Kenilworth model. The experiences of several involved users reflected these deficiencies. Three linked aspects of existing provision caused them particular concern: the 'siloed' nature of services; the existence—indeed prevalence—of clinical practice that they regarded as poor; and the lack of uniformity and conformity to 'best practice' guidance.

Those users who had personal experience of inherited cancer had generally found their treatment by the NHS characterized by encounters with multiple specialists in different fields, communication between whom was often lacking. The result for the users as patients was incoherent or even inconsistent information on their conditions, and a sense that their passage through the system was unnecessarily protracted on account of the insularity of the fields. As a disease which frequently crosses the corporeal boundaries of medical specialities, there was a sense that this was characteristic of the experience of cancer patienthood in general. Further, users noted that the genetic aspect of their conditions exacerbated this, and many had found that mainstream oncologists were slow to invoke genetics as a possible cause, and therefore consider family histories or refer to genetics specialists.

The result, then, was poor practice, and for many users, this was more prevalent in some parts of the NHS than others. A common concern was the lack of awareness of genetic risk among primary-care practitioners, again evinced by personal experience in many cases. GPs, for example, as 'gatekeepers' to the health service, were seen as having a power over provision that was frequently not justified by their knowledge. The challenges faced by Dawn were not untypical:

> "I was looking at cancer in my family 25 years ago, and they were dying in succession, about the same age range. And I tried to get on the screening programme with my then GP, and he was quite dismissive, and said, 'Go away, you're too young to get cancer.' I made myself a bit of a burden, a nuisance, but I still didn't do anything. And then when he retired there was another GP, and she was more sympathetic, but it still took me a while to convince her."

These perceptions of poor practice were often founded on extensive personal research, and users found themselves vindicated in their self-diagnoses when eventually they gained access to specialist geneticists. Views about poor practice, then, were by no means anti-medical, but rather founded in personal research using conventionally medical sources of information (cf. Nettleton & Burrows, 2003), and affirmed by the knowledge of 'high experts' of medical knowledge, such as genetics consultants. Apparent in the discourse of many involved users was the perception of a hierarchy of knowledge, in which research-active clinical geneticists in teaching hospitals and 'centres of excellence' were at the apex, with district general hospitals rather less well viewed, and generalists in primary care seen as particularly lacking in the necessary knowledge to deal appropriately with comparatively rare cancer-genetic cases.

In this view of the health service, silos between specialities, sectors and organizations were seen to exacerbate the uneven spread of good practice, rendering lack of joined-up working, incoherence of information and inequalities of provision endemic. This lack of uniformity, and the apparent contentment of many practitioners to continue to practise within their silos, frustrated users:

> "National standards, shouldn't there be? There's [Site B] doing work, [another hospital] are doing work, [Site C] have got a registry, but they all seem to be, 'We do this, we do that'. If they'd all got together and said, 'Well here's a standard, here's what we say that really you should be looked after like'. […] It's professional pride." (Harry)

What this seemed to exemplify, moreover, was an understanding of medical knowledge as a relatively unitary corpus. 'Best practice' was for users an unproblematic notion; inconsistency of provision was a result of the failure of the health service to facilitate its spread, due to a combination of structural impediments, professional insularity on the part of potential 'recipients', and insufficient efforts on the part of the evangelizing 'high experts'.

Even as they were motivated by deficiencies in service provision, then, involved users were evidently not anti-medical in their orientation. Rather, they aligned themselves with the 'high expertise' of genetics specialists and were motivated by the opportunity to be involved in spreading knowledge to 'sub-expert' practitioners elsewhere in the system. To this extent, their concerns were similar to the Kenilworth model's take on knowledge sharing and joined-up provision throughout the patient pathway. Indeed, for many, faith in these objectives and in the ability of staff to achieve this kind of integration was itself a key reason for involvement:

> "[Site G lead nurse] gives above and beyond what her role is. And I thought, if she's in place in this service, if there's anything that I can do to promote her becoming involved with women, or guys, with whatever form of cancer, then that's got to be a positive thing." (Gemma)

Universality and particularity in motivation

The self-reported disposition of the involved users, and the specific experiences that prompted many to become involved, give some indication of the identity of this group as a whole. Rather than reflecting personal interests, involved users saw themselves as reflecting the views of a wider constituency, and especially those who might struggle in the face of the kinds of barriers to provision erected by the NHS that many had themselves experienced. As 'active citizens', willing and able to contribute to improvements in health-service provision, they constructed themselves as taking the opportunity presented to work towards improvements that would benefit all. In this sense, users saw themselves as the "people affected by cancer" who could perform the role envisaged by Macmillan by relaying their views on health-service delivery and how to improve it.

However, this collective identity of involved users, and even this motivation, were not unproblematic. The lengths to which many users had gone to obtain a cancer-genetic diagnosis seemed emblematic not just of their proactivity, but also of a more general rationalistic subjectivity, reflected for example in their desire to discover their own 'genetic fate', characterized in the literature in terms of biomedical or genetic citizenship (Novas & Rose, 2000; Rose & Novas, 2005). This is not a universal trait; indeed, the bioethics and medical-sociology literatures concern themselves as much with the right *not* to know one's genetic fate (Wilson, 2005), and with the diversity of responses exhibited by individuals faced with the possibility of being 'at risk' (Parsons & Atkinson, 1992; Hallowell & Lawton, 2002; Press *et al.*, 2005). Some users expressed their incomprehension of family members who displayed a rather different attitude towards risk assessment, preferring not to know their likelihood of developing cancer rather than acting positively to confront risk and deal with it accordingly. There was a sense in which for some users, the more proactive stance that they embodied was a behavioural prescription for others:

> Chanan: Some of them, they don't want to know anything about it. They think it won't come to them.
>
> Graham: What kind of people is it that think that?
>
> Chanan: It's really if they're not educated, they don't want to know anything about cancer. Some people even don't talk about that. My husband's like that, he'll turn over if there's anything like that.

To this extent, the well intended interests of involved users in, for example, improved information provision might be seen as a particular concern deriving from their own, active disposition, rather than reflecting a universal, common interest. Similarly, the concerns of users about the need to ensure the spread of knowledge across the NHS, reducing silos and improving the practice of primary-care gatekeepers, seem benign enough in themselves. However, such improvements are not cost-neutral, and to the extent that efforts to promote such change compete with other worthwhile priorities in the NHS, the motivations and interests of involved users might not be seen in the universal terms in which they constructed them. This 'voice' of people affected by cancer, then, was a particular one, however benign the intentions of involved users. We return to this issue in Chapter 8, in considering the claims to legitimacy made by involved users in seeking to gain influence.

The 'implementation gap'

Regardless of the universality or particularity of users' contribution, however, two characteristics of the users are notable: they had often been strong-willed and proactive in dealing with health-service professionals in their prior interactions as patients, and their views on the existing deficiencies of provision aligned snugly with the Kenilworth model. Yet just as professionals found it difficult to define a contribution for involvement early on, users too were initially unable to develop a clear role for themselves.

Again, it was apparent that users expected the impetus for this to come from elsewhere. This was understandable: for all their passion for improving services and ideas about what could be done, they had been invited to become involved by their pilots. User involvement, then, was driven by staff, not by users, and it was staff too who 'owned' the projects and their design, direction and implementation. Users recognized that to attempt unilaterally to assert a role for themselves in such circumstances would be unlikely to achieve success.

Through time, however, users realized that despite recruiting them, staff had few ideas about exactly what they had recruited them for. As already noted, in the absence of direction from Macmillan, staff increasingly looked to users themselves for suggestions about how they might contribute over and above the basic, and limited, work staff had given them, on feedback on service provision and checking information provision. Users offered tentative suggestions, but remained sensitive to the fact that these were not 'their' projects, and remained largely deferential in the roles they suggested. Moreover, they frequently found that despite the apparent openness of staff to ideas about involvement, there were certain unspoken boundaries of acceptability:

> Chris: [I want] to make sure that what I'm giving is what is needed.
>
> Graham: What is needed by? Professionals?
>
> Chris: Well yes, what they're looking for. […] They almost ended up turning around and saying, "If you don't play by our rules, we don't want you!" or, "If you don't know what our rules are going to be then we don't want you!" rather than doing it the other way, to say, "This'll be useful to us."

Concurrently, as discussed in Chapter 7, users were honing an increasingly vivid and expansive picture of what they could contribute. As we see in Chapters 8-10, in response to the challenge this started to imply to professional determination of the projects, pilot staff became rather clearer about what user involvement should and should not involve. Ironically, then, it was only when proactive, bottom-up work by users began to fill the 'implementation gap' that staff began themselves to determine a local interpretation of user involvement, reactively. In most sites (though with one notable exception), then, it was not a bottom-up partnership that emerged out of Macmillan's hands-off attempt to foster local innovation, but inertia—followed, as we shall see, by reaction to a form of innovation that threatened the existing order in which user involvement was a relatively marginal concern.

Summary and discussion

This chapter has described how user involvement started to develop, as a process mandated, but not directed, by Macmillan, and then operationalized by local pilots on a largely pragmatic basis. The notion of involvement put forward by Macmillan, as providing a useful contribution to service development based on the experiences of people affected by cancer, was one to which pilot staff were happy to subscribe. However, the lack of more concrete direction about who to recruit, how to recruit them and what to do meant that there was a good deal of looseness in how this abstract notion was implemented, and uncertainty on the part of pilot staff about what users could do beyond the most obvious activities. Meanwhile, those who agreed to become involved users often seemed driven by a strong set of views on the deficiencies and potentials of provision—though it should be stressed that such self-descriptions were made retrospectively, in the context of the developing collective vision of involvement described in the next chapter. Whatever their veracity, though, these views did not translate into a determining agency that could mould a clear role for user involvement. For the time being, users were hesitant to attempt to impose their own ideas about involvement in professionally owned projects into which they had been invited.

Of note here is the break between the abstract, and universally acceptable, notion of user involvement as a means by which the experience of 'people affected by cancer' can influence health-service delivery, and the difficulties faced in putting this into practice (cf. Fudge *et al.*, 2008). In part, this might be attributed to the difficulties faced by projects in recruiting users who had direct experience of their provision, an attribute that was by definition impossible for new pilots. However, there seemed to be more to this challenge. In itself, experience is a fairly limited contribution. It may suffice as a qualification for providing feedback to services on, for example, matters of patient satisfaction. However, as pilots were discovering, in the context of face-to-face *involvement* with users, who were to be treated as *partners* in service development, this role for experience did not go far. As a rationale, then, experience was only a starting point: a necessary but insufficient basis for involvement (cf. Davies *et al.*, 2006). And even then, it was loosely defined, as reflected in the variety of users recruited, with both direct and less direct experience of cancer, genetics and NHS provision. Broad conceptions of experience formed a consensual rationale, but no more than this: operationalization implied a wider set of skills and attributes. Respondents from Macmillan responsible for user involvement hinted at some of these, and involved users, constructing themselves as the active 'joiners' who had not only the experience but also the motivation and ability to draw on this productively, signalled the kinds of attributes that they felt they could embody in making the abstract, experiential rationale a concrete, effective technology of influence. As we saw, though, some of these attributes suggest a particularity of disposition and interest that defies the homogeneity suggested by the notion of 'people affected by cancer'. In the next two chapters, we will consider these issues in depth.

Also notable from this chapter is the emergence of an 'implementation gap' in user involvement, in which each of the three parties—Macmillan facilitators, pilot staff and involved users—expect the drive for involvement to come from the others. As we have seen, Macmillan saw its role in relation to user involvement, as with its role in NHS service development and innovation more generally, as one of steering: providing sufficient encouragement to enable these things to blossom locally, but avoiding the kind of top-down determination that might stifle novel interpretations of policy to meet local needs. In seeking to encourage 'partnerships' between staff and users, the need for this kind of approach was amplified. By definition, partnership relied on voluntarism and will from the partners; to impose 'partnership' would be to destroy the very virtues that permit it to thrive. However, whether it represented a principled preference for local determination, or, as some staff intimated, an abdication of responsibility, the result was, at first, inertia. Staff were unclear about what they wanted to achieve and how; users felt unable to impose their own interpretations of user involvement on professionally owned projects. Initially, then, partnership-based user involvement faced something of an *impasse*, lacking both the top-down direction and the bottom-up coordination and agency for its achievement.

The ambiguous space left by Macmillan for discretion in implementation, then, seemed to be a space of mystification, in which the lack of clear impetus from either 'partner' resulted in inaction. A connection might be made here to Exworthy and Powell's (2004; cf. Callaghan & Wistow, 2006) analysis which stresses that policy implementation at the local level relies as much on 'little windows' of common interest between local actors as on the 'big windows' created by policymakers. In Chapter 8, though, we see how this space of mystification was also a space of opportunity, as galvanized users sought to fill it with their own ideas about involvement in partnership. Chapters 9 and 10 track how this effort to fill this space, negotiated with staff, played out, resulting in a variety of local visions of 'partnership'.

The key point for the moment, though, is that the consensus around concepts such as the worth of user involvement, the rationale of experience and the need for partnership hid much ambiguity. The looseness of these notions allowed different groups to attach to them rather divergent meanings, whilst retaining a discursive unity. The initial outcome was an implementation gap that resulted from various factors, notably the marginality of involvement to professional concerns and the reluctance of relatively powerless users to attempt to impose their own views. In the following chapters, we watch as this gap is closed.

7.

DEVELOPING AN INVOLVED-USER IDENTITY

As Chapter 6 illustrated, evident in the pilot sites early on was an 'implementation gap', whereby the unwillingness or inability of Macmillan, pilot staff and users to dictate the form of involvement gave it a peripheral role. The obvious functions which pilots did identify for users—providing feedback on service provision and checking literature for patients—were limited, both in their scope (relative to the potential anticipated by users) and in the amount of time they took. The discourse of 'partnership' propounded by Macmillan, however, insisted that users be involved on an ongoing basis in pilots' work; and to reiterate the point made by one Macmillan respondent quoted in the last chapter, "How many times can you go through a leaflet and a poster or a letter?" There was a sense on all sides that user involvement needed to do more to be sustained in the long run.

From the start of the programme, Macmillan hosted regular meetings of the National User Reference Group, intended to support users, give them opportunities to share ideas to bolster their influence within the pilots, and provide a programme-level role for involvement. According to the NURG's own final report, its role was

> to support and empower [users] to be able to work confidently within their local pilot project teams. By exchanging updates on their own involvement and discussing ways to help each other by sharing ideas, the users grew in confidence and enhanced the work of their pilots.

At the same time as negotiations about the role of involvement locally were occurring, then, users were also meeting at the NURG every three or four months. This provided a "safe atmosphere," as Macmillan respondent 4 described it at one of the meetings, in which only users and Macmillan staff were generally present. Through time, users built on their declared personal motivations to arrive at a collective image of who they were and what they could do. This offered an increasingly coherent rationale for a more extensive role within the pilots.

What this chapter tracks, then, is the development of a collective 'user voice' through the deliberations of the NURG meetings. For reasons noted in Chapter 6, Macmillan was keen to facilitate the articulation of this voice, in line with its organizational remit and views on the political efficacy of involvement. It was therefore active in helping to form this voice, in rendering it more eloquent, and in making it heard. Past research has identified the ways in which managers and organizations seek to co-opt user involvement to their own managerialist intentions. My analysis suggests that the process here was rather more subtle, involving the emergence of a confluence of interests. The model of user involvement produced through this process was something to which both parties could subscribe. However, what was also evident was that in a setting in which collective identity and purpose were built on the collective experiences and emotional ties of the participants, those who did not share these commonalities were left somewhat marginal. The consensus that emerged was one that was less the result of stepwise, iterative, rational debate, and more of a collaborative communicative endeavour in which the contributions of Macmillan staff and those of (certain) users were difficult to separate. The 'user voice' that emerged was thus one with certain exclusive overtones, although as we see in this chapter and those that follow, it was broad enough to command assent from most parties, including pilot staff, and to contain differences of interpretation that required negotiation only when users attempted to enact the role it prescribed in their pilots.

Identity formation in the NURG

I first attended a NURG meeting in April 2005, the second of 11 that took place over the course of the programme. At this point, the group was still nascent: many members who would become regulars had yet to join, others present ceased to attend later on, and the *raison d'être* of the group was still somewhat undetermined. Through time, the membership of the group stabilized, and a format to proceedings emerged. Commonly the first halves of the (day-long) meetings were spent on updates from users on the progress of the pilots and of user involvement within them, with the afternoons devoted to various group activities. These included specific tasks relating to involvement in the programme, and reflective discussions on the users' motivations, roles and contributions, which were recorded by one Macmillan respondent in order to compose 'narratives' about the users and their work. Ostensibly, these narratives were written both in order to evidence the contributions that users made, and as a means of demonstrating to reticent pilot staff the potential utility of involvement. Besides this dual instrumental purpose, though, the discussions also provided the users with an opportunity to consider the question of their purpose for themselves, and converge upon an understanding of who they were and what they did. This process, then, was a crucial means of constructing an identity, and declaring it to others and to themselves.

Open discussion and the reflexive exploration of individuals' backgrounds, motives and contributions were thus formalized within the group, and it was clear from observing the NURG in action and speaking to its participants that the narrative work was as important to its emergent identity as the substantive tasks it was given. These tasks gave the group a sense of purpose, but the coherence of this was founded in the collective identity developed through the interpersonal discussions taking place in parallel. In interview, Ava reflected on the interdependence between the discussions that took place at the NURG meetings and the more focused, task-oriented work:

> "We were just turning up and talking about what was going on in the project, which actually is not what we were there for. And then [MR1] gave us the Kenilworth model to [consider from the user's perspective]: well, now we knew what we had to do. So it was a bit of a learning experience for them, I think, on how to use such a group. In a way it was set up too early. […] On the other hand it did work to our advantage, in that we're all very good friends now."

As discussed in Chapter 6, lack of clarity from pilot staff left many users wondering exactly what they were supposed to be doing. At the NURG meetings, as Macmillan intended, users gained confidence in the legitimacy of the contribution they sought to make as they saw others in similar positions, and learn from those who had made headway with their pilots. Thus, as Macmillan respondent 5 put it, "they get a feeling that it's perfectly legitimate to express a certain point of view, or suggest such-and-such to their pilot project."

Crucially, though, the connections made between participants were not just about assisting each other in effecting user involvement in the pilot sites. The informal discussions went much deeper than this, allowing emotional bonds and friendships to blossom. Several users and Macmillan staff related to me that although not formed for this purpose, the NURG doubled up as a support group, at which users discussed matters relating not only to their involvement, but also to their families, diagnoses, dealings with the NHS and so on. Chapter 6 explored the importance of these matters to users' motivations for involvement and the contributions they saw themselves offering, and this centrality was fortified in their discussions at the NURG. Gayle described how she and Gemma, the other user from Site G, became close after attending their first NURG meeting together (the third such meeting overall), at which the first 'narrative discussion' took place:

> "We didn't know anything about each other, and as soon as we got there, they asked us to share our experiences, and it was weird because we didn't know what each other was going to come up with: we'd be learning. So going back on the train—'cause I mean going down we probably just had chit-chat—going back on the train we were really, really able to open up. So for us, this has brought us together."

It was on the basis of these kinds of deeply felt bonds that interaction at the NURG was facilitated. More than this, though, these bonds set the discursive boundaries for the NURG meetings, and consequently not only *facilitated* communication, but were themselves implicated in the *substance* of that communication (cf. Barnes, 2004). Regardless of the subject matter, users tended to speak in emotive, personal terms about the matters in hand, relating personal experience and offering words of support and affirmation to each other. United by common experiences, and faced with certain common challenges—in particular, the intransigence of pilot staff in efforts to increase involvement locally—the users shared stories, offered each other tips, and formed an increasingly coherent sense of 'us' and 'them'. Thus the group became predisposed to consensus and unison.

The boundaries of discourse within the NURG, then, were governed by personal and often emotional connections based on the totality of experiences and character traits of its participants. In their local sites, users found themselves in preformed teams with clearly bounded professional roles, and their own participation governed by their status as involved users (see Chapter 10). In the NURG, however, a much less clearly defined and unpreformed set of roles, and the unconstrained relationships that arose from this, allowed users to behave as individuals, with no artificial boundary between a narrowly specified role as involved user and wider experiences, backgrounds and identities. Macmillan respondent 3 put it thus:

> MR3: We go because we have to. But with the users, it's personal.
>
> Graham: Yeah so it's a different kind of … motivation.
>
> MR3: That's right. They use it as an opportunity to catch up with each other: where they are with their conditions or their children or grandchildren. [Harry] was saying when we met up the other day, "It's a year since my son got married." And the whole thing with the [running jokes]. You just would never get away with that in a business meeting, you wouldn't be going round the table and finding out how everybody's kids are. It just doesn't happen.

Through time, this way of relating to each other at the NURG meetings was increasingly normalized, a 'negotiated order' (Strauss *et al.*, 1963) in the absence of ground rules. However, not all involved users subscribed to these discursive norms. Fred only ever attended local meetings within Site F, avoiding NURG meetings after hearing about this 'support-group' ethos. Betty attended a few NURG meetings, but found herself alienated by what she perceived as the insularity of discourse, the focus on discussion about past experiences, and a casually anti-medical orientation within the group. As we note in the next section, for those who dissented from the discursive norms of the group, it was very difficult to break into discussions.

For those who did not, though, the NURG represented a supportive, productive environment, often in contrast to local groups. Chris and Ava both stated in interview that the bonds and products of the NURG were their main reason for persevering with involvement, as they struggled to assert themselves within their local pilots. Unconstrained by the artificial division they felt they faced locally between their identity as users and their wider social identities, the deeply felt bonds of the NURG allowed them to work productively together.

Furthermore, these bonds were not limited to the users themselves. The facilitators from Macmillan were also included within these relationships and the discursive boundaries they produced. A typical example comes from my notes of the seventh NURG meeting, during an animated discussion of the way in which pilot staff in Site D had marginalized Dawn, their involved user, in discussions about recruiting patients using GP-held records of family histories. Dawn felt that there were unaddressed issues around confidentiality; the pilot staff had sought ethical approval for their plan and felt this sufficient. At the NURG, the group closed around Dawn, condemning the pilot for its failure to include its user in these discussions, and questioning the ethical committee that had approved the idea too:

> *MR5 says that the pilot found that its approach attracted a few new referrals, and one complaint, which they dealt with to the complainant's satisfaction. But, point out Helen, Gayle and MR2, what about those others who didn't contact the service? We don't know about them; they might have been made extremely anxious by the experience. Gayle says she can't see this as a positive outcome regardless of what the pilot says. MR3 adds that the person who did complain was very annoyed indeed. […] Helen says that what is "inexcusable" about the episode is how it sidelined Dawn: she shouldn't have been put in the position where she felt forced to bring this to the NURG to get it sorted. MR2 adds that the pilot's response is typical of the defensiveness of health professionals. It would be better if they learnt from experiences like this rather than just justifying what they've done. For Ava, it's "shifting blame." MR4 then points out that even though it may have been*

through ethics, "I'd like to know how many people like us sit on these ethics committees."

If we'd been there, she adds, it would never have got through. Ava agrees.

At this relatively advanced stage in the NURG's existence, it was becoming increasingly difficult in conversations like this to distinguish between (the remaining) users and Macmillan's staff. Also notable is the collective generation of meaning in this exchange: rather than characterized by a convergence in understandings achieved through rationalistic argumentation, the tenor of the conversation is evident from the start, and each contributor affirms and adds to what has already been said by his or her predecessor. Particularly noteworthy is the reference by Macmillan respondent 4 to "people like us." This notional 'us' refers to the emergent collective of NURG members of all backgrounds, and it is clear from the following excerpt from my interview with her that the ethos of the meetings, with their emphasis on interpersonal communication between participants defined as individuals, not as users, blurred the line between users and facilitators:

> MR4: As time's gone on, I just turn up and I'm just myself now. […] It tends to just be me. Whatever bit of me comes to the fore comes to the fore. And a lot of it is just my own personality.
>
> Graham: And that's why you feel so much part of the group, because you are able to do that because your contributions are valued by the others?
>
> MR4: Yeah. And I think it's only fair to be like that, because everybody else is bringing just them and their experiences of life in general to the group. And if you sat there with a certain hat on, I don't think it would work.

Increasingly, then, contributory rights became defined by adherence to certain discursive norms of the group, with relationships governed by interpersonal connections between participants who drew from the breadth of their identities in their contributions, rather than from a constrained, contrived involved-user identity. The looseness with which the 'involved user' was defined, noted in Chapter 6, assisted this process.

More problematically, though, certain users felt themselves excluded because they did not subscribe to these discursive norms. At the final meeting, the group itself discussed the way in which it had developed in preparing its own final report. The fact that Betty had stopped attending was raised, and the group discussed the reasons for this, characterizing her decision to leave the group as reflecting (her) difficulties with the idea of working in partnership, lacking the trust and sharing mindset that this required. In interview, Harry similarly described the NURG as developing a core of participants who were best suited to the ethos of user involvement:

> "It was the strength of our group that without actually saying, 'You're not really suited', the ones who did leave left of their own free will. I mean some committees, people have been asked to leave them, 'cause they're not part of the harmony of the group. And that never happened. Nobody was asked to leave; they jumped the ship."

In this way, membership of and contributory rights to the NURG—and the 'user voice' that Macmillan saw it as embodying—shifted. They became more a matter of engaging 'appropriately', contributing to the "harmony," not disrupting it. This was characterized by group members in the more neutral terms of possessing the 'right mindset' for partnership working. However expressed, though, this orientation became more important in defining the group's boundaries than status as an involved user—albeit in part due to the haziness of the criteria by which users were selected in the first place.

Macmillan's facilitative role

Macmillan's facilitators, then, were actively involved in the NURG, seen as coparticipants with equal standing in the group by the involved users. Macmillan also had its own agenda for involvement, and Macmillan respondents explicitly acknowledged the political, strategic value of user involvement. With its growing experience of effecting user involvement in its efforts to assist NHS service reform, Macmillan also had a degree of managerial expertise in the process. With this vision of the currency of user involvement and experience of facilitating it, Macmillan's staff actively influenced the meetings in order to maximize its value and effectiveness. This, however, was not a matter of the insidious imposition of Macmillan's agenda. Rather, there was something of a confluence of interests between Macmillan and the users which gave rise to an emerging consensus on user involvement and its role, assisted by the co-productive manner, noted above, in which meaning was established.

First of all, it is important to note that there was considerable pre-existent common ground between the views of users and Macmillan on the role of user involvement. As noted in the last chapter, Macmillan was concerned to ensure that involvement drew on the experiential knowledge of users, but also that it was as strategically effective as possible. Given this, Macmillan staff recognized that just as important as that knowledge were the motivation and ability to deploy it to improve service provision. The interestedness of the users who became involved, therefore, was not just an inevitable consequence of the self-selected nature of the cohort: it was also, potentially, politically advantageous. The 'active' orientation of those who became involved in the NURG was recognized as a virtue by Macmillan, not as a distorting influence that rendered them unrepresentative (which was the view, as we see in Chapter 8, of many pilot staff). This was something that could help crystallize 'the user's' perspective on these service-delivery issues.

Equally, for many users, the care-pathway focus of the Kenilworth model was a key attraction, as we also saw in Chapter 6. And as we saw too, several found it initially difficult to make themselves heard in their pilots. To this extent, they tended to see the managerial emphasis of Macmillan as a welcome input, helping their voices to be heard at a strategic, programme level even if they were marginalized in the individual pilots. During the NURG meetings, Macmillan facilitators were open about their wish to instrumentalize involvement, and about the managerial know-how they brought to this process. Users, it seemed, appreciated this candour, and were keen to provide the inputs to assist with this common aim. Typically, group activities during the afternoons of the NURG meetings would begin with a Macmillan facilitator providing quite a detailed backdrop to the current political scene, pointing towards the policy 'levers' that could be pulled in order to further the spread of improvements to cancer-genetics services, and the place of involvement in adding weight to these. Discussions and sometimes specific tasks would follow, the explicit aim being to arrive at a collective position, which Macmillan could then translate into a politically efficacious technology: 'the user voice'.

An example of this was an exercise initiated at the third NURG meeting, which was highlighted by several users (including Ava, in the excerpt quoted earlier, p.158) as being the first task to provide the group with a sense of purpose, and which thus seemed to represent a key transition (Gersick, 1988) that shaped the group's subsequent approach to its work. The users were asked by a facilitator (MR1) to consider the most important aspects of the Kenilworth model "from a user's perspective." The results of this would be used to inform Macmillan's evaluation of the pilots, to ensure they conformed to the "essence" of the Kenilworth model by providing what 'the user' would want most from service provision. The users duly obliged, arriving at a view that was subsequently formalized into an evaluation schema by the Macmillan facilitator, who returned a draft of this for the users to approve, and rephrase to include any terms that he, "as a bureaucrat—though I mean that in a positive sense"—had not. The result was faithfully fed back to pilots and used as a means of ensuring that the care pathways they were producing were indeed what 'the user' would want.

This kind of process, then, was explicitly managerializing of user involvement, but in a way that commanded the assent and involvement of the users at the NURG, taking genuine account of their views. Such processes were framed by Macmillan's exposition of the political exigencies facing user involvement. This, though, was just the kind of structuring that many users desired. Furthermore, users were keen to become more politically skilled themselves, and Macmillan was keen to tutor them in this, to generate a politically aware cadre of users to secure the greatest influence possible in a climate where, rhetorically at least, the 'user voice' was gaining legitimacy. As Macmillan respondent 1 put it, the aim was

> "to ensure that Macmillan can manipulate—in the best sense of that word—this balance between listening, talking, leading, guiding, giving time and space for the service users to get something of their chests, express a strong view, and then finding a way of bringing that view to bear on the sponsor's objectives—or not, without dismissing it."

As the users who stayed the course of the NURG gained from the know-how of Macmillan, they too began to pursue increasingly sophisticated efforts at securing influence. Indeed, the work on the essence of the Kenilworth model described above was later reiterated in an 'open letter' written by the NURG, published in a special issue of a clinical cancer-genetics journal which focused on the programme (National User Reference Group, 2007), an idea initiated by Ava, who saw this opportunity to promote the group's work to a wider audience.

Managerialization of the work of the NURG was thus a consensual process, in part because it was a collaborative one, with a division of labour that was initially based on the experiential knowledge of the users and the managerial know-how of Macmillan, but which was reordered through time. The creation of outputs that were managerially useful required the negotiation of a collective viewpoint, through tasks such as the one detailed above, and through the more general interactions that cultivated the 'user voice'. As noted in the previous section, the normalization of particular kinds of relationships and interactions between group members impacted both on what was 'thinkable' within the NURG and on its composition. Within these (crucial) parameters, though, the NURG meetings did provide a relatively open and expansive forum for discussion of the issues in order to arrive at this kind of collective viewpoint.

These deliberations were often quite protracted, taking more time than they had been allocated, and indeed it was partly because of frustration with the lengthy and involved nature of these discussions that Betty chose to leave the NURG:

> Betty: I don't like working with the users, particularly. I feel they bring quite a lot of baggage with them.
>
> Graham: Can you say a bit more on that?
>
> Betty: Not so much with the local users group but with the national group, they all seem to have had such dreadful experiences, and I don't know how true it is or whether it was their perception, I really don't know. [...] I like to be of more *practical* use.

The length of the debates, and the emotional input made by many participants, was thus a potential source of marginalization in the context of the group's wider discursive norms. The co-productive, collaborative form taken by interactions worked to exclude those, such as Betty, who did not conform to their orientation. The momentum taken on by such discussions made it nearly impossible to interject with an opposing contribution: as I noted at the NURG's sixth meeting—the last attended by Betty—her initial efforts to contribute vocally to the group, during a conversation about poor clinical practice among doctors, quickly gave way to defensive body language and passive indications of dissent, such as rolling her eyes and sighing audibly.

Consensus between participants, then, was particularly valued, as a means of safeguarding those bonds of friendship and emphasising the boundaries of inclusion—and exclusion—in the group. In retaining this group coherence, certain notions seemed out of bounds, such as direct criticism of other users' conduct. At one meeting, Dawn was highly critical of her pilot's intransigence to her suggestions, and their refusal to take on board her suggestions about how to improve the service. During the meeting, other users and the Macmillan facilitators provided moral support to Dawn, and reiterated her criticism of how the pilot seemed to feel that it had 'ticked the box' of user involvement and need do no more. After the meeting had finished, I chatted with some of the Macmillan facilitators, and we came back to the issue of Dawn's pilot:

> *MR2 said how from meetings with the user-involvement lead in Site D, you wouldn't think that there'd be any issues, as he seems so nice and open: clearly, though, something has happened to impede involvement. MR3 agreed, adding that according to the lead, Dawn tends to speak in very global terms: she has good ideas, but not ones that the project can action. That's why she's feeling marginalized. MR2 said yes, but the pilot shouldn't marginalize her; they should discuss the issue with Dawn.*

Even this relatively mild suggestion about the need for congruence between the user and her project was not something that could be voiced in the meeting, where the criticism of the pilot staff took on a tangible momentum on account of the consensual starting point of the participants and norms of conduct. Frequently, then, discussions of the interactions of NURG members with pilot staff served to reaffirm the group's identity and its vision of the 'proper' behaviour of the involved user (discussed in more detail in the next section) in contast to the behaviour of others.

There were other ways in which the norms of conduct within the NURG constrained the things it could discuss and the outcomes it could reach. This was no

Habermasian 'ideal speech situation' in which all suggestions were objectively evaluated and deliberated on the basis of their rationality, but rather a forum in which some participants were more vociferous and persuasive than others, and where expediency in reaching conclusion was a necessary governing principle. A degree of consensus between the major actors could result in the closure of debate, perhaps prematurely. I had personal experience of this when feeding back some of my early findings to the group, which Macmillan respondent 5 challenged. As I rather inadequately defended my argument, other participants made it clear that they agreed with its thrust. In my notes from the meeting I recounted:

> *The power of consensus was tangible here when MR5 asked this question. Once Helen (nodding in support), MR1 and others had spoken in defence of what I said, the discussion was very quickly closed down to a resolution, to agreement, and to discussion stemming from that agreement, rather than further debate about whether my argument was defensible. It's probably fair to say that 'the view' of the group is something that is objectified relatively quickly (and subsequently reiterated and normalized through repeated declarations of a view by key protagonists), not through any conspiracy, nor primarily due to power imbalance, but because of the way discussion is structured, especially given the limits of time and the purposive, rather then expansive, nature of the meetings. The group comes to a resolution not through a deliberative-democracy model of progressive consensus achieved through the power of rational argument, nor (usually) through a show of hands, but through something in between, with limited deliberation, a need to resolve open questions relatively efficiently, and a critical mass of those involved backing a particular view so that it becomes established.*

In these ways, deliberation in the NURG meetings was constrained, within a wider set of discursive norms that themselves determined what could be discussed and how, and who discussed it. These constraints were also what facilitated the discussions that did take place and the productivity of the group, and as such they were arguably essentially no different from any other process of group formation and inclusion. But they were determined by a consensus that was co-produced by Macmillan respondents and *some* of the involved users, which proved impenetrable to others who dissented. Occasional managerial interventions by Macmillan—the use of narratives, for example, to help foster a collective identity, or the exercise on the 'user perspective' on the Kenilworth model—were enough to inform this process without overt imposition: small impulses to give direction to the accumulating momentum. This process resulted in the reification of a particular 'user voice', and a particular notion of the 'proper' involved service user and her/his role within a pilot, as discussed next.

The 'proper' involved user

With the developing boundaries, set of procedural norms and shedding of dissenting members outlined above, through time the participants at the NURG arrived at an increasingly coherent vision of 'who they were' (in terms of the skills, experiences, dispositions they embodied) and what they could do. Tentative early encounters between participants gave way to increasingly consensual patterns of communication and with these a 'user voice', such that (as seen above) by the seventh meeting, participants spoke as "we," and were confidently able to make claims about the identity of "people like us." With this came a concern to put forward the potential benefits of these skills and identities to others.

This built on the social identities, experiences and skills that many involved users individually identified as forming their motivation for becoming involved, and the kind of contribution they wished to make. So the NURG participants emphasised the importance of their experiential knowledge to the improvement of cancer-genetics provision, but alongside this highlighted the importance of wider skills and experiences they had accrued, often in the course of their professional lives. They constructed themselves as interested, reflexive, collaboratively oriented individuals who were willing and able to draw from these resources of experience and knowledge, and use them to contribute to tangible improvements in health-service delivery. They laid claim to a host of qualities that they brought to the table not only as patients but as individuals. The combination of skills, experiences and general disposition towards life was summarized neatly by Ava in the course of a formative conversation during the fourth NURG meeting, as she contributed to the developing imagery of who 'we' were:

> *Ava points out that "We are self-selecting," in that we've been through it, gone through the emotions and still want to make a difference, rather than thinking, "I never want to go through that again'," and putting it to the back of our minds. "We're all serious-minded people," she says: we want to make a difference and that comes through in our discussions: we're here to do a job.*

This was the kind of identity that the group increasingly sought to put forward to those outside the NURG, and especially pilot staff. This took place through outlets such as the Pilots Together events, and through the narratives about involvement, which were distributed to pilot staff to provide them with concrete examples of who users were and what they might do, and were also compiled into a published journal article for wider consumption (Donaldson *et al.*, 2007). The members of the NURG, in this account, were "a diverse group of skilled and enterprising individuals, enthusiastic about helping future patients" (Donaldson *et al.*, 2007: 249).

In arriving at this self-identity, the NURG members constructed various implicit and explicit contrasts between themselves and others. There was the distinction, already noted, between the NURG's core who were characterized by their orientation towards co-operative work, and those who dropped out 'because' they lacked this mindset. There was also an important contrast between the intrinsic motivation that possessed the NURG participants, and the more questionable motivations of certain others. At the sixth NURG meeting, Dawn revealed that her pilot in Site D had convened a series of focus groups to discuss service development, the participants at which would be paid expenses and a small honorarium (Dawn herself had only ever been paid expenses—and often struggled to get these paid promptly). The group expressed their distaste for this parallel arrangement, empathising with Dawn and questioning the validity of the contribution of those in receipt of such an inducement to participate:

> *Dawn says her main concern is whether they will get the right people if they pay. Will they be doing it for the wrong reasons? Will they come again? (The assumption here seems to be that not paying does get the right people.) For Helen, it sets a precedent for paying, and it's unfair on others who are already involved for no pay. Expenses, refreshments are fine, but payment is too great an incentive. Ava goes further, calling it a "bribe" to say the 'right' things. Helen adds that it's nice to receive perhaps a card, and a box of chocolates, but this is too much.*

For the group, it was clear that an extrinsic, financial incentive (despite its modesty in this case) was something that risked involving the 'wrong' kind of people, whose contribution was sullied and whose commitment to the process was questionable. The contrast with the 'proper', intrinsically motivated and committed user—embodied here in the participants of the NURG—was clear.[1]

Intrinsic motivation was, for the NURG, an uncomplicatedly positive trait to embody. Several other aspects of the emergent NURG self-identity, though, required careful management, treading a narrow discursive line between obviously 'good' qualities and rather more ambivalent characteristics. NURG members characterized themselves as interested, for example, without being self-interested, prejudiced or

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[1] As might be imagined, this contrasted with a rather different understanding among staff in Site D of involvement and the kind of individual it required. Chapters 8 and 9 return to this point.

pushing distorting personal agenda. Similarly, they were keen to emphasise, though interactionally skilled, reflexive and articulate, they were not 'professional committee members', an accusation occasionally levelled at them locally and at Pilots Together events. One notable discursive means by which this was managed was the construction, implicitly and occasionally explicitly, of a temporal dimension to the 'proper' involved users. Common within the NURG meetings was talk about how participants had arrived in a position to give the kind of reflective, measured, appropriate contribution that they now saw themselves as offering. As Gayle put it:

> "[You need to] make sure that you're covering all the aspects from that point of view, rather than just concentrating on the you personally. And I do feel it's about getting away from that as well, that it's your own personal experience, where if something comes up, you're, 'Oh *I've* been through all this and *I've* done.' That's not relevant, you know. Gemma and I have both come away from that side of it. Not everything that's talked about comes back to when it happened to us. You've got to look at the whole."

And similarly:

> Helen: The most important thing is that [users] have to be able to see beyond their own diagnosis and experience, and be able to work in partnership. If they can't see beyond their own experience, good or bad, then they'll not bring the wider picture.
>
> Graham: And how do they go beyond that experience?
>
> Helen: By travelling and being open, 'cause I think the more you become involved, listen and become aware, the more you actually are not representing your own experience: you're identifying similarities, similar themes to your experience, and that's good.

This, then, was a progressivist discourse, which saw the proper involved user as developing from the anger, introspection and concern for self experienced at diagnosis, into a realization of the 'bigger picture' and how the user might help improve it. The users saw themselves as having experienced this process personally, and it was furthered by the contact with others and awareness of the political exigencies of the NHS that membership of the NURG brought with it. For Macmillan, too, this narrative, of self-absorption giving way to an awareness of, and keenness to work towards, collective interests, was a powerful one, which it played up in advocating a partnership model of involvement:

> MR2: Some people aren't in the right place to work in partnership. They're not at the right place within the 'journey', in inverted commas, because they're still very angry or they're still carrying emotional issues. 'Cause really, partnership working is wanting to make a service improvement, it's about moving from your own personal want, need, to the greater need.
>
> Graham: And if you have a bad specific experience, it's about drawing other lessons from that rather than being tunnel-visioned.
>
> MR2: Yeah. And some people can do that even if they are still quite new to it all. They can still see the benefit. And by the same token, you don't want to dismiss people that have had a particular experience that could help the partnership group's thinking.

This 'proper' form of involvement—partnership in pursuit of service improvement—required the proper involved user, as someone who could slip the constraints of personal experience (whilst still able to draw on that experience) and make a contribution with wider utility. The partnership model encouraged by Macmillan thus needed the kinds of proper involved users that the NURG members were becoming.

The notion of the status of 'proper' involved user as something to be attained through time was a discursively interesting one. In the excerpt above, Macmillan respondent 2 ties this progressive narrative into the wider discursive trope of the 'cancer journey', the stepwise psychological progression of an individual following the traumatic life event of a cancer diagnosis (cf. Daykin *et al.*, 2004). The effect of this construction of the proper involved user was simultaneously inclusive and exclusive. It was inclusive in that it could incorporate those with the right mindset (including, of course, the several involved users who had not themselves had cancer). More importantly, in constructing the proper-involved-user status as something to be achieved at the end of a unilinear, progressive 'journey', it theoretically included anyone—but only once they had reached the point at which a collectivist mentality succeeded preoccupation with personal experience. In practice, then, it could also be exclusive, as seen above, of those deemed to have failed to achieve this point.

> "Any people, I should think, can do it. Any people at all really, that are understanding, can listen, could put their point of view across, basically anyone really could be a user, if they got to know about it and wanted to do it. And got interested in it." (Emma)

Most particularly, though, it was discursively useful in the way that it posited appropriateness in user involvement as something to be *achieved* rather than a default position: something to become rather than to be. In relation to the one-off focus groups convened in Site D, then, the NURG's criticisms related as much to the view that participants might not be committed to a sustained, progressive contribution as to the notion that payment might attract people with improper motivations. Dawn herself attended the focus groups as an observer and confirmed the NURG's fears:

> "For one meeting that lasted a little while, giving them money—and they knew that upfront—I don't think that's OK. There was one lady there who'd come because she thought that she was going to get compensation

> for her husband's death, and another wanted to go on the screening programme, so they weren't really there for the right things."

Once again, the contrast with the motivations and contributions of the NURG users—"such a great national user group, no-one's got their own agenda, they're all there for everybody else" (Dawn)—was clear.

Notably, though, in a general sense this progressivist discourse of user involvement was one to which nearly all concerned subscribed—including some of those it seemed to exclude. This was perhaps indicative of its discursive strength and integrity. After all, who would want a self-obsessed, angry user with no interest in making service-level improvements with wider benefits? So for example the user-involvement lead in Site D, responsible for convening the focus groups to which the NURG had so vehemently objected, articulated a very similar vision of the 'ideal' involved user, as somebody who has "been through the service and has experience of life outside of the service as well," somebody who could "talk passionately about their own experience," but also have "a sense of rights and what should be available." Betty's notion of the proper involved user similarly emphasised the need to escape the confines of personal experience and provide a more constructive input, but for her most of the other members of the NURG failed this test, remaining narcissistically critical and failing to contribute to service improvements. Staff, users and Macmillan alike were adamant that involved users should not have distorting personal 'agenda', but subtle differences in what constituted such agenda became apparent during interviews.

A general consensus on a discursive level between varied parties thus concealed noticeable disparities in their construction of how this discourse of proper user involvement should be enacted. In the next chapter, furthermore, we see more clearly how these differences related to fundamentally different understandings of user involvement, the identities of involved users, and the relationship between these and the wider public of patients, potential patients and citizens.

Discussion

What I hope is evident from this chapter is the important role played by the deliberations of the NURG meetings in the emergence of a collective identity for involved users, assisting their sense of purpose and providing a resource for persuading pilots of the worth of a more expansive role for involvement (a process explored in Chapter 8). This was achieved through a process that drew discursive and substantive boundaries of inclusion and exclusion in arriving at an increasingly particular notion of what constituted the 'proper' involved user. This process was also guided by an explicit instrumentalism, deriving from the desire to achieve legitimacy and influence, and resulting in an increasingly overt strategic consciousness.

This instrumentalization was not, though, the same as many examples described in the literature. For a start, it was clear that the experiential knowledge of those involved was a core component of the deliberative process, rather than something to be 'managed out' because it could not be contained within prevailing managerial approaches to involvement (Barnes, 2002; Hodge, 2005; Carr, 2007). As with the women's group discussed by Barnes *et al.* (2004a: 98), the managerial power of the Macmillan facilitators was not experienced as exclusive or coercive, "because the overall conditions for deliberation offered recognition and respect for members' own experiences as authoritative and legitimate contributions." Furthermore, there was little sign of the working of external power in the 'black boxing' of the deliberations of user involvement as a legitimating moment of agreement with managerial aims, as found in much other research (Mort *et al.*, 1996; Harrison & Mort, 1998; Milewa *et al.*, 1998; Williams, 2004). Macmillan made clear its belief in the need for instrumentalization, and its own managerial nous in achieving this, to NURG members from the outset, and they assented to this process, and indeed became increasingly skilled in it themselves as they sought to increase their own legitimacy and leverage within their local sites. In some ways, then, this seemed to represent the users themselves learning how to play what Mort *et al.* (1996: 1140) call 'the user card':

> It takes a highly skilled, politicised user group to exploit this potential. Alliances are crucial. The ground is restless and shifting and the 'game' can be exhausting for anyone with a disability or mental health problem. An independent, radical user group, which can avoid being overmanaged and institutionalised by the agencies, could have much to gain.

In this conception, Macmillan provided the kind of facilitative role identified by Mort *et al.*, among others (e.g. Richardson *et al.*, 2005), as crucial if users are to form the alliances that might secure them influence in the health service. The potential for such alliances between managers and users has been suggested elsewhere (Barnes *et al.*, 2003), though a key difference here is the status of Macmillan as an independent organization outside the NHS. Other authors have highlighted the tensions for public-service managers torn between an increasing commitment to the causes of users and their own accountability to the state (Milewa *et al.*, 1999; Newman *et al.*, 2004). The horizontal leverage on the governance of the NHS sought by Macmillan may offer a less fraught means of achieving influence for users than attempts to forge alliances with managers who must 'hold the ring' between numerous competing interests.

The process for reaching the outcomes that might be effectively managerialized was the deliberative endeavour of the NURG, as it gradually worked through its identity and purpose to reach a coherent 'user voice' and image of the 'proper user'. As we have seen, this process was not limited by rationalistic or masculinist assumptions that marginalized emotive and personal contributions to the debate (Scott, 2000; Barnes, 2002; Carr, 2007). Rather, conversation was governed by feminine norms of interaction and conversation (Davies & Burgess, 2004), which relied on informal connections to build social capital. Thus Young's (2000: 59) notion of 'greeting'—functioning "to acknowledge relations of discursive equality and mutual respect among the parties to discussion, as well as to establish trust and forge connection based on the previous relationships among the parties"—had an important role in structuring the NURG's interactions. Greeting, and the associated social rituals of the NURG, worked to reduce some of the potential power imbalances—for example, between Macmillan participants and users. It was also, as Barnes *et al.* (2006: 202) found, "a means through which the sense of 'we' could develop."

Simultaneously, however, the manner in which the NURG worked served to exclude as well as include. The emotional dynamics and norms of the group had an important *substantive*, as well as facilitative, role in determining what could and could not be said. Rather than accomplishing a Habermasian 'ideal speech situation' or the model of interaction put forward by deliberative-democracy theorists, then, these dynamics sometimes suppressed deliberation. The form of interaction at the NURG mirrored that found by Davies *et al.* (2006: 204), in which deliberation

> does not entail positions being taken by individuals and defended through other-regarding exchanges. Instead it is a more collaborative form, involving multiple participants in a process of jointly reflective and open-ended discussion.

This, they argue, is "a more nuanced, encompassing understanding of the actuality of interaction between citizens" (Davies *et al.*, 2006: 205). But this actuality, they also found, could give rise to the exclusion of certain groups. Similarly in the NURG, there was a sense in which the basis of interaction in personal relationships and bonds of trust gave rise to exchanges in which the 'group viewpoint' quickly became established and unassailable, and in which occasionally "slavish obedience [to a dependent group culture] may be preferred to democratic debate" (Thompson & Hoggett, 2001: 356). As others have noted in wider contexts, the dynamics of groups are established rapidly, and destabilized only with difficulty, with "a framework of behavioral patterns and assumptions through which the group approaches its project" disrupted only by major challenges (Gersick, 1988: 302).

The foundation of deliberation within the NURG, on participants' broad identities as individuals rather than their constrained identities as patients, would appear to be a positive trait, permitting a more expansive debate and set of contributions from the NURG members. Certainly, the participants themselves pointed towards the importance of acting 'as themselves', rather than setting up an artificial separation between the contributions that they could make 'as users', deriving from their experiences as patients, and contributions arising from the rest of their lives. However, this seemed to cloud the rationale for involved users' participation, as the adoption of a particular mindset and collaborative disposition seemed to take precedence over status as 'an involved user' in determining contributory rights. This was perhaps in part because that status was already itself quite a nebulous one; nevertheless, the progressive normalization of a particular, collaborative disposition as characterizing the 'proper' involved user, which included Macmillan facilitators ahead of 'inappropriate' users, seemed problematic. While the literature points to the positive outcomes that may arise from the hybrid identities of managers working with involvement processes, in this light it seemed more ambivalent, as staff participated in the co-production of meaning through collaborative dialogue in ways which effectively contributed to the closing down of debate. This co-productive—rather than coercive or impositional—way of contributing to the NURG's identity formation, along with managerial inputs (narrative writing, group tasks) which could effect transitions in the orientation of the group (cf. Gersick, 1988), contributed to an output that fulfilled the needs of the organization.

The structuring, instrumentalizing work of Macmillan facilitators—accepted and welcomed by involved users—was thus accompanied by participation in the co-production of meaning, in a group where contributory rights had become rather "amorphous and fluid," in the words of Barnes *et al.* (2003: 396). This suggests that in forums like this—where managers and users are brought together in an outcome-oriented partnership—there can be no clear determination of who it is that is playing the 'user card'.

The definition of a proper involved-user orientation, and the articulation of a clear and coherent user voice, were determined, then, both by the exigencies of user involvement and by the dynamics of the group itself. As Ryfe (2002) has suggested, this kind of instrumentalization may close down debate in deliberative forums rather prematurely, and clearly it is debatable how far the NURG succeeded in being a genuinely open forum—a "'parallel discursive arena'" (Barnes *et al.*, 2004a: 106)—free of the pressures of engagement with officials. Once it was accepted that a 'user voice' was a political necessity for the success of involvement, though, this kind of closing down of identity and voice was going to be necessary, and for all the imperfections one might highlight in the deliberative process that precipitated this, it certainly seemed more user led than some described in the literature. A rather more vexing question centres on the mismatch between the degree of heterogeneity of users' perspectives and the very need to 'black box', distil the perspectives of users into a univocal output that might be managerially useful. The disparity between the system's need for singularity and the polyvocal reality, which these deliberations attempted to remedy, suggests rather different constructions of the user and her/his contribution. And as we discover in the following three chapters, the coherence achieved by the NURG's negotiations only partially addressed this difference.

8.

CONFLICTING VISIONS OF USER INVOLVEMENT[1]

Through time, the original motivations that had driven individuals to become involved users were moulded into a coherent collective identity and a singular 'user voice' at the national level. The central aim of the NURG, though, was to "support and empower [users] to be able to work confidently within their local pilot project teams" (NURG final report), and it is to the dynamics of user involvement in these local sites that we now return. How far did the sense of purpose and potential that the participants of the NURG had co-produced translate into something that could be operationalized in the developing involvement in the pilots? The answer, of course, depended not only on the users themselves, but also on the responses of the pilot staff, who remained responsible for their projects' work, and thus retained most power in determining the nature of the projects' user-involvement components.

This chapter, then, starts to fill in the picture sketched in Chapters 6 and 7 by considering in detail the developing ideas about involvement of the pilot staff and the

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[1] Much of this chapter is published as 'Representativeness, legitimacy and power in public involvement in health-care management', *Social Science & Medicine* **67**(11): 1757-1765 (Martin, 2008b).

users. The 'stand off' caused by the 'implementation gap' was beginning to be diminished by the assertive set of users that the NURG was producing. It was only as this gap closed that the divergences between the views of (most) users and (most) staff started to come into sharper relief. Crudely, the ideas put forward by users illustrated to staff what they did *not* want of user involvement, even if they were still somewhat unclear as to what, beyond the basics, they did want from it. What I attempt to enunciate here is the nature of the contribution that the self-defined 'proper' involved users felt they could offer to the pilots, which derived from a breadth of knowledge that went far beyond their experience as cancer-genetic patients—and which contrasted strongly with the views of staff on the same question. This divergence reflected fundamental differences not only in the understanding of the purpose of involvement and the construction of the involved-user identity, but also, I argue, in the conception of the wider (uninvolved) public, and its relationship to the professional expertise of the health service. This presages discussion in the following chapters of how users and staff negotiated compromises between these conflicting visions for user involvement.

Plugging the 'implementation gap'

Several users and Macmillan respondents averred that the NURG had served a significant capacity-building role, the commonality and coherence of ideas giving them the confidence to return to their sites invigorated and prepared to demonstrate the useful contribution they could make. As Ava declared at the fourth NURG meeting, "I am ready to show them [Site A's staff] how useful I am!" The contrast between the spirited proactivity and coherence of aims at the NURG meetings and the inertia within local sites was palpable for many, and exemplified in the reaction of the users from Site E when they attended the NURG for the first (and, as it turned out, only) time, at its seventh meeting. During a discussion of how involvement might support the spread of the Kenilworth model nationally to non-pilot sites, they both commented on the contrast between the scope of this work and what they had been doing with their pilot:

> *Emily says this has been an eye-opener compared to what she and Emma have been doing locally. They've been shown literature and asked for comments, but nothing more than this. Emma, agreeing, says that it makes her wonder what she's been doing for the last year! MR2 asks them: Do you feel empowered to go back and get more involved with your service? Both Site E users seem to agree.*

The dynamics of involvement in the local sites, though, were somewhat different to those of the NURG. Most fundamentally, the openness which characterized NURG meetings, especially early on, was missing from meetings in the local sites. There was not the opportunity, so important in the NURG, for users to work through in their own time the nature of their role in a convivial environment. Rather, users were thrust locally into pre-existent teams, already strongly action oriented, with a focus on achieving the service-reform objectives set out for them inside their three years of start-up funding. Lack of clarity over objectives here, then, translated into a need to locate a functional input quickly, rather than deliberate about the purpose of involvement.

The most obvious functional contributions for users to make, though, were the kinds of relatively constrained inputs outlined in Chapter 6: checking the literature produced by the pilots, providing feedback on the flaws of current provision, and so on. Pilot staff were keen to draw on these contributions from users, and users were happy to give them, but they only filled up so much time. Beyond these, there was a sense that staff were genuinely unsure about what they could ask of users. The user-involvement lead in Site F was frank about her uncertainty about the role of involvement:

> "With the patient satisfaction survey, you've got a feel of what somebody, how their experience was using the service. But I'm not sure what else they could offer to a group like this. Apart from the frustration of not being

> able to make this a permanent service, that would be the major thing that people that have gone through the service would, I'm sure, be interested in."

Despite these doubts—which were shared to varying extents by staff in all pilots except Site G—through time, staff and users managed to negotiate certain extra roles for the users. Sometimes, though, these seemed to extend little beyond the initial literature-checking and patient-satisfaction activities. Following the NURG meeting at which Site E's users expressed their desire for more extensive local involvement, for example, I attended four successive steering-group meetings in Site E. My notes on the section devoted to user involvement at the first meeting read as follows:

> *Item 4: User involvement*
>
> *Lead nurse says, "I know that Emily and Emma attended the national meeting." Genetic counsellor seems pleased: "Very good." Emma says it was "an eye opener, very interesting," but doesn't expand, and others present don't ask how or why. The lead nurse continues: one thing I want them to look at is the risk-assessment section in the automated letter that our software produces. This is not yet satisfactory, and so far we've been writing each one individually instead. So we'd like the users to look at this and write a template. "So that's the next bit of work for user involvement."*

And so the meeting moved on to the next item. At the following meeting (at which neither user was present), the lead nurse confirmed that the users were still currently working on this, but since the software was not currently operating, there was no urgency to this work. At the third meeting and the fourth (which took place some six months after the first), this was still the mainstay of the users' work.

Making a more extensive contribution, then, was not easy for users locally, especially where (as in Site E) they were comparatively detached from their projects. In some sites, though, the activities negotiated to fill the implementation gap were a little more wideranging than this. These are considered in more detail at the start of the next chapter, where I review involvement in each of the sites individually, but one or two negotiated roles are worth mentioning now. Several pilot staff mentioned the benefit they gained from having someone present at meetings who was not subject to the socialization of the health service. "With not being in the NHS, perhaps, she looks at things slightly differently," said a nurse in Site A of Ava's contributions. Pilot staff, though, were unable to articulate exactly how this was useful, beyond providing a general sensitization to professionals' discussions at local meetings. Somewhat more productively, in a number of sites users and staff saw a potential role for users in connecting with the public: talking about their experience of cancer and genetics in public forums, to raise awareness and encourage those concerned about inherited cancer to do something about it. This kind of activity was pursued in several sites, with varying degrees of success.

Despite these efforts, though, it became increasingly apparent that in most sites, users and staff had rather different ideas about what involvement could and should address. Notwithstanding the rhetorical appeal that the idea of the 'proper' involved user offered to users and many pilot staff, there was a sense that this was not quite what pilot staff had anticipated user involvement to be about. Staff were not critical of their users in interview, and often praised the efforts they had put into involvement, but also indicated that the qualities possessed by these users were not quite what was needed. The views expressed by a genetic counsellor in Site A were typical:

> "[Ava] is keen and she's focused, and that's good. She's motivated—you wouldn't want her demotivated!—but you want someone looking at it from a different perspective. […] You need more than one person to represent everybody else. And Ava's always been very motivated in patient and carer groups. She's one of those people—very motivated to do that, but you

> could do with some other people who have just got an opinion to give."

Whilst not wishing to criticize the energy devoted by Ava to the cause, then, this respondent expressed a view characteristic of many staff that suggested a slightly different emphasis in relation to the core aims of involvement. Let us now consider this professional understanding of involvement in more detail.

Laity and patienthood: professional constructions of involvement

The words of Site A's genetic counsellor above reflected a growing realization among staff across sites of the consequence of their pragmatic approach to recruitment for user involvement. The motivation and skills offered by users, which in the NURG's notion of the proper involved user were constructed as assets, were rather more ambivalent qualities for many professionals. There was unease about the particularity of identity of the users who had become involved, and the consequences of this for the nature of their contribution. This concern was exemplified in my interview conversation with a clinical geneticist in Site D, quoted at length here both to map the contours of the concern and to show the caution with which she voiced it:

> Geneticist: Dawn came because she'd been seen in the genetics department. She was a known kind of user activist, so she came on board. But recruitment was usually by asking people who'd attended the surgery whether they'd like to be involved.
>
> Graham: And are they different compared to Dawn's contributions as a user activist?
>
> Geneticist: Well yes, because she comes from a different perspective and so she's a sort of professional user, isn't she? Whereas the others are just, kind of, users.
>
> Graham: How do you mean professional user?
>
> Geneticist: Well, she's involved deeply in all sorts of patient groups and

> things, Macmillan and so on, so she knows a lot. But also she looks at it from a more professional point of view, I suppose.
>
> Graham: In what sense?
>
> Geneticist: Well she—because it's not—well, her own personal experience is of genetic counselling within the general genetics department.
>
> Graham: I see, yeah.
>
> Geneticist: So she wasn't referred in so she doesn't specifically have experience of the project itself, but she knows *about* it. That is slightly different.

In this site, of course, Dawn's contributions were complemented by the focus groups convened to involve more uninterested, and therefore disinterested, former patients of the service to give this different perspective, much to the NURG's displeasure.

In other sites, too, there was concern that the 'proper' involved users recruited were not quite able to give what was expected of them. This is not to say that the skilled contributions they offered were not valued: on the contrary, the professional copyediting knowledge brought by Betty to Site B, the career in accountancy of Fred in Site F, and even Dawn's background as an information technology (IT) project manager in Site D were welcomed by professional staff. This, though, was only insofar as these skills offered specific inputs that contributed to the pilots' aims. In terms of the general contribution of involvement, users' professional backgrounds were seen less as an asset and more as a kind of interference with the contribution they 'should' be providing.

In other words, the concerns of staff centred on the unrepresentativeness of those who became involved (cf., e.g., Crawford *et al.*, 2003). In some sites, this was seen as a crippling obstacle to any partnership-oriented user involvement beyond what was required by Macmillan. In Site A, for example, the project lead preferred more consultative approaches to gaining user input, premised on larger-scale surveys of the user body and the statistical representativeness that this might offer, to the partnership-oriented involvement that the involved user and Macmillan wished to see:

> "I don't think [Ava] feels that we've had enough patient input. And maybe we're open to criticism for that: we involved them a lot at the beginning, we've done two satisfaction surveys along the way, but we haven't had an ongoing dialogue with patients for a variety of reasons, one of which is it's very difficult to find a representative body of users." (Clinical geneticist, Site A)

Consequently in this site, face-to-face involvement was limited to Ava and one other user, despite their appeals for a more wideranging partnership with a broader user group. Similar concerns elsewhere, however, did not always lead to a principled objection to involvement, but a more pragmatic compromise. Mindful, perhaps, of the fact that it was their own efforts at recruitment that had given rise to this 'atypical' body of involved users, staff in several sites did not see unrepresentativeness *as such* as an impediment to legitimacy. Rather, they highlighted some potential value in the contribution that this particular group of users could offer—but often couched this in terms of *the degree to which* the users were reasonably 'typical' or 'representative' of their peers. For example, back in Site D:

> UI lead: Each of [the users] who attended were clear about who they were as individuals and their backgrounds: a lawyer, advertiser, and a project manager. So they were very much expressing *their* views and *their* experience. I don't think they were representing the views of users generally, because—by that I mean the makeup of users, I imagine, is so varied that it would be very difficult to get one perspective on that.
>
> Graham: Yeah, one typical user who reflects all those things.

> UI lead: Indeed. But the issues that they were addressing, in terms of accessibility, information, the clarity of communication, those were clearly generic.

Particularity of background and experience meant for this staff member that involved users were explicitly not representative. Yet notwithstanding this, their ability to speak to "generic" issues, where views were not dependent upon particularities of class or motivation or background, gave their input a wider validity. What is notable in this construction of user involvement, then—in contrast to the NURG's construction—is that the contribution is valid *despite*, not because of, the particular intersection of skills, motivations and experiences that characterized the users.

In other sites, staff offered similar interpretations of involvement. By and large, concerns over the representative legitimacy of those who had become involved translated not into efforts to marginalize their input, but saw staff construct it in a specific—and constrained—way. In particular, staff identified two areas where a certain representative legitimacy was possible despite users' particularities.

Firstly, user involvement could offer a *patient perspective* on provision. Experiences of health-service provision and views on how it might be improved were seen as sufficiently generalizable for the contributions of users on such issues to possess a viable external validity despite their particularities. As the user-involvement lead in Site C put it, "I think you need to get other people's opinions, and I suppose if they are users of a service that's being developed, then their opinions are based on their experience." On a similar basis, the user-involvement lead in Site B outlined both the scope and the limits of the contribution that could be made by her group of predominantly retired or unemployed involved users:

> "It's important to have people who have been through the service, 'cause they're commenting on how we've contacted them, how they knew about

> this service, how they were treated at their appointments, letters and follow-up. We've been through all that with the user group: you can't really tell how you'd feel getting that letter unless you've actually got one. […] The problem I've found is that we have people who don't work, because we have our meetings in the day. […] People who don't work will have a particular view on things, even if it's locations and times of clinics and things: they're not working people and they don't have those issues."

The ability of Site B's cohort of users to give a generalizable opinion on the access process was not matched, for this respondent, by their ability to give a view on the timings of clinics, on account of their particular backgrounds.[2]

Alongside this contribution premised on the perspective offered by users as patients, staff secondly saw involvement as providing a *lay perspective* on their work. In Site E, for example, Emma's commonality with the wider public was constructed as an important contribution in itself by the lead nurse:

> "[Emma thinks] she doesn't know enough, whereas for us that's not what it's about. What she does know about is what we want from her, her experience and thoughts about it as Jo Public, with no medical background."

The user's laity—her lack of professional knowledge—was thus an important resource for this service and others. Involvement was something which could help professionals interact with laypeople in an appropriate and effective way: helping them to communicate informatively without provoking excessive anxiety, comprehensibly without being patronizing. This formed the rationale for the six-month period of user

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[2] Nevertheless, it might be noted, the respondent went on to say that this had been a main point of discussion in the group despite these concerns, since the staff felt they needed some kind of user perspective on the issue.

involvement in the phrasing of Site E's computerized letter-writing system noted above:

> "Because [involvement] has been a bit patchy, the main things we have used them for is right at the beginning. We didn't have Emily then, but Emma looked at the information that was available so we could see whether we need to devise our own information or use existing information, and we went for the Cancerbackup stuff, so she was involved with that. She has been involved with different letters that are going to be put on the software. […] So she has been looking at those things from a patient view."

And similarly in Site F, the user-involvement lead stressed the positive input that could derive from the absence of a perspective professionalized by occupation and socialized by the NHS:

> "When you're coming from a nursing professional background, you instantly forget that people aren't so able to understand some of the jargon that you use, whereas [the users] could swap those sentences round and make it easy to read for people. And definitely, what they achieved was really good, easy-to-read, literature. […] We [professional staff] designed the leaflets for the GPs and health professionals. That was fine, we could write that no problem. But it was difficult to find the right level for the general public. And [the users] got it spot on."

In this way, then, an absence of professional knowledge could be constructed as an asset with a particular utility for the service which only users could provide.

But an absence, nevertheless, it was. The idea of involvement as providing a perspective defined by the users' *biomedical and lay identities* as *patients and laypeople* contrasted strongly with the users' own ideas about the proper involved user, as someone with a host of contributions to make, based on a wider conception of their knowledge, experience and the relevance of these to the NHS. Certain features of the degree of validity conferred by pilot professionals' dual conceptions of the user contribution might be noted before we contrast it with users' own conceptions.

For one thing, it constrained as well as giving scope to the contribution. By constructing the legitimacy of involvement principally in terms of representativeness (or typicality) of the contribution, staff frequently confined it to something close to the original, limited, roles described in Chapter 6. Biomedical identity as a patient implied a contribution on issues like patient satisfaction; non-professional identity as a layperson implied contributions of the kind described by staff from Sites E and F above, providing input on various aspects of the pilots' efforts to connect with their publics. Intermittently, pilot staff would appeal to Macmillan for suggestions on extra roles for involvement, so that they could expand it beyond these basic contributions. During the latter part of the pilot period, Macmillan moved on from its initial, non-committal stance that emphasised local bottom-up innovation, and started to provide concrete suggestions, often deriving from the more expansive involvement occurring in Site G. Faced with these suggestions, though, most pilots tended to revert to their more conservative conceptions of user involvement.

We explore this interplay in Chapter 9; for now, it is clear that this constricted notion of involvement, resting on users' biomedical and lay identities, provided its substantive basis. As emphasised in the sixth chapter, with many other competing demands on their time, staff had devoted little thought to the nature and purpose of involvement. It might be observed from the interview excerpts quoted in this chapter, too, that many staff seemed doubtful about the legitimacy they perceived for user involvement: think of Site D's geneticist's struggle to articulate the contrast between Dawn as a "professional user" and others who had been involved, who were "just users"; or of Site C's user-involvement lead explaining how "I suppose" users provide an input based on their clinical experience; or of the use of Site B's user-involvement group to consider issues about the timing of clinics despite the user-involvement lead's concern about its lack of representative legitimacy in this regard. From interviews and observation alike, the impression I got in most sites was of a lack of detailed thinking on the part of staff about exactly what they wanted from involvement (in strong contrast to the increasing conviction with which the NURG constructed user involvement's role). Given this, and in the face of pressures from many of their users for a more expansive, partnership-oriented user involvement, the idea of users as *patients* and *laypeople* was a comfortable, commonsense conceptualization to which they could default.

An ironic—and perhaps instructive—exception to this was Site D. Notwithstanding the struggle of the clinical geneticist to express her feelings about the "professional user" she had found in Dawn, the user-involvement lead here had a much clearer idea of what he wanted from involvement. With a background in research, he devoted much effort to user involvement, and set up the focus groups that caused such objection from the NURG. In interview, he explained how he saw involvement as an important supplementary source of evaluatory data on the service, which might contribute to the care-pathway reconfiguration his pilot was trying to achieve:

> "User involvement provides a rich resource in terms of patient experience and patient views, and I also think it's a good way of checking actually that services are working and functioning effectively, because although it's not a strict evaluation, it's a form of evaluation. Without that, I think something is missing which is very important to service development."

Ironically, then, it was this clarity of thought on the purpose of user involvement that gave rise to the conflict with the NURG. Rather than regressing to a default set of presumptions about the identities of users and the purpose of involvement, a clearly thought out rationale—which was out of kilter with the equally well thought out NURG rationale—resulted in considerable discord. In Site A, too, as we noted in passing above and will see in more detail in the next chapter, it was concern for, not neglect of, involvement and its underlying premises that resulted in an overt clash rather than grumbling disagreement.

What seemed apparent in most sites, though, was how lack of reflection gave rise to the default understanding of users defined by their biomedical and lay identities. This constraining conception of user involvement did not, then, seem to reflect a deliberate marginalizing strategy, of the kind identified by several past authors who interpret professional challenges to representativeness as a means of maintaining the *status quo* (Beresford & Campbell, 1994; Bowl, 1996; Crawford *et al.*, 2003). Indeed, as we have seen, for staff, constructing a degree of representative legitimacy was as much about defining what users *could* contribute as what they felt they could not. However, it will be noted that, intentionally or not, the 'commonsense' understanding of user involvement of most staff fitted snugly with their own professional interests, offering a contribution that was amenable to professional control and providing managerializable inputs on questions directly relevant to service delivery, such as the quality of provision and the appropriateness of literature. Moreover, this predominant professional account of legitimacy constructed user involvement itself as a *source of data* that might help to answer certain questions as defined by health professionals rather than as a more active, open-ended and self-defining contribution. As we see next, this understanding conflicted strongly with users' interpretations of involvement, informed by their deliberations in the NURG, even in relation to these managerially oriented questions.

Experience, knowledge and irreducibility: users' constructions of involvement

The emergent NURG discourse about the characteristics of the proper involved user emphasised the productive capabilities arising from the users' particular intersections of skills, background and experience. However, as already noted, even as this idea developed, involved users were happy to respond to questions of patient satisfaction and effective communication put to them by staff. In contrast to professionals, though, they did not construct even these contributions in the limited terms of their laity or biomedical status. Rather, they tended to emphasise much more the importance of their own role in interpreting and reflecting on these questions in making their contributions valid. Take, for example, Gemma's description of her own contribution to the literature provided for patients in Site G:

> "Being involved early on with the literature, that's made a difference. Just tweaking it really, because I thought, 'If I'm going to read something, if I was picking up something for the first time, how would I want it to be worded?' I wouldn't want it to be patronizing and I wouldn't want it to assume that I was uneducated, but then I also have to think, 'Well not everybody uses the same language that I use'. So it was important to get it as sensitive as it possibly could be, making sure it was readable for most people."

Here, then, a contribution to information provision was constructed not as the input of a more-or-less 'typical' user whose views must be balanced by the health professional and given credence according to the degree to which they are 'representative' or 'generic'. Rather, this process of scrutiny and analysis was something best done reflexively by the user herself, better placed to carry out this interpretive work than the health professional.

Common to most involved users was this construction of experiential knowledge as something unamenable to health professionals, beyond their epistemic grasp. Rather than an inert source of data to be drawn upon by professionals and reduced to their service-oriented frames of reference, clinical experience was something that could be accessed, interpreted and understood only by those who possessed it. It was up to users, then, to translate this into a valid contribution to improving health-service provision, not professionals. Among other implications, this meant quite a different characterization of the notions of representativeness and representation. Where staff seemed bound by a notion of representativeness as 'typicality', or at least the ability to speak to 'generic' issues, users constructed it more as a skill than an innate characteristic. As Harry put it, no two individual experiences could be quite the same. This diversity, though, was what made user involvement necessary in the first place, and it was through personal experience, and the degree to which this overlapped with that of others, that representativeness was possible:

> "You could never know how somebody felt, but at least now I can say to some people, 'Well I do know how you must feel, 'cause we've been through similar things'. […] You can understand how they must feel, […] you've been there and, although your bit's different, in the end it's the same."

Helen similarly saw her representative legitimacy as an active project, something which she had developed through time on account of her own experiences and those of others in similar situations with whom she had come into contact through her various voluntary activities. In this way, through time, "my voice became *the* voice. Not that I'm the voice of the populace, but I was not only doing it for myself: I was saying, actually, someone's got to say something here, it's not right."

In line with the discourse of the NURG described in the last chapter, then, status as a proper involved user was something to be achieved through time, and this applied just as much to representative legitimacy as it did to the other progressivist qualities required of the proper user. This saw experiential knowledge as an epistemically distinct domain that could not be reduced to the narrow frameworks of its worth and potential held by staff. Partly this was because of its emotive, subjective nature. More than this, though, it was because for users, staff's interpretive frameworks were shaped by the kinds of structural impediments to service delivery that the experiences of users led them to challenge. We noted in Chapter 6 how cancer-genetics service provision saw many users cross multiple 'silos' in the NHS, resulting in a somewhat fragmented experience. For many users, despite the 'joining-up' ethos of the Kenilworth model, the perspectives of many staff remained occluded by the silos in which they worked. In Site A, for example, Ava was keen to encourage her pilot to expand its educational work in primary care. Largely, though, she found her pleas falling on deaf ears:

> "I would have thought that one of the main points [of a Kenilworth pilot], apart from getting however many thousand through the sausage machine, was to raise awareness, really build a foundation of understanding within the health community, among district nurses, lead nurses. So I was expecting—I mean I've obviously got it wrong—but I was expecting it to be far more getting into [GP] surgeries, because that's what our lot need."

As Ava and others discovered, though, despite the degree of joining up to be achieved through the Kenilworth model, there remained significant aversion to their more radical ideas about integration deriving from their experiences of disjointed provision.

The notion of experiential knowledge, and the representativeness and legitimacy attached to it, that users held thus differed significantly from the more manageable, narrowly construed idea of experience as reducible to professional frameworks. The same was true of the contributions that users felt they could offer on account of their wider backgrounds and life experiences. As we have seen, professionals were willing to draw on certain skills of users if they fitted projects' stated aims. As such, contributions such as professional design or copyediting experience were particularly welcome. Users, though, saw a much greater potential for their involvement, often relating to the same managerial inadequacies that they perceived to have precipitated fragmented patient experiences. By and large, their contributions were clinically conservative, limited to criticism of inconsistencies of advice between clinicians, or perceived failures of 'sub-expert' clinicians to take on board the guidelines of 'centres of excellence'. Managerially, though, users were ambitious in the contributions they suggested, often drawing on their own professional backgrounds.

Once again, then, atypicality was seen by users as an aid to their legitimacy, not an impediment. If health professionals reduced users' contributions to their biomedical or lay identity, then for users they were neglecting the swathe of potentially useful contributions that involvement might provide. For users, the most potent aspects of their contribution derived from the very professionality of their perspectives, not from the constrained perspective of patient or layperson.

> "You don't become a different species just because you are [a cancer patient], and there's still all the same things that you know: you work in the same manner, your head works in the same manner, it's just on a different subject. […] The involvement of everybody is so important—it's using people's skills. I think there's a lot out there to be tapped, […] besides the information, and besides not being told what you want, […] I think there's a lot of skills out there they can tap." (Gayle)

As with particular experiences that might provide the commonality necessary for comprehension and translation into a valuable contribution, skills too were for users a source of legitimacy in themselves, not mere 'interference' with their ability to speak to 'generic' issues as patients or laypeople:

> "On the patient and carers group, we've got quite a good mix of people there with professional backgrounds, so some of us do know how things work. We might not know how the NHS works, but I mean we have an ex-bank manager. He has definitely sorted how the funding's going. We all have skills to bring to this, and this is what gets to me. All my professional

> experience has been on sharing skills, and if you're good at it, then why don't they let you run some workshops? Why don't they? How stupid! […] It's just having a clue about where people come from. One of my particular friends on the patient and carer group has got an MA in counselling from [University of Site A]. Right? So we're a pretty unusual crowd of folk, actually. And if you didn't know that about Asher, you would miss out on being able to use what he's got." (Ava)

Conflicting notions of involvement, the user and the public

In relation both to the constrained contributions that both parties agreed were legitimate, and to the more expansive contributions over which they generally disagreed, rather different interpretations of the role of involvement and the legitimacy of the user identity were evident. From the users' perspective, health professionals were characterizing their input in terms of its alterity: as a biomedicalized or lay 'other' to clinical professional expertise. In so doing, they were constraining the potential of involvement by limiting it to an unnecessarily narrow conception of representative legitimacy, and missing out on the range of skilled contributions that users could make by drawing on their wider life experiences, including professional knowledge. This was a distinctive body of knowledge with an epistemic autonomy over which they alone had sovereignty. Accordingly, the user identity needed to be defined not by what it *wasn't* ('lay' rather than professional; a subordinate 'patient' identity to the superordinate clinician), but by what users *did* and could do thanks to the rich breadth of their backgrounds and experiences, and their development into 'proper' involved users. Staff, though, were wary of such potential contributions, and tended to prefer a user input premised on much narrower identities and roles. These fitted in with their commonsense frames of reference about what involvement was for, or in some cases with their more nuanced and theorized understandings of its purpose, which diverged significantly from the NURG-inspired users' take on the same question. In particular, legitimacy was seen as resulting from disinterest rather than interest, in line with most staff's conception of representativeness as typicality rather than the result of a transformative process.

More fundamentally, what this divergence seemed to reflect was the rather different general assumptions of professionals and users about the relationship between the health service and the public, or between professional experts and 'lay' citizens. Staff recognized users' input as relevant only insofar as it conformed with their views of the legitimate domain of patients or laypeople, and as useful only insofar as it could be managed within their project's structurally confined role within the NHS. Once again, it is important to emphasise that this did not (to me) seem to be a matter of deliberate conspiracy to justify marginalization of unpalatable contributions, though professional self-identity and the organizational structures of the health service did seem to be implicated. Rather, it seemed that on the basis of the limited consideration health professionals had given to such matters, this was the 'natural' role for user involvement. Essentially, then, for most staff, the relationship was a deferential one, in which the user's contribution was about fine-tuning the 'end product' to make it as polished as possible:

> UI lead: Probably the most helpful thing about them is that they're members of the public, and they're a little bit removed.
>
> Graham: Removed from what, from sort of the day-to-day work or…
>
> UI lead: Well from the project. We can sit down and go, "How should this letter sound?" and someone outside of that can say.
>
> Graham: Why, I mean, why would they have a different view of that?
>
> UI lead: Well because it's all about jargon and how we express things and

> what we're trying to get out of it as opposed to what the end user wants out of it. It's sometimes easy to forget that you work for the user, and not for our purposes. (User-involvement lead, Site B)

This essentially consumerist model of involvement contrasted with the users' model which saw them more as active citizens speaking on behalf of their less motivated or able peers. As Macmillan respondent 2 put it to the users at the seventh NURG meeting, they were "stakeholders," not "patients," with an expansive role to play. Having highlighted the concordance with professional interests of staff's conception of involvement, though, it is important not to neglect the instrumentality of users' self-conception, too. Their legitimacy rested on their self-ascribed status as somehow representative of a wider public—itself loosely defined in the shifting terms of 'patients', 'potential patients', and the 'general public'—despite their particularity. Similarly, the influence they wanted to secure for themselves rested on a construction of their input as something which would lose its meaning and utility if reduced to professional frames of reference. Users described the efforts they had made to understand others' perspectives in order to make contributions that spoke to a collective interest, and the transformative process through which many went in the course of the NURG did indeed seem to involve a good deal of reflexivity on how they might offer a contribution that was somehow representative of wider interests, even if not typically or electorally so. Foundationally, though, their claim to representativeness was no more inherently valid than the claims of staff (Contandriopoulos *et al.*, 2004), and so required legitimacy work. It is at least partially in terms of this that one must understand exchanges of the kind I occasionally witnessed at the Pilots Together events: as struggles for influence based as much on the need to secure legitimacy as on substantive differences of philosophy:

> *MR5 speaks about the aims of the narratives being compiled at the NURG. Site B's clinical lead asks the presenter if a more 'authentic' approach to producing narratives*

> *might not be to talk to patients themselves rather than their representatives. Of course, responds MR5, most (though not all) of the users are patients too, but they are also mediating the narratives of others. One user (Helen) adds with some anger, "We are users: we represent more people than just ourselves."*

Discussion

Efforts to overcome the 'implementation gap' and put involvement into practice in the pilot sites generally faced protracted negotiations between users and staff, on account of the rather different notions of involvement they held. Despite the fact that staff's conceptions were generally less thoroughly thought through than users', they retained a determining power over what user involvement did in their sites (considered further in the next chapter). Negotiations around involvement therefore tended to result in uneasy compromises rather than overt stand-offs, and these compromises tended to involve contributions that were close to the focus on patient satisfaction and information provision that the process had originally involved.

To a large extent, the difference of expectations seemed related to the question of 'representativeness', which as Chapter 2 recounted is a vexed one in relation to public participation. For users, representativeness went beyond mere 'typicality', and was rather something that demanded active adaptation on their part, as they became representative through time. Additionally, the utility of the contributions they made was not limited to their representativeness, but was also premised on the skills that they could offer. For staff, a more constrained notion of representativeness dominated their interpretation of involvement, but despite the clear lack of formal, electoral or statistical representativeness on the part of involved users, staff did not use this to undermine their legitimacy. Instead, they led user involvement towards certain restricted domains, where the particularity that users embodied did not 'interfere' with their ability to give a perspective that was more widely valid.

There is a degree of divergence in this empirical narrative from that prominent in the literature. Rather than contesting the legitimacy of users, the construction of involvement articulated by the various staff tended to frame it, constituting its boundaries to fit with professionally acceptable terms of reference. This contrasts to some extent with the view that professional challenges to representative legitimacy are primarily about the retention of power: that "people's representativeness assumes importance if what they say threatens or challenges the *status quo*. This suggests that the function the argument serves is to neutralise and exclude" (Beresford & Campbell, 1994: 318; cf. Bowl, 1996; Crawford *et al.*, 2003; Contandriopoulos, 2004). The findings also seem to contrast with previous research which has found the acceptance of legitimacy by professionals and managers to be a means of pursuing strategic interests: "where a particular set of officials happens to be in agreement with a user group but in disagreement with other officials […] it makes sense to build up the legitimacy accorded to the user group" (Harrison & Mort, 1998: 66; cf. Daykin *et al.*, 2004). The concerns about representativeness held by professionals considered above seem considerably more substantive in nature, relating to the degree of legitimacy that could be accorded on the basis of 'typicality' in the absence of other forms of representativeness. This is not to say that they were not influenced also by a degree of instrumentality, and certainly their views seemed informed by the expectation of a relatively conservative power relationship between staff and users. However, the concerns could not be reduced to a logic of power retention or the pursuit of professional interests.

The particularities of the case may partly illuminate the reasons for this divergence. In common with many initiatives (e.g. Rutter *et al.*, 2004; Fudge *et al.*, 2008), the brief for involvement in this field—to secure the influence of "people affected by cancer"—was a broad one, subject to interpretation by the parties involved. However, the work of Macmillan to ensure that involvement in some form was put into practice meant that pilots needed to demonstrate that user involvement was being granted legitimacy and influence, not simply being marginalized. For staff, legitimate influence was about the narrow inputs noted above; for involved users, it extended to a more wideranging input, that included technocratic contributions and the role of representing a wider (though unclearly defined), disempowered public. Both constructions of the legitimate role for user involvement thus diverged to some extent from the loose, original remit as defined by the sponsors, and it may be significant here that the identity this ascribed—"people affected by cancer"—is not an especially oppressed or oppositional one, at least compared to other groups (for example, mental-health-service survivors) where user movements have been strong and their missions clearer. The rather more ambivalent user identity in this field, and the heterogeneity of the users asked to enact it, thus seemed to require a degree of reinterpretation on the part of both parties involved.

Practice on the ground, then, seemed somewhat detached from the constellation of policy-level rationales discussed in Chapter 2. The constructions of representativeness and the proper role for involvement put forward by each party could find justification in different strands of policy rhetoric. In Barnes *et al.*'s (2007) terms, users constructed participation in terms of a 'stakeholder' discourse, in which their status as users (in some sense) of the service gave them a stake and role in its good governance, and to some extent in terms of an 'empowerment' discourse, in which they articulated an input on behalf of a disempowered public which challenged dominant professional modes of service delivery. Staff saw participation in more 'consumerist' terms, though this was a rather more deferential consumerism than that envisaged in policy, reworked in the same way as Newman and Vidler (2006: 204) find professionals adopting the government's language of 'choice': through an "attempt to appropriate elements of consumerist discourse in order to secure the professional goals of improved health outcomes." But the degree to which any of these discourses was realized in practice was governed less by principle than by pragmatic negotiation within the sites, processes which the next chapter will consider in more detail. In this way, the findings emphasise Barnes et al.'s (2003, p.397) point, that "the importance of the micro processes through which official and lay discourses of the notion of 'representation' and legitimate participation are being negotiated suggests that the analysis of official discourse alone is insufficient to understand how 'the public' is constituted for public participation."

This leads to the more general question of exactly why representativeness is apparently so highly valued by professionals in relation to involvement initiatives. Even if, as argued here, there is a substantive, rather than purely instrumental, dimension to professional appeals to representativeness as a 'gold standard' for involvement, it is evident that for various reasons, consultative or participatory inputs to the health service that are deemed 'representative' in some sense tend to align closely with professional interests and other institutional forces. For example, quantitative surveys of patient satisfaction tend to produce verdicts that are largely positive (Fitzpatrick, 1991), and, when they are negative, they provide actionable suggestions that are reformist rather than revolutionary, conservative in their scope, deferential. Whether this alignment is due to a genuine conservatism and deference among 'the general public' itself, or to flaws in the tools of representation, is debatable. A more practical question might be whether professionals' interest in representativeness is due to genuine belief in its importance, or because representativeness seems to be a proxy for deference, conservatism and manageability. If initiatives that were considered representative made less manageable contributions, would representativeness still be seen as such a gold standard?

The next two chapters consider how involvement played out, nationally and locally, in the light of these emerging tensions. I begin by surveying the 'state of play' across the seven sites, illustrating certain constant themes in the views of staff, users and Macmillan facilitators on involvement—as well as certain differences between pilot sites, which until now have been glossed over somewhat.

9.

NEGOTIATING THE ROLE FOR INVOLVEMENT: USERS, PILOT STAFF AND MACMILLAN

This chapter begins by taking a brief 'tour' of the seven pilot sites, mapping the place of involvement in each. We see the results of the ambivalence over involvement described in Chapter 6, the emergent collective view of users in Chapter 7, and the conflict between this view and that of staff described in Chapter 8, in each pilot site. We also start to apprehend the differences, as well as the similarities, between the relationships operating in each site, which were perhaps missed by the aggregate-level analysis of previous chapters. After summarizing the commonalities and differences and highlighting particular issues of interest, the second part of the chapter returns to the national level. In response to these local situations, users and Macmillan started to take a slightly more proactive approach to guiding the development of involvement. Generally, this did not mean replacing the model of persuasion preferred by Macmillan with something more didactic, but it did involve a slightly more overt strategy of influence, which sought to hold up models of good practice for the less 'progressive' pilot staff to follow. Even this approach, however, was tempered for Macmillan and even for users by a desire not to undermine the approaches to involvement adopted elsewhere. For all concerned, there was a need to value all examples of involvement, however extensive or marginal, since the efforts of all parties—Macmillan, users, pilot staff—were implicated in their success or failure. In slightly more provocative terms, there was a 'conspiracy' to see worth in all forms of involvement, since uneasy compromises were better for everyone than the disintegration of whatever had been achieved. This tension—between offering a model of best practice, and valuing all approaches in their diversity—is crystallized in the existence of two parallel constructions of involvement notable in the discourse of Macmillan respondents, as a hierarchy or a spectrum of approaches.

User involvement in the seven pilot sites

First of all, though, we consider the practice of user involvement in each pilot. As noted above, the focus of analysis so far will perhaps have masked some of the diversity of views among users and staff. For example, Chapter 7's description of an emergent collective user perspective focused on the NURG, and so missed out the views of the users in Sites B and F, who either dissented from that perspective or were never present at the NURG. This section seeks, then, to do justice to the empirical detail and variation present in the seven sites. It also brings to the fore, though, some strikingly recurrent themes, some of which have already been discussed,[1] some of which will be noted in passing now, and some of which will be considered later.

Site A

From the start, the lead in Site A, a clinical geneticist, was keen to ensure that the service gained acceptance from wideranging stakeholders across the local cancer network. It relied on referrals from symptomatic cancer services which had previously performed

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[1] Where issues have already been discussed, I provide cross-references to original discussions.

their own risk assessments for patients with suspected family histories. Consequently, gaining the co-operation of the practitioners in these services was crucial to the pilot's sustainability.[2] Early on, a network-wide 'visioning event' was convened, which included the network's active patient and carer group—noted in a recent peer review of the network for its strong integration within the network's decision-making processes. For Ava, this had been a promising day which boded well for partnership between practitioners and users in further developments. There were, though, rather differing accounts from Ava and the service lead about the influence that the patient group had had on the day's proceedings. Ava felt that the contribution had been extensive and well received; for the lead, the day had been amicable, but users' inputs had been marginal:

> Lead: [The users'] comments, I can't remember them now but at the time I remember thinking, "My goodness, what an insightful comment, what a useful thought."
>
> Graham: What kind of things?
>
> Lead: They came up with [the titles given to the pilot nurses], and so we had a bit of a laugh about that. They didn't change the overall structure of the model, just tweaked bits, and they helped us produce monthly letters and information leaflets that go to the patients. So their involvement was very useful and relevant, but at no point did they actually change the structure in any major way.

As the project got underway, Ava became the main involved user, also taking an active role in the NURG. Through time, though, she became disillusioned with the extent to which any partnership between users and staff was actually emerging. For one

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[2] For more details on the pilot in Site A, see Martin *et al.* (2009a), in which Site A is referred to as 'Derton'.

thing, as someone who had never had cancer herself, she was keen that the pilot should broaden its user group to include those with direct experience of the service. The service lead was keen to ensure representation of the views of this constituency, but saw the more passive input of a patient-satisfaction survey as a more appropriate approach to this, since finding "a representative body of users" was unviable (see p.188f.).

For another thing, it became apparent that there was a fundamental difference between the priorities for the pilot defined by its lead, and those identified by Ava. Early on, in establishing the new care pathway across the network, the lead and his colleagues had provided several educational seminars for GPs in the area, instructing them on protocols, referral criteria and so on. Ava argued that this work could have gone much further, to build a "foundation of understanding" across the area, but found that the focus of the pilot was on throughput rather than educational needs in primary care (see p.198f.). For the service lead, though, this was never really the pilot's aim:

Lead: [Ava and I] have a fundamental disagreement about what the role of that teaching was, and every time we have a project group we nearly always end up talking about this disagreement.

Graham: What's the nature of the disagreement?

Lead: The project was set up with a programme of education to raise awareness about cancer genetics, about risk assessment and about the service. So you could argue that we weren't really teaching but advertising, but in a rather detailed way. I've never gone back to get feedback to say, "Was that helpful? Would you like more in the future?" Ava feels that I really should. I haven't had the time to do it; I didn't see that as a priority because what I was doing was using the teaching as a vehicle to get this service up and running: I wasn't doing teacher for teaching's sake.

At the root of this disagreement lay two crucial differences of perspective. Firstly, for Ava, the potential benefit of the pilot lay in the wider improvements in knowledge and provision it could instil across the health community. For the lead, service delivery was the priority—and when the project team was struck by staff departures and long-term sick leave, other aspects had to be sacrificed to ensure that service delivery continued. Secondly, the two parties disagreed about what constituted a legitimate outcome for the project, with the lead much more concerned with concrete, quantitative measures—of the kind that might be valued by NHS commissioners—than with more qualitative evaluations of effectiveness and learning points highlighted by Ava.

The nature of this difference of perspective was exemplified in a debate at the site's final project-group meeting. Ava advocated the potential benefit of a place for user involvement in the clinical pathway, whereby population-risk patients discharged by the service could contact members of the user-involvement group for further information or support. The project lead was sceptical; the nurse and genetic counsellor on the project attempted to mediate. My notes take up the story:

> *Lead says that we'd need to show how this would make a difference, because "like it or not, the NHS likes measures." Nurse: what about the PPI policy documents: they provide evidence of what involvement can achieve. Lead queries whether or not these are evidence based. Ava comments—in good humour but with evident frustration—"That's the problem, you're all scientists!" Lead says that this could be an opportunity to show the merit of user involvement in these (quantitative) terms. Ava says perhaps, then, we should keep a record of user involvement's input to evidence what we do. Nurse asks, but why does it always have to be quantified? Lead responds: because it does cost money, even if it's done on a voluntary basis. So we need to be able to "demonstrate the added value." You can describe this qualitatively, as long as you can also show the quantitative improvement: e.g. a saved outpatient appointment. "I'm a very quantitative person, I'll*

> *make no bones about it."*

There were clearly differing perspectives here, as evinced by Ava's rhetorical "you're all scientists!" and the lead's acceptance that he was indeed "a very quantitative person." This was not the sole source of the disagreement, though. An adjustment to the care pathway to include the opportunity for discussions with involved users would require sign-up from service commissioners. If it was not cost-neutral, it would need demonstrably to contribute to the service's utility. The lead went on to say that if including an advice service offered by the user group could save, say, 50 outpatient appointments a year, there would be a strong case for its inclusion in the pathway.

The obstacles to a more extensive involvement of users in the development and delivery of the service in Site A, then, were not just about the epistemic differences between user and professionals, though these were implicated. It was also clear that the expectations created by a commissioning process premised on measurable outcomes militated against the incorporation of users' ideas about a service which might offer psychosocial value to patients. Ironically, then, the commissioning system—which stresses the importance of involvement in service provision—seemed partly responsible for marginalizing its influence here, reducing it to something of a box-ticking exercise.

Site B

The pilot here focused on providing community-based clinics to improve accessibility for possible cancer-genetics patients, through referral from primary-care practitioners and self-referral, with a particular aim of improving uptake among minority-ethnic groups. Consequently, a key aim of involvement was obtaining the views of various individuals from these groups about how to do this most effectively. Betty was one of several users who put themselves forward, but it quickly became apparent that in the main, these weren't exactly the kinds of users that pilot staff had envisaged. There was only one 'real user', who had experienced the pilot service. Some others had been through the hospital's established cancer-genetics service, but the project's user-involvement lead bemoaned the fact they were at raised risk of cancer, and so there was no input from patients reassured of their population-level risk status about their experience.

The user-involvement lead, then, had had to settle for a group that did not really meet her requirements. Furthermore, in contrast to most other sites, it had no really vociferous members keen to contribute to the user-involvement agenda. Ultimately, with little to discuss at the user-group meetings, two years into the project, the user-involvement lead decided to cancel them, explaining:

> "I don't want to bring people in: unless we've got a lot of interesting things for them to talk about, it's a waste of their time. […] It's not a support group. They come here for a very specific reason."

In the absence of a clear and achievable rationale from the pilot, and with little impetus from users to keep the meetings going, involvement here became quickly marginalized.

Before it was disbanded, though, the user group did make some contributions. Despite the lack of members of the key target groups, users discussed issues of accessibility for those groups (see p.190f.). There was a sense, though, that the expectations of Macmillan were what guided these discussions, rather than an anticipation that they would provide a worthwhile contribution:

> "They're not actually users, most of them, so they can't come to me and say, 'When I came to the appointment, such and such, and then I wasn't comfortable about that'. That's not going to happen because only one of them has actually been through the service. So I always have an agenda. The conversation flows and often goes in a different direction, but I always have things to bring to them, because they don't know what's happening."
>
> (User-involvement lead)

As in Site A, the input of involvement was limited to relatively marginal tweaks, the structures of NHS systems and commissioning processes once again blamed for this:

> "We can't really do much about the care pathway that the users could influence. We have a care pathway set by the lead clinicians. I don't think the pathway into secondary or tertiary care could be revised like that. But for instance I'd like to change the name. […] One of the things we've had that at the user meeting is, 'What does this mean? Why put it there? Is it a support group?' Nobody really knew what it was, so we took it off fairly quickly. So that sort of thing I would take to the users, and say, 'Well, what do you think? Do you like this name? What would make more sense?' That kind of thing." (User-involvement lead)

This marginal user contribution in Site B was confirmed in the user-involvement section of the project's final report, quoted here in its entirety:

> Service users were recruited through the Clinical Genetics Department and the community clinics. Service users' ideas were sought about the location and promotion of the clinics and the design and content of all the publicity and patient letters.
>
> A patient satisfaction survey was devised with the help of the Service User Group and distributed to everyone attending the clinic over a 6 month period.

For Betty, it ultimately seemed that there was little for involvement to contribute beyond these consumerist basics. She was slightly disappointed that this left her marginal to decision-making, but accepted that 'the team'—i.e. the pilot's staff—had the service more-or-less sewn up:

> Graham: Are there any particular things that the service missed out on that it could have used you or the others for?

> Betty: I don't think so. It was very much the team. And they had a very strong team at [Site B]. […] They were very inclusive of me. But I didn't think I could do much, that's all. I really couldn't. I just attended meetings.

Site C

This pilot, too, was concerned with improving accessibility for ethnic-minority groups (the deprived Muslim south Asian community in particular), as well as those of lower socio-economic status more generally. The project struggled to find involved users, and it was only following an intervention from Macmillan respondent 4 that Chris—who had been involved with Cancerbackup locally—was recruited. With Chris onboard, the user-involvement lead searched for further users from backgrounds more in keeping with the target populations, and eventually recruited two south Asian users, Chanan and Chunna. The idea was that they would provide knowledge of the barriers preventing south Asian people from accessing cancer-genetics provision. This plan, the user-involvement lead acknowledged, was not exactly realized. Neither of the south Asian users recruited seemed to fit the representative bill she had had in mind:

> "[Chanan is] Sikh, middle-class, well educated, full-time job; I don't know what her husband does; I know that they live in a really big house in a nice area of [Site C], and they're a lovely family. Their children are all well educated and have got very good jobs, and they're very proud of them—quite rightly so—but she's not representative of the people that we're aiming the project at. Just because she's British Asian, I'm not sure makes her any more a representative of that group of people in [deprived area of Site C] than I am representative of somebody who lived in [that area] in a council house and had five kids and made 60 quid a week."

Chunna, though Muslim and working class, had told the user-involvement lead that she was "more Westernized than Asian," and so similarly was not seen to represent the service's target population.

The role anticipated, then, was not one the users could fulfil. Chunna withdrew from involvement for personal reasons; Chanan offered various inputs, but these were not as someone who had experienced barriers to access for south Asian people, but as an individual knowledgeable about these barriers, and about ways of encouraging uptake. She constructed herself as something of an intermediary, aware of the issues surrounding accessibility for south Asian patients, but not subject to them herself:

> Chanan: [The service wanted] somebody to be Asian there, 'cause the Asian community is very backward isn't it?
>
> Graham: In what way?
>
> Chanan: They won't come forward you know, they're shy and things like that. And especially the ladies.

What Chanan sought to offer to the service was a knowledge *about* the needs and wishes of the south Asian community—rather than a knowledge *from* direct experience of the barriers it faced—mirroring the kind of role anticipated by the NURG in Chapter 7 which envisaged representative capability as an active skill to be developed rather than a passive, innate attribute. Status as an individual of south Asian heritage informed this knowledge, but its abstract, rather than experiential, nature was not what the user-involvement lead had hoped for from involvement. There were certain useful contributions that Chanan and Chunna were able to make—for example, informing the service of a local Asian radio station that could help with publicity activities—but in the main, the user-involvement lead and her colleagues struggled to find productive activities for these users who lacked the socio-cultural or socio-economic identity sought. The user-involvement lead was reflective about what she saw as her own failure to recruit the 'right' kind of users:

> Nurse: Instead of the objective for me being, "I've got to recruit some user reps, and I would like them to be Asian," perhaps I should have taken a couple of steps and said, "OK, which group of society living in which area do I want to recruit these people from? Who can I go to to ask, to talk to people about this?" I should have done a mini-research thing. Found out what they needed.
>
> Graham: If you'd had the time and resources.
>
> Nurse: And hindsight. And I feel quite embarrassed now that it was just, you know, "I need to get a couple of Asian faces."

Lacking a clear remit beyond the unrealizable brief the user-involvement lead had initiated, involvement became marginal in this site, too. Chanan organized some awareness-raising events among the local Sikh population, and Chris continued to attend the project's steering-group meetings regularly. Staff from the project made occasional awareness-raising visits to Muslim community groups, and consulted with 'community leaders', but found this had little if any impact on referral rates. Meanwhile, user involvement felt increasingly like an activity in search of a rationale. At the steering-group meetings I attended in Site C, Chris was always present, but although she was willing to offer her views on the various issues raised, there was no discernable area where her involvement seemed central or influential. Rather, in these business meetings, with their focus on budgets, commissioning arrangements, engaging GPs and the like, there seemed little for involvement to offer (see Chapter 10 for further discussion). The user-involvement lead affirmed:

> "Whilst I firmly believe it is important to involve user representatives when you're talking about service development, I know that we haven't used our user representatives to their maximum abilities. But I don't know what to ask them to do. And I do feel that we've just been politically correct by

having them there."

Chris, too, was reflective about her involvement. Partnership working in Site C had been limited, she acknowledged in follow-up interview, but this was excused by the particular aims of the pilot's work, which made anything more wideranging unviable:

> Chris: There can be partnership. It depends how it's set up. It's just that [Site C] was very specific—you look at all of them, this was the most specific of the whole lot.
>
> Graham: The most ethnically focused I suppose.
>
> Chris: Yes, it was focused on a very—quite rightly—very specific subgroup.

Site D

As Chapter 7 described, for the NURG, the situation in Site D became emblematic of the problems caused by professionals' tendency to disregard the aims and potential of involvement. The consternation caused by the project's lack of consultation with its users on the letter sent out to potentially at-risk patients (see p.161f.), and by its preference for focus groups that might be populated by people with the 'wrong' kinds of motivations (p.175f.), was particularly notable. As also noted, though, the NURG's characterization was perhaps not wholly justified. Rather, as described in Chapter 8 (p.194f.), the user-involvement lead took involvement very seriously—but had an understanding of its place that differed markedly from that developing in the NURG.

One key aim of this pilot was establishing outreach nurse-led community clinics for self-referrals, aimed especially at ethnic-minority groups (south Asian groups again prominent among these). User involvement was focused, as we have seen, on questions of accessibility and evaluation of service quality in these clinics. As the user-involvement lead put it, "it's a good way of checking actually that services are working and functioning effectively, because although it's not a strict evaluation, it's a form of evaluation" (see the full quotation, p.194).

As in Site C, however, finding the right people to provide this anticipated contribution was not easy. In the course of the project, the user group comprised various individuals, some of whom had been through the service, but most were involved only temporarily, and neither of the two users who stayed the course—Dawn and one other—had been through the community clinics, though both had experience of inherited cancer. Both also envisaged rather more wideranging contributions than the staff, a divergence which arose, as far as the user-involvement lead was concerned, from a misunderstanding of the project's remit on the users' part. In relation to the second longstanding user, for example, the user-involvement lead explained:

> "There were larger issues about reducing the time that GPs would actually take to see somebody, which the project could do nothing about *per se*, and that's where [involvement] wasn't so useful, because it was ultimately going to be frustrating for her, because she may have misunderstood, actually, how much of an impact this project could have."

Dawn, similarly, tended towards the unrealistically wideranging in her contributions for the user-involvement lead (see p.168f.).

The lack of 'real users' in the group—and especially of minority-ethnic participants—was problematic for pilot staff. As in Site C, the project sought to consult certain 'experts' on ethnic-minority access to the NHS, including community leaders and employees of third-sector organizations, to assist with this. Again, though, the impact on referral levels from targeted groups was, by the admission of the pilot's final report, negligible. Meanwhile, the two focus groups were convened to obtain views from patients of the service on questions of access, experience and satisfaction. The user-involvement lead stated that the focus groups had provided some useful input to service development; for Dawn, though, they were undermined by the personal agenda of those who attended, as well as by their largely white, middle-class backgrounds:

> "They weren't really there for the right things. […] Unfortunately, the focus group were white, middle upper-middle class people, extremely articulate, and extremely intelligent. And what we wanted was to have the hard-to-reach people. The ethnic minorities, you know. Failed again."

It is not for me to reconcile this difference of perspectives on the success or otherwise of the focus groups. However, there is an interesting tension here in Dawn's testimony about the qualities required of 'appropriate' involved users. In the passage above, she sees the articulacy of the focus-group participants as a flaw in the process. Elsewhere, though, she constructs this as essential for the involved user: indeed in the same interview, she cites articulacy as "fairly top on my list" of required qualities. The crux of this apparent paradox seems to be in the contribution Dawn saw herself as offering the service. In line with the user-defined role of the 'proper user' presented in Chapters 7 and 8, it was in her skilled input that she saw value for the service, not in her identity as patient or layperson of a particular background. She described how she had offered various contributions to the service, including some based on her knowledge of deterrents to accessing the health service for south Asian communities, conversations with her own contacts in those communities, and her own observations. Clearly there are limits to the utility of such knowledge. But for Dawn, the service's own efforts were failing to provide anything that was appropriate or useful, and were bypassing, devaluing and undermining her persistent efforts to make what contribution she could. The service, meanwhile—as in Site C—preferred a user contribution based on knowledge *from* a community, rather than knowledge *about* it, as reflected in the rationale for the focus groups. When a more abstracted contribution was required, it was sought from more 'objective' sources, such as community leaders and third-sector organizations.

Site E

In Site E, the mode of delivering the Kenilworth model was slightly anomalous. It added risk assessment and triaging work to the existing portfolio of a team of community-based cancer nurses, accepting referrals from primary-care health professionals and referring onward for screening and genetic testing as necessary. Consequently, there was no pressing need here to achieve a requisite number of cases—indeed, a greater concern was that too many patients would result in overload—and this pilot had the lowest throughput of the seven. The pilot team focused on ensuring the staff of local GP practices were versed in referral criteria, on getting their IT system up and running, and on working with commissioners and hospital-based providers to put in place a screening service for those at moderately raised risk of inherited breast cancer—something which, despite a NICE mandate, had previously gone unfunded. Given this preoccupation, and the fact that self-referrals were not accepted for fear they might result in overwhelming demand, there was a sense, even from interviews with staff, that involvement was driven by Macmillan's mandate rather than from any expectation of major benefits:

> "[The users] have been useful in looking at the educational information we give to patients; they have been representing us at the wider user groups [i.e. the NURG]. So we have meetings about the project and the way forward, they obviously have an input there and put forward their opinions and views. So yes, they have been really important, it has been good value." (Genetic counsellor)

The marginality of user involvement to the pilot's preoccupations was also clear to the users, especially early on:

> Emma: I found it totally confusing, the first meeting, I have to say. Because they were talking about the computer side of it, and they

were talking about how they didn't have enough doctors on board and all this sort of thing, and it did seem a little bit—not a shambles, I wouldn't say shambles, because they were all very organized, but it just didn't seem to be going anywhere.

Graham: Yeah. And it wasn't clear at that time what you could contribute?

Emma: No, that's right, I just felt, "I'm not going to do any good here at all. I don't know why they want me here."

Graham: Mm. Do you think *they* knew why they wanted you there at that point?

Emma: I think they'd been told that they wanted me there. But I don't know if they realized why.

Later on, as seen in Chapter 7 (p.183f.), attendance at the NURG galvanized Emma and Emily somewhat, and both spoke in interviews (shortly after that NURG meeting) about how they might bring a more active contribution in future. This, though, did not transpire, as Emma attended only one further steering-group meeting in Site E, while Emily could not attend any.[3] Consequently, involvement remained limited to commenting on literature and patient-communication strategies, such as the automated letters the software—once functioning correctly—would produce for patients (see p.185f.). Alongside this, pilot staff conducted qualitative interviews with patients of the service to obtain feedback on provision, which were cited as an example of user involvement in its final report.

Seeking a greater level of involvement, Emma offered her time and energy to set up and run an information and support stall in the local hospital for anyone concerned about their risk of inherited cancer, following a model pursued in Site G. The staff in Site E did not reject this idea, but neither did they support it:

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[3] In contrast to most of the users elsewhere, both Emma and Emily had full-time jobs.

Emma: On the first diagnosis, 'cause a lot of people are so upset, that if there's somebody, non-professional, they could go in a room and sit with—obviously it would be voluntary, so you couldn't be there all the time—but I just think that would be quite a good idea.

Graham: So almost like a support group, only one-on-one kind of basis.

Emma: Yeah.

Graham: And did you say you had mentioned that to them?

Emma: I had, yeah, to a couple, but they said, "Oh yeah, that's a good idea," but nothing's ever happened.

Graham: What they've got other priorities or?

Emma: I don't really know. It's nothing to do with funding if it's voluntary, but perhaps they don't feel that we're qualified, they'd be a little bit frightened in case we did something wrong. But I did see that the girls from [Site G] in [the NURG], they've been trained. So it can be done. I don't know why [Site E] hasn't picked up on that really.

Whatever the specifics of the reasons for Site E's reluctance to sponsor such activity, in general terms it was clear that in a service-oriented project with multiple organizational challenges to address, this kind of supplementary idea was of insufficient importance to engage staff. This was in contrast to Site G, where the pilot was much more dependent on its users' efforts for its throughput and long-term viability.

Site F

After Site E, Site F's pilot had the next lowest patient throughput of the seven. Here, though, this was a considerable threat to the viability of the service, which employed two nurses full-time to cover a wide, sparsely populated area. Initially closed to self-referrals, the project changed its policy midway through the pilot period in order to boost throughput, and attempted various means of increasing referral numbers.

This included user involvement. From the start, here, involvement was notable for the proactive input of the two most prominent users, Fred and Fiona. Both had previously been assessed as at genetic risk of cancer, and both had clear ideas about the skills they could deploy in helping the pilot to establish itself. Fred—a retired accountant—applied himself to the pilot's business case for ongoing funding, offering expert input on this, and declaring himself astounded at the "illogical" NHS structures the pilot nurses had to deal with. Fiona, whose background was in communications, helped the service to maximize its exposure in the local media, offering advice about obtaining editorial coverage, for example. Both users also offered input into patient-satisfaction questionnaires and publicity materials. Neither attended the NURG at any point (Site F was the only pilot which never 'sent' any user to a NURG meeting).

Site F was somewhat unusual, then, in that staff here were seemingly rather more open to the skills-based suggestions of the users than in other pilots (Site G excepted). Nevertheless, even here, the limits to the utility of involvement were evident. There was a sense from my interview with the user-involvement lead that she doubted how far the users' contributions would in practice be helpful, despite their undoubted professional expertise. For example, in relation to Fred's work on the business case:

> Nurse: He's got the ideas, but how I can use those ideas has been difficult, because this is the way we work, and I can't change that alone, and it's been difficult to take forward those ideas he's had.
>
> Graham: Yeah to sort of translate them into the language they need to be in.
>
> Nurse: Yeah. I mean what he's said is so valid. But I suppose a lot of it, when it comes to writing our final report and bid strategy for the future, I think his comments *are* very valid, and I will take that onboard, go through that with [other nurse], because she's going

> to be doing the final figures. But we would have done that anyway, because the audit work to find out what's happened to all these people and how we can demonstrate that we are saving the NHS money, we would have done that anyway, even if Fred hadn't come up with those ideas.

To some extent, then, here too there was a sense that these skills-based activities were filling time, giving users something to do, after basic activities such as literature checking had been exhausted. It was easy, the user-involvement lead acknowledged, for staff to put involvement "on the backburner" given the other, pressing tasks they could apply themselves to, and in the absence of a connection with the NURG, this work at least kept the group occupied:

> "They were ready, they were here, they were willing, but I didn't really know what else to do with the group, because we'd had so many discussions initially about their own experience, and the potential new project, that kind of thing, and then it all calmed down, and they wanted me to find them work to do. And apart from putting up posters, which they've all done in their areas, I didn't know really what else to do with them, and perhaps that's the fault of myself. But from speaking to the other pilots, I think they felt similar."

One possibility that the user-involvement lead did regard as promising was a more proactive role for involved users in the marketing activities in which the pilot was engaging, in an effort to boost referral rates. Learning of the success of such efforts in Site G at a Pilots Together event, the user-involvement lead asked the users if they would like to attend the town-centre stalls that the pilot was organizing. None was willing. Similarly, following its shortlisting for a regional NHS innovation award, the service was asked to film a video involving interviews with past patients. Again, none of the users was willing to participate.

When the NURG discussed the absence of users from certain pilots, the assumption tended to be that staff were not offering their users sufficient encouragement to attend the meetings. Similarly, the failure of other pilots to emulate the good practice of Site G, with its active involvement of users described next, was blamed on staff unwillingness. In Site F, this was not the case: the pilot's aims, its search for impetus on involvement and its struggle to increase throughput saw its staff trying hard to encourage both of these things, but without success, emphasising the importance of the willingness of users to fulfil such tasks, as well as the power of staff.

Site G

Led by a nurse and PCT-based manager, this pilot sought to improve provision and accessibility for the population of the ethnically diverse, economically deprived area of Site G, accepting referrals from health professionals and self-referrals. From the start, its staff were proactive in seeking out users to assist with this. The two users, Gayle and Gemma, were selected purposively by the user-involvement lead from her past patients for their skills, experiences and complementarity:

> "One reason was that I had a really good relationship with them because of my previous role: I was their clinical nurse specialist for breast cancer. Two, they both had very different stories to tell, very different backgrounds, but I felt their backgrounds probably complemented each other to a certain extent. Which was a gamble because I didn't know if they would. They both have just the right personality to be able to do this and they both have commitment; I perceived they would have commitment to the project."

Either Gayle, Gemma or both were present at nearly every project-group meeting I attended in Site G, and were always central to discussions, the staff actively encouraging their contributions to all aspects of the pilot. Their backgrounds—in project management and education—informed this input. The pilot's manager commented to me in interview, only half-jokingly, "I think they could manage our service, actually."

The most important aspect of their input, though, according to the users themselves and the staff, was their contribution to publicity. This was a key rationale from the start, and the staff attributed much of the service's success in terms of throughput to the users' efforts in initiating media coverage and attending publicity events, presenting their 'stories' to those in attendance:

> "They have gone out and sold the service with us by telling their story as to why they've become involved. […] And they're just wonderful. We wouldn't have been able to sell this service without their interaction because no matter how well we sell it, it's when people hear their stories that it actually is sold to the people we're talking to." (User-involvement lead)

In presentations to professionals and potential patients, the users gave accounts of their experiences of risk assessment for hereditary cancer—from initial shock, through struggling to come to terms, to a realization of the benefits of diagnosis to them and their families—which provided an emotional counterpoint to the staff's drier presentations about prevalence, referral criteria and the care pathway. For the users, then, this was a role that successfully melded their skills and wider life experiences into a productive contribution. It left users and staff alike satisfied with their synergistic partnership, and provided a model of involvement which Macmillan began to proffer to other sites as an example of good practice (see later in this chapter).

This is not to say this partnership emerged without the need for negotiation, or without some conflict, however well managed. In particular, what was notable was the compromise required between what users saw as the irreducibility of their contribution, and the need for their input to contribute to the interests of the service. Gemma, for example, described the disagreement she had had with the user-involvement lead as they incorporated her personal contribution into public presentations:

> "[User-involvement lead] tried to pull one of my slides out of the presentation and I just said, 'I don't think so! That slides is really important to me'. We'd discussed it, why she felt it wasn't appropriate for this particular presentation. Because obviously it's my story and I'm passionate about it. I said, 'Well actually, I want it to stay in', and we had a discussion about it. […] We went away again, and I thought again about she'd been saying to me, and I had to take myself out and try and think, 'Does it actually fit into this presentation? What is she saying to me?' Tried to take the personal element out of it. 'Is it relevant? Is it going to be distressing for this certain group? Am I trying to package it for this certain group?' So I had to go through a massive questioning, and I saw where she was coming from, and I actually ended up agreeing with her."

For Gemma, her personal history rested on its narrative integrity for its authenticity, and so to remove a central part of it (the slide in question depicted Gemma in hospital, at the low point of her cancer therapy) in order to 'package' it for an audience seemed instinctively inappropriate. Gemma was resistant to "prettying it up," seeing the power of her story in engaging audiences as deriving from its lows as well as its highs: "I'm there as the person that I am—that's the balance. This is where I've been; I'm here now; and look, I'm alright—alright as I can be." To alter her story according to audience was for Gemma to betray personal integrity for professional expediency, although sometimes she was prepared to compromise on this.

Gayle, too, made presentations about her experience, though she found it less difficult to 'package' her autobiography than Gemma:

> "[It] isn't a problem for me, because it's the sort of thing I did in my working life. […] Gemma found it more difficult, as it is very important to

> her to talk about her journey and the effects, and so she's reluctant to let certain parts of it go. Whereas [user-involvement lead] would say, 'These people are not really involved in that angle any more'. I suppose in that sense, I can treat it more as a business than Gemma."

Through time, opportunities for presenting about the service to new groups decreased, and Gemma and Gayle became involved more closely with the pilot's plans for sustainability. They were involved in face-to-face meetings with commissioners, testifying to the service's worth, and were granted volunteer status by Site G's PCT, allowing them to claim expenses for their work, and formalizing their contribution into a specific role description (see Chapter 10).

The service received ongoing funding from the PCT, after which Gemma withdrew for personal reasons, but Gayle continued, and assisted the manager in her efforts to improve integration with wider services, and to extend provision to neighbouring PCTs. Again, Gayle's contributions seemed valued:

> "Gayle has agreed to join [a palliative care group] with me, but she knows that if anything hits a raw nerve or gets a bit close, she can back off at any point. But, I must admit, we've only had one meeting and the first time I took her, the phone calls I've had since: 'Fantastic patient user', how wonderful she was, and 'I can't believe she has so much to say about it all and she's so sensible'. But that's perhaps because she's got so used to that sort of professional environment." (Pilot manager)

In particular, then, Gayle's ability to tailor her contribution for professional audiences seemed valued by the professionals she encountered in her still-developing role.

Issues arising from the seven sites

By considering each pilot in turn, the section above has, I hope, grounded some of the themes delineated earlier, as well as highlighting others given more attention later. Certain issues are relevant across most sites, though apparent also are exceptions that were perhaps glossed over by the aggregate analysis pursued in previous chapters.

First of all, it is clear that in each site, staff ultimately retained control over the form involvement took. This is an obvious observation, but one that is perhaps elided by the connotations of the term 'partnership', and academic definitions, such as that of Chadderton (1995) (quoted on p.137), which emphasise "shared power" and "equality of influence." Even in the one site universally characterized by its staff, users, the NURG and Macmillan as representing a partnership, users had to ensure that their contribution fitted professionally determined agenda. More generally, what also emerges as a trend from the seven sites is that the degree of integration or marginality of involvement seemed to rest in part on the form taken by the local interpretation of the Kenilworth model. The pilots in Sites A, C and E were oriented towards shifting responsibilities between professionals within the health system, and this seemed to limit user involvement's potential contribution—at least as far as staff were concerned. In contrast, in Sites G and, later, F, the reliance in part on self-referrals precipitated concerted efforts to raise awareness among the public, and attempts (of differing success) to involve the users in this process. For staff, then, legitimate boundaries to involvement's influence were determined by these organizational issues—although for users (as seen, for example, in Site D), these boundaries were often illegitimate, the result of the institutionalized perspective of professionals bounded by health-service silos. The institutional constraints on user involvement are well documented in the literature (Brown, 2001; Callaghan & Wistow, 2006; Carr, 2007; Daykin *et al.*, 2004; Harrison & Mort, 1998; Rowe & Shepherd, 2002); the contrast between the sites in this study illustrates how such forces may also, though, encourage involvement (of certain kinds). It should also be noted—in contrast to the emerging discourse of the NURG—

that where involvement was not so extensive, this was not always due to professional resistance, but sometimes the result of users' own preferences—as with the absence of Site F's users from the NURG, for example.

Generally speaking, though, involvement did not appear to be high among professionals' priorities. There were signs in Sites A, B, C and E that it was one extra task on top of many others. Although, in the context of interviews on the subject, professional respondents were understandably keen to highlight their enthusiasm for involvement, it was sometimes apparent that their work was driven more by the need to do something than by faith in what it might produce. There was a sense from some sites (A and B) that NHS commissioning arrangements militated against greater involvement in the clinical aspects of planning and provision on account of the need for (quantitative) evidence of the effectiveness of all parts of the care pathway—though it should be noted that this did not prevent Site G, with its extensive user-involvement component, from receiving ongoing funding. Nevertheless, the potential tension between evidence-based medicine (EBM) and involvement is noted elsewhere (Jones *et al.*, 2004; Sanders *et al.*, 2008), and despite a policy-level emphasis on public participation in commissioning (Secretary of State for Health, 2006; Martin, 2009c), concern for the requirements of commissioners often seemed to discourage more wideranging involvement.

Another point arising from the tour of the sites is the contrast between users' and professionals' understandings of the role and aim of involvement. This, of course, was the focus of Chapter 8, but a few supplementary points might be made from the above analysis. In various sites (notably B, C and D), a key concern of user-involvement leads, at least early on in their efforts, was to attempt to involve users who were 'representative' or 'typical' of those at whom provision was aimed. Commonly, these included people from minority-ethnic (and particularly Muslim south Asian) backgrounds, though target groups also included the wider socio-economically disadvantaged population, and (in Site B) those who had been through the service, and were found not to be at raised hereditary risk of cancer. For various reasons, most of the users recruited in practice were not, in the eyes of user-involvement leads, what was required. Rather than offering a contribution premised on their commonality with the target groups, these users gave a more detached perspective, speaking from their self-perceived knowledge *about* what would be of concern to members of the target populations. Rightly or wrongly, user-involvement leads did not see the comments of Chanan, for example, on the best ways to access the south Asian population, or the views of Dawn on the barriers preventing south Asian individuals from taking up the service, as useful contributions. They did, though, consult with more formal sources of abstract knowledge of the barriers to provision faced by these 'hard-to-reach' groups: 'experts of community' (Rose, 1999) such as third-sector outreach activists, community leaders and, indeed, academics. But what they were looking for from their involved users was something different: subjective, insider knowledge, not this more abstracted, objectivized, expert perspective. This view reversed the NURG's emphasis on the need for those involved to develop into 'proper involved users', to become rather than to be. This emphasises the point made in Chapter 8 about the differing notions of representativeness held by users and most staff—and highlights, perhaps, the problematic tensions in each.

Such a contribution was not, however, forthcoming, and it seemed in a sense that user-involvement leads were searching for a chimaera. The user required would be an 'authentic' member of the community targeted—sharing key commonalities of ethnicity, socio-economic status, culture, geography and so on—but would also have succeeded in accessing the service. Consequently, they would be able to advise about what it was that was preventing others from the same community from accessing that service, and how to intervene to improve uptake from that community. Rather than 'objective experts' on the barriers to provision, user-involvement leads wanted individuals who could explain the barriers faced by their peers, how they overcame these themselves, and how others might overcome them too. It was perhaps inevitable that such individuals—typical of the population being targeted but also able personally to overcome the barriers to provision, and thereby provide this insider information to health professionals—could not be found. This essentially behaviourist conception of the obstacles to provision faced by 'hard-to-reach' groups, and how they might be overcome by interventions to encourage individual agency, reflects the search for representatives of communities to inform targeted policy interventions described by Green (2005: 134), with the public asked "to contribute to thinking through how they can best be shaped and governed." The concerns of staff for representativeness among their users outlined in the previous chapter, then, might also be understood in this light, with user involvement a means of enunciating the barriers faced by 'typical' members of a public, so that the health service could ameliorate those problems so that others could access provision.

One final point from the individual sites should be made. What is clear from all seven pilots is that involvement, whether extensive or not, was shaped, primarily, by pragmatic negotiations between staff and users locally, and the viable compromises between the needs and wishes of the project staff and the capacities and wishes of the users. Despite the broad rhetorical aim outlined in Chapters 4 and 6, of giving voice to "people affected by cancer," or the even broader rationales outlined in Chapters 1 and 2, such as plugging the democratic deficit, user involvement emerged as a pragmatic response to local circumstance. The need for a contribution to Site G's publicity activities, or to service evaluation in Site D, or for some kind of evidence of user involvement of any kind in many of the sites, took precedence over such abstract aims.

The extent to which user involvement was taken seriously, then, did not necessarily correlate with the extent to which the grand potential claimed for involvement in general was fulfilled. The gap between policy intention and practical realization is taken up in the discussion chapter.

National-level negotiations

The disparities in user-involvement practice across the seven sites were a source of some consternation for the members of the NURG, as Chapter 7 began to show. In all but one of the pilots, involvement seemed comparatively marginal. At best, staff were failing to make use of the skills that the NURG's users felt they could offer. The partnership that was seen to emerge in Site G fuelled the NURG's discontent about the situation in the other pilots, informing its vision of what could—and should—be achieved. As early as the fourth meeting of the NURG, these concerns were evident, and with them, a growing sense among users that Macmillan's non-directive stance needed some adjustment:

> *Ava argues that there's a need for a 'how to' list on involvement: the pilots know why they are doing it but not how to. […] "They're not complacent, that's too strong a word, but they are happy to do user involvement as they've ticked the box"—they need to be made to see how involvement can help them. Yes, says, MR1, we need to "turn the light on." The event for user-involvement leads sought to achieve this, he adds. According to Ava, however (others agree), it did not, and we need further sessions for the leads to show them the 'how'. MR1 suggests that one possibility is a user attending the next event for user-involvement leads, or to use other examples from Macmillan's experience to show how involvement has made a difference to health professionals: "living examples" of its worth. Dawn agrees with Ava: Site D's attitude was "We've got the users, yes! Now tick the box." They need a list of things for which users can be used.*

A second event for user-involvement leads did indeed follow, but at the NURG, the users were increasingly keen to see direct interventions from Macmillan about how the seven sites should accomplish involvement, pushing them towards a model more in keeping with Site G's partnership approach.

Macmillan staff, though, remained keen to avoid imposition as far as possible. For one thing, as discussed in Chapter 6, this was in tune with the organization's wider remit as a body which sought to affect the NHS through lateral influence, in keeping with the prevailing tendency of policy towards 'network governance' rather than top-down diktat. More pragmatically, Macmillan respondents were concerned that to impose 'partnership' would be to destroy its very essence. Partnership relied for its existence on mutual respect, the bracketing of power relationships, and above all, an investment from both sides premised on belief in the *worth* of partnership working—not because of external requirement.

> "It's very much about partnership working and influence, not about 'It is our right; therefore you must do': it's not about that, because that undermines the whole point. […] The whole thing is about talking with health-care professionals, and health-care professionals talking to patients and carers. Not about patients and carers saying, 'We must have this; you must do that'." (MR2)

If driven by exogenous pressure rather than by intrinsic motivation—faith in the value of working with the other party—then partnership was an illusion. *Real* partnership required collaborative will to reach mutually agreeable outcomes through discussion, from both parties.

Broadly, the involved users on the NURG accepted this reasoning. As Ava put it at the fifth NURG meeting, there was no shortcut to partnership: it required work to achieve "respect for each other: you have to feel personally part of the group, part of the team." On only one occasion, therefore, did the users and the Macmillan staff at the NURG agree to issue a direct instruction to a pilot: in relation to the letter sent to at-risk patients in Site D without Dawn's knowledge or comment. Rather, in general, they saw the task as being one of instilling the right attitude in the parties concerned with user involvement, so that it might blossom elsewhere as in Site G. As Macmillan respondent 2 put it, reaching this attitude required a major shift in mentality for both parties:

> "The dialogue needs to be person to person. That actually requires a change of mindset. If you are a health-care professional, and you're used to diagnosing, providing treatment, providing pain relief, whatever, it is what you're doing as a health-care professional *to* that patient. But actually when you're working in partnership with somebody, it's not patient [to] health-care professional, it's actually human being to human being, and it's quite difficult—on both parts—to come at the relationship from that perspective."

As seen in Chapter 7, however, in their notion of the 'proper' involved user, this 'right attitude' was something that members of the NURG tended to see themselves as already embodying. They had escaped the role of the patient, and their progressive, collaboratively oriented outlook meant they were well prepared for partnership working. The task, therefore, was to imbue a similar mentality among staff, whom they saw as remaining mired in the paternalistic perspective of the health-care professional.

Rather than imposing a vision of what involvement should do or how it should do it, then, this approach instead worked to normalize a view of what constituted a 'proper' mentality with regard to user involvement. It called for an openness and collaborative spirit that were seemingly neutral, inherently positive, and applicable to both sides—but which also seemed to place a particular onus on staff to alter their approach. Constructing user involvement as an exchange between equals, it rendered professional conceptions of involvement as 'evaluation' or needs assessment untenable, as falling short of this partnership standard. Pilot staff, meanwhile, had no national forum of their own in which to articulate an alternative conceptualization of user involvement (along the lines, say, of consultation rather than partnership working). Consequently, as time passed, Macmillan became somewhat clearer in defining what user involvement should be about. In communicating this view of involvement as partnership to the pilots, its staff remained careful not to impose. What was discernible from its discourse, however, was a rather more normative emphasis on the need for orientation towards partnership, which applied in principle equally to users and staff—but which in practice was clearly aimed principally at staff in sites where involvement was marginal.

Imbuing partnership

This effort involved various discursive strategies. At the biannual Pilots Together events, there was always at least one slot devoted to involvement. Early on, these tended to be round-table events at which pilots could share knowledge, experience and tips, but through time, they became slightly more instructive (at the request of the pilot staff, too, who, as Chapter 6 noted, were often struggling to maintain user involvement as they ran out of ideas about what to do). At the sixth NURG meeting, the question of how to convey the need for a change of attitude to staff was discussed. Macmillan respondent 4 suggested

> *a session at the Together event on the user's and the professional's perspective: a real honest look at how they feel, how they change, what they learn from each other. MR3 sees this as a good idea, and knows some professionals she can call on who would be willing to do this, and say how they've changed, what their fears were, etc.*

The purpose of this exercise, then, was to present a case of the 'converted' professional to help to spread the word to the unconverted. In a similar vein, the second meeting for user-involvement leads included (as mooted in the excerpt from the NURG on p.235) a joint presentation from Gayle and Site G's user-involvement lead, as Macmillan sought to spread the learning from this example of 'best practice' to the other sites.

Similarly, the narratives composed at the NURG meetings (see p.157f.) served a parallel instrumental objective, and were circulated at Pilots Together events to illustrate the potential benefits of involvement. Written by a Macmillan staff member who drew on the testimony of the users at the NURG meetings, these constructed a desirable image of the potential of partnership, given the right attitudes from involved users and staff. One narrative, for example, described the early influence of Ava in Site A, when the cancer network's 'visioning event' brought together stakeholders including users and various professionals. This typified the construction of successful involvement as requiring an openness and reflexivity on the part of professionals:

> The pilot lead (a consultant) said [following the visioning event] how much he'd learnt on that day. Laughing, he admitted he had been "furious" on his drive home because he could see that he would have to "think his beautiful plan through again!" He later commented that he "never thought he would get so much from a user group."[4]

The selection of cases for the narratives was explicitly guided by a degree of instrumentality in trying to convey messages about the 'right attitude'. Macmillan respondent 5 explained the reasons for choosing Ava as a subject:

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[4] It should be noted that upon reading it, the consultant in question took issue with the way he had been represented in the narrative, as derived from the Macmillan staff member's interpretation of Ava's account of his actions. In interview he said: "I remember reading this in my office and going through to [genetic counsellor] and saying, 'Have you seen this? Bloody hell, what a cheek!'" This perhaps indicates how, through their various stages of mediation, these narratives were subject to some 'artistic licence' to achieve their instrumental purpose.

> "That was before [Site G] got going with their service-user involvement, so at the stage, when we were looking for a case study, she was the example, she was the service user who had most influenced her project. She's articulate and she's got quite a general view, she definitely doesn't have a hobby horse. So I think she was just chosen for that reason, really."

Through the examples of best practice, the narratives, and the reflections of 'converted' professionals, then, Macmillan sought not only to present ideas about what (partnership-oriented) involvement could do and how it could be achieved, but also to demonstrate the *necessity* of an open and reflective disposition among staff. As Macmillan respondent 3 put it, it was, she felt, the absence of this attitude to involvement that had been responsible for its marginality in six of the seven sites:

> "When I look at the projects that are struggling, I think, 'If you had only said, 'Right, what can you do to help us achieve this?' I think they would be having a similar success to [Site G], you know."

Pilot staff, however, were less convinced that the difficulties they faced could be so easily overcome. For many, the organizational remit of their pilot precluded the kind of extensive involvement witnessed in Site G in relation to the pilot's publicity activities. Even those pilots that did put considerable effort into user involvement (for example, Sites C and F) found that its scope remained limited. Nevertheless, the calls from Macmillan for pilot staff to adopt the 'right attitude' in dealing with users did have some impact. If nothing else, being *seen* to be approaching involvement in the proper way seemed to become an important preoccupation for the pilots.

Consequently, the prevalent view among involved users, accepted by Macmillan staff—that many pilots had treated involvement as a 'box-ticking exercise'—became an important one for pilots to counter. Presentations from the pilots at later Pilots Together events almost always included a slide or two devoted to user involvement, and often acknowledgement of the valued input of involved users at the end. There was sometimes a disjuncture between public declarations of user involvement's value and private confessions, in interview, to exasperation or continued confusion about the worth of the exercise. For example, take the words of Site C's user-involvement lead on Chris's contribution:

> "We never ask her to do anything really. She comes to the meetings and she contributes to what's said in the meetings. She goes to the national user group, and I don't know what she says there about this damned project. And I wish—I wish!—I had something that I could say, 'Oh Chris, I really want you to be involved in this,' but I don't know. I wouldn't know what to ask her."

Even within interviews, there were tensions between general expressions of the value of involvement to projects, and more specific admissions of bewilderment about what exactly it could contribute to service development, beyond the basics. As Site F's user-involvement lead put it, "I don't want to say that we haven't achieved a lot, 'cause I think we have, but I'm not sure of what exact benefit it's been really."

Macmillan's insistence, then, on the importance of a transformed mentality among staff towards involvement meant that pilots had at least to show willing, even if outcomes were lacking. Effectively, not being seen to treat involvement as a 'box-ticking exercise' became an important box to tick! Moreover, this 'proper attitude' towards involvement implied seeing users as equal partners, rather than just patients or laypeople to be consulted—in contrast to the prevailing view of user involvement among staff, discussed in Chapter 8. Rhetorically, then, the normative view of involvement seemed to be shifting towards that of the users, with involvement as partnership between staff and users, and users' contribution as epistemically equivalent to that of staff, irreducible to their frames of reference.

Partnership: apex of a hierarchy or hue in a spectrum?

Yet this construction of involvement was tempered by Macmillan's own discourse. On the one hand, partnership was an ideal to which to aspire, involving transformation of attitudes and engagement of equals, and the manifold benefits these might produce. On the other hand, partnership was concurrently constructed as one option among many, different from, but not superior to, other forms of involvement, such as consultation. Macmillan respondent 2 summarized this second construction:

> "Within Macmillan there is a growing trend to say that you can get involved in a number of ways, on a number of different levels. And self-help and support is seen as a level of getting involved. There isn't any requirement to make changes to service improvement, but you're still becoming involved: you're supporting others. […] So that's a level of involvement, whereas partnership working, at the other end of the spectrum, there is a definite requirement within the partnership groups to have an impact on service improvement. So there's two complete opposite ends of a spectrum, but they're all user involvement. […] And this isn't meant to mean that one's more important than the other."

Official Macmillan documents trod a narrow discursive path between these two constructions of involvement and the status of partnership within it:

> [People] can gain emotional strength from their membership [of support groups] and as a consequence find themselves wanting to be more active and to 'move along the line toward partnership working'. Between self help and support and partnership working there are numerous ways in which people affected by cancer can and do get involved. (Macmillan, 2005: 12)

The emphasis in such documents was on the validity and utility of all these "numerous ways" for people to be involved, even as they spoke of desire to "become more active and 'move along the line toward partnership'" in a way that recalls the progressivist NURG discourse discussed in Chapter 7.

There was thus a difficult balancing act for Macmillan to manage. Whilst seeking to value the partnership-based involvement that it (and the NURG) saw as constituting best practice, it was important also to ensure that those diverging from this ideal were not alienated by this tactic of persuasion. This applied not only to pilot staff, but also to users who were content with less active involvement, such as Betty. Thus Macmillan staff were keen to emphasise that there was a place for all contributions in the broad church of involvement. This included those not (yet) at the 'right point' in the 'cancer journey' to make a contribution in partnership:

> "Partnership working is wanting to make a service improvement, it's about moving from your own personal want, need, to the greater need. […] If a person isn't necessarily going to benefit, and neither is the group, then you say, 'This might be better, maybe a self-help and support group', if there happens to be one in your area, or, 'Maybe you want to get involved in campaigns'. Just that they might not be ready." (MR2)

For the sake of users as well as staff, then, it was important to view these diverse forms of involvement as different from, but not inferior to, partnership.

All three parties—Macmillan, users, and pilot staff—had a stake in the perceived success of involvement, since it depended on the skills and efforts of each. Thus attempts by Macmillan to promote 'best practice' were alloyed by a concern not to alienate those staff (and users) who held different ideas, since any form of involvement—even the uneasy compromises that had emerged in some areas—was seen as better than none. Those involved were thus generally content to suffer compromises in which all could envision some success. Even whilst highlighting the good work done in Site G, then, presentations from Macmillan staff on involvement at the Pilots

Together events recognized the efforts being made by other pilots. Outputs from the programme similarly emphasised the range of user involvement across the sites and its centrality to all of them. For example, an editorial on the pilot programme, co-authored by a team including Macmillan staff and one pilot lead, stated simply that "users were a key and central part of this pilot programme" (Eeles *et al.*, 2007: 166). Even the paper on the NURG derived from the narratives concluded:

> After more than two years, user involvement still varied across the seven projects. It was certainly more 'visible' in some projects than others, judging by the conversations of the group. […] This does not mean, however, that these projects do not have user involvement processes. In coming months, it will be worth investigating in more depth the different forms of user involvement in the pilot projects, from basic consultation to full partnership. (Donaldson *et al.*, 2007: 255)

Thus in the context of Macmillan's more general reluctance to dictate, the increasing tendency to identify models of good practice for the pilots to follow, valuing 'partnership' (and the attitudinal shifts it implied) as the optimal form of involvement, was always tempered, and never amounted to something that Macmillan sought to impose forcibly on the pilots which 'fell short'.

Summary

The disparity in the ways involvement was put into practice across the seven sites was an increasing cause of concern for the NURG, which transmitted its views to Macmillan. This resulted in a slightly more directive approach from Macmillan staff towards the pilot sites, but one which focused on the proper 'attitude' required to make involvement work meaningfully, rather than on the substance of what it should involve. Even then, this directiveness was tempered by the need of all parties—Macmillan and the users themselves included—to value what existed, since each had a stake in finding success in its endeavours, and any involvement was better than risking alienating those sites which fell short of best practice. The outcome, then, reflects Fudge *et al.*'s (2008: 314-316) account of user involvement in a stroke-service improvement programme, which similarly ostensibly emphasised the importance of 'partnership working':

> 'Involvement' requires both professionals and service users to reconceptualise the traditional category of patient to accommodate the notion that service users have a contribution to make to service planning and development, a transformation that was not always easily achieved. […] As user involvement was loosely defined in programme documentation there was little dissent about whether activities constituted 'real' involvement or not. […] User involvement in this setting did not transform patient and professional relationships in the way that policy documents promoting involvement imply.

The need for a shift in professional mindsets to achieve partnership is also advocated in the academic literature (e.g. Barnes, 2002; Carr, 2007). Carr (2007: 274), for example, argues for the need for "pluralistic and 'passionate' dialogue" that might exploit the "opportunity to explore and benefit from any commonality between 'us' (professionals) and 'them' (service users)." This was reflected in the discourse of the NURG, and increasingly of Macmillan staff in their calls for involvement based not on "patient [to] health-care professional" but "human being to human being" dialogue. But there were obstacles to such change. Firstly, as illustrated in Chapter 8 and in the first half of this chapter, staff constructed involvement rather differently, and this was reinforced to varying extents in the seven pilots by their organizational set-up and objectives. Secondly, Macmillan was hesitant to be overtly directive about the preferability of this attitudinal change over the other forms of involvement being pursued, since it shared with the other parties an interest in valuing what existed and avoiding breakdowns in already-fragile local relationships. Thirdly, one might add, it is difficult to see how any external effort to effect a change in the intrinsic motivation for involvement held by the sites could succeed. All that resulted was an eagerness among the pilots to show that they were indeed taking involvement seriously, not just 'ticking a box'.

These difficulties in promulgating involvement seem to reflect the challenges identified by Newman *et al.* (2004) of effecting public involvement in public services regulated through 'network governance'. They argue for the need for mechanisms to make the co-dependency inherent in such a system work effectively, rather than resulting in "frustration and powerlessness" (Newman *et al.*, 2004: 218). What seems apparent from this analysis, though, is the ineffectiveness of lateral governance in spreading a model of good practice across sites. With its unwillingness to impose a substantive model of user involvement, Macmillan sought to inseminate the 'right attitude' to user involvement across the seven sites. As others have noted, though, and as intimated in Chapter 8, such attitudes to involvement seemed rooted in institutional factors which often tend to orient professionals towards consultation rather than partnership (Milewa, 2004; Callaghan & Wistow, 2006; Rutter *et al.*, 2004), and so were resistant to such efforts. Thus, in the absence of imposition, with staff retaining determining power, with no explicit external judgements about the performance of involvement (except for whether it existed at all), and with organizational set-ups remaining the dominant concern for staff, in most cases, involvement remained comparatively marginal, falling well short of the notional partnership articulated by users and Macmillan.

10.

CONGRUENCIES, COMPROMISES, CONTRADICTIONS: USER INVOLVEMENT ACHIEVED

As the programme came towards its close, the forms taken by involvement in the seven sites began to ossify. As Chapter 9 discussed, the stake that Macmillan staff shared with the pilots, and with users themselves, in recognizing the achievements as well as the shortcomings of involvement limited the extent of its directiveness on issues such as 'partnership'. Rather, as we have seen, joint events and published outputs from the programme emphasised these achievements: user involvement had indeed been developed in all seven pilots (and this was more than had been managed in the non-cancer pilots in the wider genetics programme), even if in one it had ceased midway through the pilot period and in five others could hardly be characterized as partnership.

This chapter, then, examines the nature of the user-involvement set-ups that were established in the pilots and nationally. First of all, I consider in more detail the micro-level factors that precluded a more partnership-based model of involvement in six of the sites, linking the analysis from Chapters 8 and 9 to the organizational characteristics of these pilots. Following this, I consider how similarly, at a national level, what seemed to emerge from the lack of common ambition between staff and users was not partnership, but meetings where there was little overlap between the contributions of staff and users, even as they occupied the same space. Nevertheless, for users, even inhabiting this space was something of a triumph, reflecting recognition of a degree of legitimacy of users' contributions among staff, even if their influence was not—yet—established.

Returning to a local level of analysis, I then look at the situation in Site G, where, on the verdict of staff and users alike, partnership was achieved. The differences between this site and others, in terms of relationships and organizational set-up, were clearly evident. However, also evident through time was how the partnership here seemed to imply something of a transformation of the role of user involvement, taking it away from its original (though loosely defined) rationale towards a more professionalized contribution, as the project moved from developmental questions to more managerial matters about how to consolidate its place within the local health economy, expand provision and obtain ongoing funding from commissioners. While this 'professionalization'—such as it was—was not perceived as problematic in Site G, at a national level, similar developments of the user input resulted in a degree of friction between Macmillan and the involved users, as the former became concerned to ensure that the 'user voice' was a fresh one rather than institutionalized and 'established'.

Organizational barriers to partnership-oriented involvement

As detailed in Chapter 8, there was a fundamental difference in the understanding of the role of user involvement between staff and users. Users tended to construct staff's resistance to their vision in terms of reluctance to cede power to a more mutualistic, partnership-based relationship; it could also, though, be seen in terms of what seemed to professional staff to be a commonsense, hierarchical relationship between (superordinate) clinical knowledge and (subordinate) patient/lay knowledge. This section considers specific aspects of the way involvement was organized and realized in Sites A-F which reinforced this commonsense construction, serving to marginalize involvement rather than encouraging a more partnership-oriented model.

Firstly, as seen in Chapter 6, a lack of clarity over the aims of involvement led to a recruitment process that was generally expedient rather than considered. Relatedly, the absence of a specification from Macmillan of what involvement was to accomplish led to an approach that was, by the admission of some of the staff themselves, rather marginal to the pilots' main work. Other aspects of their work were more exactingly performance managed by Macmillan; ongoing funding would rest principally on patient throughput; there were, simply put, other priorities for staff. As a nurse in Site E acknowledged, "perhaps we were happy that we had a user representative and we ticked that box." Site F's user-involvement lead similarly admitted that for her, the main function of the events for user-involvement leads organized by Macmillan had been to reassure her that her project was not a 'negative outlier'.

Secondly, the wider structures of the NHS seemed to orient staff inwards, towards their own professional preoccupations, rather than outwards, towards the expansive suggestions users were making. Involved users sensed a general aversion to joined-up working among staff, of the kind noted in institutional analyses of the barriers to knowledge sharing in the contemporary NHS (e.g. Currie & Suhomlinova, 2006):

> "They're one of the excellent centres in certain things, and a good hospital, but you feel as if there's a lot of information that they could use, but for *some* reason they're not prepared—not 'not prepared': they don't see the need. They don't see the need to be aware of what others are doing. 'Cause what they're doing is, 'We're getting on alright,' you know." (Harry)

For some users, such tendencies were reflected in the pilot programme, with pilots viewing each other as competitors, and a concomitant disinclination to share knowledge, noted by Gayle in relation to the development of new nursing roles:

> "Rather than everybody doing their own training and everything, can't they work out what the specialist nurse does so that they've got a qualification for it? It's seeing this business of everybody reinventing the wheel over. […] Things like that, I keep banging on about that."

In such debates, users found their efforts to broaden the horizons of staff largely futile. Furthermore, the concerns of staff for their own core roles and responsibilities seemed sometimes to serve to limit the 'joining-up' ambitions of the Kenilworth model itself. In Site A, for example, Ava was keen to emphasise the importance given in the Kenilworth model to the upskilling of primary-care practitioners. The pilot lead, though, was clear that in this hospital-based pilot, this was of marginal concern: the focus was on embedding the project within secondary care, and achieving sufficient patient throughput to ensure the service's sustainability (see pp.198 and 211).

From such debates, it was clear who had the final say on the function of the service. In the contest between professional priorities and user influence, there was generally only one winner, even where, as above, users invoked the Kenilworth model itself in seeking to legitimize their ideas. But it was not just these top-down pressures on staff's behaviour that worked to preclude partnership, but also—thirdly—the way in which they interacted with local organizational set-ups. These resulted in clear boundaries between staff and users that were difficult to overcome. The expedient process by which users were recruited, for example, meant that in most sites, anyone willing and available was adopted as an involved user. In contrast to the process of staff recruitment, users were not judged according to any formal criteria about their skills and competencies. Consequently, when users sought to offer a skilled contribution, staff were cautious or even, in the view of some involved users, suspicious. Similarly, we saw in the last chapter how the south-Asian users recruited opportunistically in Site C were unable to fulfil the pilot's expectations for their role. The recruitment process, then, was not in general something which supported the development of a partnership in which the contribution that users felt they could provide was encouraged and valued by staff.

The absence of formal vetting was accompanied by a lack of informal opportunities to foster the kinds of relationships of trust and reciprocity implied by partnership. While those employed on the pilots had frequent opportunities to interact with one another in their day-to-day work, in most sites the sole point at which they came into contact with involved users was at steering- or project-group meetings, often as much as three months apart. These meetings were formal affairs, governed by tight agenda and frequently involving not only pilot staff and users, but also wider stakeholders, such as a Macmillan representative, or managers from the cancer network, PCT or hospital. Consequently, users found themselves trying to foster trusting relationships with staff at meetings where formality precluded the building of much social capital, and trying to argue for more expansive, wideranging remits at the points at which staff were most focused on narrow concerns of budget, throughput and sustainability (cf. Taylor, 2006). At the local meetings I observed, users were usually present, but the focus of agenda on tightly bounded areas—which often required detailed knowledge of service delivery, NHS priorities or local funding mechanisms—offered little opportunity for them to make significant contributions. At the insistence of Macmillan, all such meetings were to include user involvement among their agenda, but if anything, this seemed to separate it from wider matters of importance to the service, and thereby to reinforce its marginality. If there was an opportunity to open the minds of staff to partnership working and open the remits of projects to more wideranging ambitions, this was not it.

In these kinds of ways, institutional impediments to a more partnership-oriented form of involvement were reinforced by its pilot-level organization, which reinforced the division between those who were in the 'team'—staff on the projects—and those who were outsiders—the users (and other wider stakeholders, who could generally, though, rely on positional power for influence). The team itself may not have been characterized by accord and mutuality, but it did at least benefit from ongoing contact that enabled its members to get to know each other and build a sense of commonality and purpose. The performance focus of staff (particularly, it seemed, service leads) did not encourage them to enter partnerships with individuals whom they hardly knew, who wished to influence pilots but would not be held accountable for their success or failure, and whose contributions were out of kilter with the main agenda of the meetings they attended. Thus the absence of the opportunity to develop the 'social' aspects of partnership—trust, reciprocity, a consistent working relationship built through time—combined with wider forces to preclude the emergence of the functional aspects of partnership: the decision-making processes and division of labour within pilots.

An exemplary situation was in Site A. Here, Ava recounted her growing disappointment with the fact that the 'team' she thought she had joined was not quite as harmonious as it had first appeared. She described her realization that even within the project's staff, there were professional hierarchies for which her own professional background (in teaching) had not prepared her, as well as inter-personal fractures between some of the pilot's employees. She, meanwhile, found herself on the margins even of this dysfunctional team, as an 'unknown quantity' to staff:

> "Their idea of partnership I find quite disturbing, because you've instantly got their hierarchies round the table, between themselves, let alone when the service user turns up. So you've got this consultant thing, and you get your senior nurses, and then you get some sort of also-ran, and some sort

> of administrative person, and then lower than that is this member of the public that they've had to tick a box to say they had. So I've never felt that they've really come to grips with partnership within their own team, let alone with a member of the public arriving."

Through time, Ava found that the pilot's aims were bounded by the lead's eagerness to secure as large a throughput of patients as possible (indeed, Site A was the most successful pilot in the programme by this criterion). Her own efforts to broaden the remit of the project—especially in terms of improving knowledge among primary-care practitioners, addressing the area's ethnic-minority community, and bolstering user involvement in the pilot—were unsuccessful, and she felt that even insofar as a team existed, she was indubitably not part of it.

Intriguingly, Site A's lead, a clinical geneticist, and Ava used the same analogy to describe their experiences of trying to gain legitimacy and influence in the project and in wider NHS cancer provision, comparing it with their experiences of moving into small villages. Their accounts diverged tellingly in the outcomes they describe:

> "You make yourself available for talks and things, and you bump into people in the corridor, and you develop a professional relationship where it's friendly. So now I can speak to [breast surgeon] up at [neighbouring hospital] on a friendly basis, whereas before it was senior surgeon, junior consultant, but now we're more level. [...] So in some ways it's like moving into a small village and fitting in. And this is exactly what I've done here." (Lead, Site A)
>
> "I've lived in this village long enough to know that in a feudal village, you've got a very strange mix of folk, from very different backgrounds, and you can easily offend locals—real locals—by being the incomer. [...] You don't start making pronouncements about farming or sheep prices round here!

> So really it's just having learnt to be circumspect." (Ava)

Making friends, influencing people and forming partnerships in the NHS 'village', then, was a rather different prospect for consultant compared to an involved user. Ava acknowledged, though, that the suspicion she felt she had encountered from Site A's staff was a natural reaction to the inclusion of an individual about whom they knew little, and with whom they had few opportunities to form interpersonal bonds or establish common ground. Eventually—and through, by her account, dogged determination—Ava felt that she did succeed in gaining a modicum of influence among the staff, though long after Site A's other involved user had given up, and only at the very end of the pilot period:

> "There was a real move forward. I felt that there was trust. That was the word that I kept on thinking. There was a lot of holding back—I mean, I don't blame them. They don't know who these service users are. They don't know how trustworthy they are. I mean they might be off to the local paper, and spill all sorts of dreadful beans, mightn't they? So I felt that in a way, they'd been right to be cautious. And now they knew it was OK. So I felt that we had a professional kind of relationship, come the end."

Marginality and integration at the national level

In the main, then, users felt marginal to their pilots: estranged from the team of professional staff, and unable to wield any real influence. What seemed a particular frustration for users was that this was not, on the face of it, the result of conscious efforts to marginalize them. In the main, the problem seemed to be that involvement was simply not a prominent concern for staff. This was not a matter of bloody-mindedness or obstinacy: rather, their attitudes seemed highly entrenched, and resistant to change. Site C's user-involvement lead, for example, admitted her site's shortcomings around user involvement in an information CD it was preparing for potential patients, illustrating the kind of marginality common to most sites:

> "The specific meetings for the CD, no, [Chris] wasn't invited to the meetings. I don't think—she wasn't actively excluded: I don't think there was ever an idea in anybody's head to invite her."

For users, the persistence of the commonsense professional mindset was illustrated in particular by the manner adopted by staff in interacting with them, and especially by professionals' language. Poor communication on the part of staff was a source of annoyance to users from the start, who found staff often at a loss as to the purpose of involvement, but reluctant to engage in dialogue with users to define one. Involved users thus often found themselves on the edges of professionally dominated meetings, making occasional tentative suggestions that staff were more inclined to politely ignore than engage with critically in pursuit of a mutually agreeable, useful contribution. This was perhaps more excluding for users than overt conflict, as Macmillan respondent 2 highlighted:

> "What people should be doing if they don't understand is asking, because how can you then say, 'Yes, that's really useful,' or, 'Actually, we need to park that, because it's not quite relevant at the moment,' if you don't understand what they're saying? So if we're going to get this to go where it takes you, and utilize to its full potential the involvement that users can have, then you have to fully understand, and sometimes that can feel like quite a protracted process."

For all the reasons already discussed, however, staff generally found it easier to avoid conflict and maintain an arms-length relationship with users built on their conventional understandings of the limited purpose of involvement.

At early Pilots Together events, the result was that some users felt like they had stumbled into a members-only club. Though Macmillan took care with its seating arrangements to ensure mixing between staff and users, these had the character of professional networking events, with staff—often already well known to one other in the small world of clinical genetics—learning about each other's projects, discussing current developments and comparing their progress. During breaks, involved users tended to congregate, unable (or unwilling) to penetrate these professional conversations. The sense was that these meetings represented 'business as usual' for the staff, with little need to acknowledge the presence of users in their company, save for the slots that Macmillan reserved for presentations on involvement.

This was highlighted in an incident at the first Pilots Together event, at which one user, Harry, was due to speak about the role of involvement in the programme and pilots. His slot was preceded by a presentation by Site B's lead, who spoke about his pilot's IT system and plans for service delivery. He mentioned, in passing, how the service would attempt to draw in "the punters" from the local area—a turn of phrase which caused considerable annoyance to several users, including Harry:

> "Fine among your own type of people, talking, referring to people, whatever terminology you use, fine. But when you've got a mixed group of people, you don't think who might be there. […] I was due to give a five-minute talk after [Site B lead] passed his comment about 'punters'. And it changed completely."

Harry began his talk by listing various terms used by health professionals to label him—"I've been referred to as a punter, a genetic rarity, like gold dust"—and made the point that staff needed to reconsider the way they thought about users if they were to learn from their input. In Site A, similarly, Ava complained about the belittling comments made by staff about the drag on resources generated by 'worried-well' middle-class women, again, from Ava's perspective, as if she was not there. This was, she acknowledged, "probably a jokey department thing you say in a meeting. I can't think that they're delivering worse services [to the 'worried well']. I just think it's a sad attitude of mind." Above all, it signalled the fact that these meetings remained governed by a professionally determined language and perspective on the world, which staff saw no need to moderate on account of users' presence.

Through time, this situation did change. Users became noticeably more confident in speaking up at Pilots Together meetings, perhaps bolstered by the discourse of the NURG meetings. Simultaneously, however, the opportunities for users to contribute in the expansive ways they envisaged diminished. Pilots Together events and other national meetings (save for the NURG) focused increasingly on questions of sustainability, business planning and so on: issues in which an intimate knowledge of NHS structures and funding mechanisms was almost a prerequisite for participation. At the three 'evaluation-group meetings' convened by Macmillan, for example, two or three users were always present, to provide the 'user's perspective' on the question of the best criteria for judging the performance of the pilots and programme. Their contributions to the day-long meetings, though, were minimal, typically coming only in response to questions aimed at them specifically. My notes about one such moment during the second evaluation-group meeting read as follows:

> *MR1 says a key questions for the programme is who is the best person to do a risk assessment, "not just from the professional's viewpoint but from the patient's perspective." Would users prefer to see a professional that they know and trust or an expert? "And the answer is probably, 'Yes'!" DH representative agrees, adding that we need GPs to know enough and to know where to refer when they need more expertise. But what, she asks, do the users here think? Harry says that as long as it's someone you trust, it's fine: you can always ask to be referred on if they don't know enough. Dawn adds that it's too much to expect GPs to know everything; they've got other things to do and 10 minutes is*

> *too little. Harry adds that it's important they sound interested in you. Dawn points out that support groups can provide information to worried patients, too. DH representative agrees: people get information from lots of sources: this shouldn't be one size fits all.*

At these meetings, users were entitled, and would, I suspect, have been welcome, to raise points themselves. But in meetings dominated by quite specific technical expertise, there seemed little opportunity for them to do so. Thus their input was largely contained to issues on which they were invited to contribute, usually (as above) in relation to specific, bounded questions with apparent direct relevance to 'the patient experience'. These bounded questions tended, furthermore, to structure the responses, limiting them (as in the example above) to a choice from a number of options, rather than allowing them to open up the issue to wider considerations.[1]

'Pseudo-patients' and 'quasi-professionals'

At the later Pilots Together events, a similar pattern was evident. In plenary sessions, users raised more expansive points, which facilitators acknowledged as important, but which rarely overlapped with the concerns of staff. In the more focused, group-based sessions, the seating arrangements orchestrated by Macmillan ensured that each group included at least one user, alongside staff from various pilots, staff from Macmillan and assorted others present. The topics of conversation, though, having moved from the blue-skies brainstorming of earlier events to the more mundane, laborious realities of achieving change in a resistant NHS, tended to rule out skills-based or expansive

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[1] It is worth noting in passing that the question of access to cancer-genetics provision was one that had been discussed at length in the NURG meetings, with many users of the view that GPs were ill-equipped to deal adequately with the needs of possible cancer-genetics patients. Dawn herself had expressed views of this kind in the NURG meetings and in interview. Yet in this instance, their contribution was apparently constrained by a closed question in the context of a time-limited meeting with many other issues to cover, and so the total of their substantive input was the limited contribution detailed above.

contributions. Rather, there seemed to be two possible prescriptions for users' contributions to these discussions. Those users who had spent the three years of the programme gaining knowledge about cancer-genetics provision within the wider NHS, about funding mechanisms and the challenges of service reform, could make a 'quasi-professional' contribution, speaking in the same language as staff and offering input on the same issues. Those with less interest in these organizational issues, meanwhile, offered input from the patient's perspective, effectively filling a bounded role that conformed to professional constructions of the user. At the final Pilots Together event, for example, I sat at a table with Chris, one Macmillan employee, and staff from various pilots. For the group-based session, each table was asked to discuss (i) what commissioners had asked pilots seeking ongoing funding, (ii) what commissioners should have asked them, and (iii) whether pilots were able to answer these questions. The 'insider knowledge' required to answer the first and third questions is self-evident, and the second needed at the very least a keen interest in the abstruse intricacies of NHS commissioning. Chris, nevertheless, participated in the discussion, but her contribution was limited to talking about the 'patient perspective', providing input on things patients might want from services, the importance of care closer to home, the need for clear information provision, and so on. Never was she excluded from the conversation; at each point her contribution was acknowledged; but none of her input was included in the summary composed by the table's scribe (the Macmillan employee).

While the marginality of users at the national level seemed less profound than in the pilot sites, this did not then imply that the expansive role users envisaged gained much credence. Rather, a combination of institutional forces and the organizational particularities of the mechanisms by which staff and users were brought together again resulted in a role for users that fell short of the skills-based contribution they felt they offered. Instead, they operated as 'quasi-professionals', speaking in the same organizational vernacular as staff, or 'pseudo-patients' (Chris, we should not forget, had no personal experience of inherited cancer or of the pilot service provision), forced to constrain themselves to the biomedical or lay identity rejected by the NURG in order to provide a 'user's perspective' that was valued in settings dominated by organizational concerns.

For the users, however, attaining some kind of discursive legitimacy in professional company that had seemed impenetrable was an achievement not to be belittled. One particular example of this achievement, highlighted by several users during follow-up interviews, was the open letter written by the NURG and published in the special issue of an academic cancer-genetics journal alongside papers on each pilot (National User Reference Group, 2007). I was present at the NURG meeting at which this letter was composed, over the course of an afternoon, with those present exchanging ideas and drawing on their earlier work outlining the most important aspects of the Kenilworth model from the 'user's perspective'. The three priorities identified—a named point of contact in primary care, a clear care pathway and up-to-date information provision—were presented in the letter, which amounted to only 307 words in total. These prescriptions were close to the letter and spirit of the Kenilworth model itself, and far from the more radical ideas occasionally mooted in the NURG meetings. The result seemed to me to be a very conservative few paragraphs which made mundane suggestions with which no-one could disagree. As I discussed the letter with users in follow-up interviews, however, I realized that this was not the point. Rather, the letter's achievement was that it placed involved users in the same discursive arena as professional staff. As such it was merely a first step towards establishing a more thoroughgoing involvement in the longer run. As Harry put it,

> "it'll make some realize that there are patients out in the in the world that have a lot to offer. And not just to say, 'Well this went wrong and that

> went wrong and I want compensation'. But, 'These things didn't go quite right, and there are ways that we might be able to improve it'."

Given the context and limited space, it was perhaps inevitable that the letter would deal in generalities, adopting the 'pseudo-patient' role to make a contribution from 'the user's perspective' rather than something genuinely grounded in the users' actual experiences and wideranging ideas. But ultimately, this was not what mattered: it evidenced the existence and energy of the involved users and might, therefore, help future readers to realize that such a group could have a legitimate contribution to service development. The letter's rather restrained content was what was required to gain an initial foothold in the professional discursive arena, and although it fell short of the expansive contributions the NURG felt it could offer, it was a starting point at least, constituting what Lowndes and Sullivan (2004: 64) call a 'little victory', "presaging future long term change."

Site G: partnership achieved?

As already discussed, one site was seen as far more successful in its user-involvement activities than the others. In Site G, users and staff alike saw their work as a genuine partnership, a perspective shared by the NURG and Macmillan staff:

> "They are as much a part of that project as any of the health professionals working on it. It's absolutely true partnership working. And I have to say, as a model it's absolutely outstanding, it's worked exceptionally well. The other projects haven't been quite as successful in that respect." (MR3)

Certain differences between the set-up in Site G and most of the other sites seemed to assist this achievement. For example, where recruitment elsewhere was characterized primarily by expediency, in Site G the two main users, Gayle and Gemma, were selected purposively by the nurse from her past patients on account of their personal characteristics and skills. From the start, then, the users here were far less 'outsiders' than elsewhere. Project-group meetings were frequent, with the core group of practitioners and users coming together once a month, and at times more frequently in relation to specific issues to be tackled. It also seemed that the relatively small team, which seemed less hierarchically governed than in most other sites, was well suited to integrating the users. On an inter-personal level, it was clear that users and staff were both keen to form close, informal bonds that might support their work together. Consequently, they seemed more familiar with one another even than the core staff in some sites:

> "It's great, it really is, it really works out well because when we've gone to London, we stayed over last time, and we all went out, and there was no barriers at all. […] The barriers are not there, and they haven't been at all with [Site G manager], and it's just such an easy atmosphere, and you feel that you can totally participate, you don't feel have to think, 'Ooh, should I be commenting like that?'" (Gayle)

That the purposive recruitment process had allowed staff to involve the 'right kind' of users, with appropriate attitudes and skills, was certainly crucial to this inter-personal openness and apparent partnership. The manager commented on the importance of careful selection, to avoid recruiting someone "with a gripe because they've had a raw deal in the service [and to make sure that] it isn't a way of them sabotaging what you're wanting to do." Similarly, the nurse stressed the importance to her choice of her prior familiarity with the users: "I knew they would be on the same wavelength as me, so that was going to make my life easier than somebody who's very difficult."

This undoubtedly helped the flow of the project-group meetings, which were characterized by a consensual decision-making process and often lengthy conversations about the matters in hand, followed by apparent agreement among all present about the way forward. Users reported that they felt that no area of discussion was out of bounds to them in these meetings:

> "They've used our experience and our expertise, and at no time have I felt like a patient. Which, talking to a lot of other people in the other projects, they certainly have, and haven't had the same involvement. [Site G have] really involved us, and enclosed us. I've felt totally valued, and more than valued: it's not just a case of you say something and somebody takes it onboard, it's more than that, almost everything has tipped towards what we say, what we want, because they valued it, [and] because I suppose they were very much using our background." (Gayle)

An initial congruence of visions for the service, then, was complemented by strong social capital and a conscious effort to ensure that involved users were actively included in meetings to create Site G's partnership. Where there were disagreements—as over the content of Gemma's presentations on her cancer-genetic 'journey' (see p.229f.)—these were resolved through negotiation, to reach a compromise seen by both parties as being in the pilot's best interests.

From the start, it was as much for the specific skills from their backgrounds in project management and teaching that Gayle and Gemma were valued as for their experiences as patients. In their contribution to publicity events and in their contribution to the strategic management of the pilot, both made contributions that they felt incorporated the entirety of their experiences and skills, in a way that users in other sites rarely felt involvement achieved. Through time, however, as the pilot moved from working out its purpose, remit and how to achieve these into a more settled phase of service delivery, the role for involved users became more constrained. The commitment of the staff to involving users remained—indeed they actively sought to recruit further users—but the scope for their involvement now seemed more limited.

Gayle described the need for further users in the following terms:

> "I don't think we at this stage need somebody who can go into all the technical side and sort that out, because I think we've muddled through all that, and sorted that out. It's now the people skills [that are needed from future users], I think, to build the awareness and move it on."

With the remit and scope of the project established through the discussions of the earlier project-group meetings, the need now was for users to contribute what they could to the success of the project. Effectively, then, users were to draw on their particular skills, alongside professional staff drawing on theirs, to assist progress towards two agreed goals: maximum possible throughput and ongoing funding. To these ends, Gemma and Gayle continued to contribute to publicity events for the pilot, and also attended meetings with commissioners alongside pilot staff to signal the commitment of the pilot to genuine user involvement, and demonstrate their own enthusiasm about its work.

Midway through the pilot period, Gemma and Gayle were granted 'volunteer status' by Site G's PCT, the pilot's host organization. Apart from allowing them to make expenses claims, this development also represented an interesting formalization of their roles and responsibilities:

> Gayle: It's very much like when you're employed, there's a job description, and you have the discussion with your supervisor or whatever to make sure that you're not having to do things you shouldn't be doing, and that you're comfortable with what you're doing, and it looks at us from the point of view to make sure that we're handling things OK. It does the real supervisor bit so to have that, really, that's very interesting.
>
> Graham: Yeah it does formalize it quite a lot!

> Gayle: Yeah but it's good to see it in that way, and we had total input on that, when they built up the volunteer pack. […] It's whether we want expenses and things like that, and just what our remit is, how far it goes. And also if we've done presentations, whether we could be funded for those, depending on what happens. It just formalizes it more.

This contractual formality—accompanied, as we have seen, by inter-personal *informality* in the relationships between users and staff in Site G—reflected the increasingly professional role that Gayle and Gemma were performing. After receiving ongoing funding from the PCT, staff began working to expand the service to cover neighbouring areas. By this point, Gemma had withdrawn, but the service's manager saw an important ongoing role for Gayle and any future involved users in this expansion process, giving more presentations in the nearby towns to which the service was being extended. As the manager explained, volunteer status meant that Gayle's contribution to this could now be properly recognized and rewarded:

> "They'll get the travel expenses and the food and that sort of thing, but we also pay them something if they're speaking at the events. It's more of a talk, and it's not the full consultancy rate or anything like that! But we try to say 'thank you' in some way. I must admit, at one point it was as if they were full time like we were in the pilot, because they were so committed."

Through time, then, as Site G's purpose and processes became settled, the role for involvement became more narrowly defined by the needs of the project, in terms of sustainability, throughput and expansion. From the start, this had been a crucial component of the input of users chosen in part for the complementarity of their skills. Attaining volunteer status, though, seemed to reflect an evolution of the users' roles, whereby their skills became the defining characteristic of their roles. Macmillan respondent 3 commented, enthusiastically, that Site G's users were "not seen as users any longer: they're part of the team." This innocuous comment seemed to highlight a tension in the achievement of 'partnership' in Site G, where an alignment of interests and a social integration of involvement seemed somehow to precipitate the loss of the distinctive identity and contribution of the involved user. The existence of the social and structural prerequisites for partnership combined with the emergence, through time, of a stable model of service delivery to give rise to a 'quasi-professionalization' which was more complete than elsewhere, extending to a formalization of roles and the payment of honoraria. Of course, the purpose of user involvement was only ever nebulously defined from the start. Nevertheless, this partnership model, involving a complementary contribution from users towards a closed aim, did seem to move away from the original ambition of providing the views of 'people affected by cancer', through development of the role rather than any explicit attempt to co-opt.

Partnership and professionalization at the national level

As noted earlier, national events which brought together users and staff from the seven sites were somewhat successful in bridging the discursive gap between the two groups, but did so in a way that seemed to force users to develop a degree of fluency in the language and concerns of professionals, or else to speak as rather abstract 'pseudo-patients'. Within the NURG and beyond, though, the users sought out other opportunities to enact the more expansive role they saw for themselves in influencing service provision. Several took advantage of the new competencies, confidence and networks that their involvement had provided, to pursue other opportunities to influence cancer-genetic service provision. During his follow-up interview, for example, Harry counted 15 events for health professionals at which he had been invited to present in the last year, and described the support group he had co-founded for others with the same genetic predisposition. Frustrated at her lack of influence in Site A, Ava put her efforts into working with local cancer-information centres, assisting those who dropped by with information on genetic risk and service provision. Dawn co-founded a cancer charity in the area around Site D, which offered information, support and annual complementary-therapy events, and which secured funding from the local PCT.

Within Macmillan, too, there were opportunities for users to continue the role they had envisaged in the NURG. Macmillan formulated plans that would involve users in a post-pilot 'spread programme' aimed at taking the lessons of the pilots to the rest of the NHS, to 'mainstream' the new cancer-genetic care pathways throughout the system:

> "Our pool of service-user expertise has improved enormously, the quality. And we want to find new ways of applying that expertise into the good-practice spread programme for the next two to three years. So the story continues." (MR1)

Due to lack of funding, these plans never reached fruition, but Macmillan respondents stressed their desire not to lose the experiences, learning and skills amassed by the users involved in the cancer-genetics programme.

Yet this recognition of the development of a useful resource in the form of the NURG members was tinged, for Macmillan respondents, by a degree of cautiousness about the risk of ending up with a 'professionalized' group of users.

> "The challenge for Macmillan is to ensure that as far as humanly possible, we are obtaining contemporary views, fresh views, and listening and talking with the right people, rather than getting sucked into the user bureaucracies, or not keeping our user involvement influencing mechanisms fresh. And that's a real issue, I have to tell you." (MR1)

Whilst valuing the "expertise" developed by users and its potential role in supporting spread, then, Macmillan staff were conscious of the need for turnover among users, in order to maintain practical relevance and political credibility. At the end of the pilot period, with the spread programme unfunded, the NURG was disbanded, though contact details were retained by Macmillan in case further relevant opportunities for involvement emerged.

The users largely recognized the logic of this reasoning, but nevertheless, some found disbandment hard to take. The degree of commitment invested by some users was significant, and had involved not only attending meetings and carrying out tasks requested of them, but often also significant supplementary efforts to improve their knowledge of the clinical and organizational field, and to develop skills and networks. But this quasi-professionalization of the user role was not matched by a concomitant change in the relationship to Macmillan. On the contrary, it was something which compromised, rather than bolstering, their status. The result for some was considerable disillusionment:

> Helen: You can't be working together for x amount of years—and at the same time no-one's saying, like any job, you should be making work out of nothing, but there is work there.
>
> Graham: Yeah, there's work to be done.
>
> Helen: There's work to be done from those people. So that's what I'm saying about raising expectations. Huge expectations, you know.

Whether paid or not, several users gained significant satisfaction from their role, and worked hard at self-development to increase the value of their contribution. But professionalization, they discovered, did not always cut both ways, at least given the political and practical exigencies faced by Macmillan, and so their investments in self-development served rather to undermine their ongoing involvement.

Summary and discussion

Despite the disputes described on the preceding pages, it should be emphasised that the effort put into involvement across the seven pilot sites was far from inconsiderable. Macmillan, the pilots and even the users themselves highlighted the successes of involvement, especially in public forums, and by way of comparison, more was done by these pilots than by those in the wider genetics programme. However, in most sites it fell short of partnership, defined as shared planning and decision making (Charles & DeMaio, 1993; Chadderton, 1995; Rutter *et al.*, 2004; Macmillan, 2005).

Where some of the macro-level reasons for this were explored in Chapter 8, this chapter has focused on processes at the micro-level where general differences of perspective and institutional forces translated into specific barriers to involvement. Several of these seem to reflect the more general issues identified as obstacles to 'joined-up' working within the NHS, for example in relation to inter-professional boundaries between actors within ostensibly co-operative teams (Finn, 2008) or efforts to introduce networked service delivery (Martin *et al.*, 2009a). In these terms, involvement faced the same kind of problems encountered by efforts to accomplish multidisciplinary teams, often resulting more in fragmentation by profession than integrated working (Donnellon, 1996; Payne, 2000). The social and organizational boundaries separating users from professionals seem even more entrenched than those between different professional groups, in terms of the norms of inclusion and exclusion, differences of perspectives and horizons, and opportunities to build commonality and trust. There are also echoes of the institutional barriers to public participation specifically identified in the literature (e.g. Barnes, 1999b; Beresford & Branfield, 2006; Taylor, 2006).

Furthermore, it seemed that through time—as users became more knowledgeable, confident and able to make the expansive contribution they envisaged—the opportunities for such a contribution became closed off. The aims of pilots and modes of service delivery became increasingly fixed, and correspondingly the concerns of staff—particularly as expressed in the comparatively business-focused context of steering-group and project-group meetings—became more constrained. Several of the users I interviewed stressed how, looking back, they felt the best opportunity for influence had been right at the beginning of projects, to create a precedent that might be sustained through time, and this reflects the verdict of some of the literature (e.g. Lowndes *et al.*, 2001b; Beresford & Branfield, 2006; Young, 2006). Given the durability of staff's conceptions of involvement as providing 'lay and patient perspectives', how much users could have achieved by being more proactive earlier on is perhaps doubtful. However, what did seem apparent was how the increasing focus, of individual pilots and the programme as a whole, on administrative matters internal to the NHS marginalized the more expansive concerns of users still further.

As these concerns were 'squeezed out' of discursive arenas locally and nationally, it seemed that users who still wished to be heard were left with the choice of two roles. They could contribute as 'quasi-professionals', seeking to provide input on the same, administrative level as health professionals, deploying the knowledge they had acquired through time and perhaps also the own managerial expertise they drew from wider professional experience. Alternatively, they could attempt to fill the role which I have termed 'pseudo-patient'. As seen in earlier chapters, this was not the role which users saw themselves as best placed to fill, with its artificial constraints on the nature and scope of the contribution. Furthermore, several of the users had never been patients of the pilot services specifically, or of cancer-genetics provision more generally. More than this, though, the perspective seemed to be 'pseudo' because the contribution called for by the meetings' focus was not one that could be grounded in the specificities of particular past patient experiences. Rather, it was a more abstract perspective, a generalized 'patient view' on what patients might make of the plans being drawn up for future provision. Thus it drew neither on specific experiences as patients, nor on users' wider skills and identities, but instead demanded that users posit themselves as a kind of 'universal patient', and offer from this perspective views on what might or might not be acceptable and desirable. For the users, though, this contribution was better than nothing, and to maintain a contribution within the discursive arena of professionals at least meant that the possibility of a more profound level of influence remained. To continue to exist, then, was an important preoccupation for involvement in this field, as elsewhere (e.g. Hodge, 2005).

What was notable, again, about this process was that it did not seem to arise from any overt attempt to sideline users, or to marginalize what they had to say (Williams, 2004). Rather, it seemed to result from a mismatch between the need for manageable contributions to the increasingly organizational challenges faced by pilots, and the irreducibility of the kinds of contributions that users felt they could make. Sometimes, the concerns of pilots were ones where such esoteric knowledge was required that an expansive user contribution was excluded almost inevitably: for example, in the discussions at the last Pilots Together event of commissioning arrangements. At other times—for example in the evaluation-group meetings—the concerns of staff were very close to the issues discussed by users in the NURG, but required brief, almost pithy, inputs in relation to questions which the NURG had cumulatively spent many hours deliberating, without reaching such a delimitable conclusion. The tension between the need to value the fruits of participation arising from the deliberative process itself, and the need to 'black box' the outputs of involvement, is documented in the literature (Mort *et al.*, 1996; Harrison & Mort, 1998; Milewa *et al.*, 1998), and it is worth noting that such tensions remained here even though this process was recognized by users as necessary, as discussed in Chapter 7.

Things were somewhat different in Site G, with its success in fostering a partnership between staff and users that won the praises of Macmillan. However, here too, the evolution of the pilot through time, as the aims of the project and its means of achieving them became established, seemed to close down the role for the users. Their contribution was still valued by those involved, but it became premised more exclusively on skills, and ability to connect with health professionals and potential patients within and beyond the PCT. This process seemed exemplified in the attainment of 'volunteer status' by Gayle and Gemma, which saw their remit formally defined. Here, then, both the informal integration of the users into the professional team, and the formalization of their role according to the needs of the pilot, contrasted strongly with the formal and informal separateness of the users in most, if not all, other sites. But there were tensions in this process, too. On the one hand, the influence of the users, and their apparent near-equality of status with the staff, seemed to accord with the Macmillan (2005: 4) definition of partnership working—"where patients, carers and health professionals work collaboratively to bring about tangible service improvements"—which itself reflected academic definitions (e.g. Charles & DeMaio, 1993; Chadderton, 1995). On the other hand, this quasi-professionalization of the user role seemed also to deviate somewhat from the original—albeit loosely defined—rationale for involvement, to draw on the experiences of 'people affected by cancer' in service development. The difference which defined the distinction between the contributions of professional staff and users therefore seemed to be elided, as the users were valued in terms of their skilled contribution to the ongoing success of the service. Of course, from the start, the skills offered by Gayle and Gemma had been an important reason for their recruitment, which was rather more purposive here than in the other sites, and this clearly aided the development of partnership. Given the looseness of the rationale and the expediency with which recruitment was carried out elsewhere, then, Site G's approach could hardly be seen as a distortion of the rationale for involvement. At the same time, though, the alignment and collaborative ethos that emerged in Site G's partnership was ultimately professionally determined rather than resulting from a synthesis of disparate perspectives.

The dissolution of formal and informal boundaries in Site G and resultant quasi-professionalization of the contribution contrasts with studies of partnerships between users and staff elsewhere (Richardson *et al.*, 2005; Callaghan & Wistow, 2006). In these examples, partnerships were between organizations and groups that remained institutionally separate, suggesting the importance of this in maintaining the distinctiveness of perspectives (cf. Barnes *et al.*, 2007). Partnerships involving individuals as users, then, are perhaps more susceptible to this process than partnerships between structurally separated groups or organizations. The contrast between the results of the quasi-professionalization of users in Site G and the parallel process that occurred on the national level, in the relationship between the members of the NURG and Macmillan, indicates the importance of the wider organizational context, too. Where Site G's pilot was able to continue to present the contribution of its users as a positive feature of its work, for example to local commissioners, for Macmillan, the 'freshness of experience' of its users was a much more pressing concern, for both practical and political reasons (cf. Mort *et al.*, 1996). The rather different outcome for users on this level indicates how quasi-professionalization did not necessarily cut both ways, leaving users who had put time, energy and emotion into their contribution—obtaining a degree of fulfilment common to those participating in such activities (e.g. Simmons & Birchall, 2005)—frustrated that their investment was not matched by a similar commitment from their sponsor.

11.
DISCUSSION

This chapter seeks to bring together the overarching themes from the empirical work presented in Chapters 6-10, in relation to literature discussed in the first three chapters, in order to offer some answers to the questions posed at the end of Chapter 3. In doing this, I attempt to focus on certain generalizable findings without losing sight of the specificities of the field studied, and of the particularity of the methods chosen to investigate it. Notwithstanding the nuances which the preceding five chapters have aired, here the need is to return to a more generalized level of analysis, speaking, for example, of the three groups of actors—involved users, pilot staff and Macmillan staff—in aggregate, and largely glossing over the internal differences within these groups.

The three sets of research questions set out in Chapter 3 encompassed different levels of analysis, moving out from the more directly empirical—focusing on the conduct of user involvement—through questions about the place of involvement in relation to wider policy and the contemporary governance of public-service provision, to more theoretical concerns relating to the theories of reflexive modernization and governmentality discussed in the first chapter. I take each of these levels of analysis in turn, starting in the first section with questions of how user involvement, its contribution and its legitimacy were constituted in implementation and practice.

The findings and questions of constitution, contribution and legitimacy

The first set of research questions posed in Chapter 3 asked:

- Who are involved users? How do they construct themselves, how are they constructed by (various actors within) the system, how do these constructions change and develop?
- What do the different actors consider that involved users contribute (for example some form of expertise, democratic input, the views of typical patients, etc.) to the management and delivery of services? How does this contribution develop through the process of involvement? What does the system demand of involved users *vis-à-vis* what they try to provide?
- What are the views of different actors in the user-involvement process about the legitimacy and utility of the knowledge produced?

In large part, my findings as they relate to these questions are put forward in the discussion sections of the previous five chapters. Nevertheless, there are certain overarching points that should be brought together here, highlighting features and tensions illuminated by the study that may be relevant to the practice of involvement elsewhere, too.

If nothing else, what will have been starkly evident from the data and analysis presented in the preceding chapters is the stark contrast between the ambitions for user involvement held by most involved users and developed by them in the NURG, and the opportunities for effecting such a role in practice. In most pilot sites, and to a large extent on the programme level too, the roles that emerged for involved users did not match up with their own expectations, as these clashed with the views of professionals and even to some extent, as seen in Chapter 10, with the corporate line of Macmillan. This was despite the fact that the positions taken by involved users, and the ideas they sought to put forward to pilot staff, were far from the oppositional standpoints of user groups in some other fields, such as mental health (Carr, 2007), where there is substantive disagreement over both diagnosis and appropriate treatment between practitioners and service users. The knowledge that users sought to offer was not anti-medical or confrontational. Rather, on the whole, the views of users were closely aligned with those of conventional medicine, emphasising the point that user groups occupy a spectrum of standpoints, from challenge to conformity (Fox & Ward, 2006). This perspective, though, was combined with experiences of deficient NHS provision in practice, in which the gaps between clinical specialities and between 'best practice' and provision on the ground seemed obvious to involved users. This led them to offer contributions relating to the need for connections between NHS 'silos' that were often not welcomed by the staff with whom they dealt, as well as certain skilled contributions that were acceptable only to the extent that they did not imply a shift away from clinical (often medical) control over the direction of the pilots. Staff, meanwhile, held onto what I have called their 'commonsense' constructions of what involvement was for and of the nature of the representativeness of involved users, seeing the limits of their legitimacy in terms of their ability to speak to 'generic' issues such as patient satisfaction and quality of communication. The form taken by involvement in most of the sites, explored in the last two empirical chapters, seemed to reinforce this situation, by failing to facilitate closer working between users and staff of the kind that might allow more creative roles for user involvement to emerge. This confirms the importance of opportunities to build social capital to the realization of more expansive forms of involvement (Brown, 2001; Taylor, 2006).

To this extent, then, the study adds to a number of well rehearsed arguments made in the literature about the difficulties of enacting user involvement in a public-service context rife with structural impediments and powerful professional interest groups whose understanding of the role and purpose of user involvement is often rather different to that of users. However, there was more to the story than this. The combination of methods deployed in this study, together with its longitudinal aspects, illuminate how the field and the tensions therein were not static, but the product of an ongoing set of negotiations between the actors involved, on both national and local levels. The constitution of user involvement and the involved users was a dynamic process in which enactment seemed far more important than any rational planning or preconceived intentions.

At the root of this situation was the openness of the mandate for involvement articulated by Macmillan (see Chapters 4 and 6), and the looseness with which it was to be put into practice. For all three groups—involved users, pilot staff, Macmillan staff—there was a sense in which the worth of user involvement was self-evident, with no need to articulate it. It was only when the time came to put these tacit ideas about involvement into practice that complications emerged, differences between conceptualizations came into relief, and so the groups started to consider more explicitly their own normative views on exactly what user involvement should be about. Thus the 'conflicting visions of user involvement', to redeploy Chapter 8's title, emerged above all *relationally*, through the practice of involvement, rather than primarily from the rationale put forward by Macmillan, the preformed motivations of users, or the prior expectations of pilot staff.

This was evident, for example, in the negotiation of the involved-user identity in the NURG discussed in Chapter 7. As users found their legitimacy and influence challenged by staff in most of the pilot sites, the NURG provided them with an opportunity to develop an understanding in which their wider social identities were an asset, rather than an obstacle, to worthwhile involvement. To some extent, this meant drawing on the motivations they had cited in explaining their original decision to become involved, but these were framed by the need to reject the narrowly defined constructions of user involvement that were emerging through interactions with pilot staff. Also implicated in the emergent construction of involvement and the user in the NURG was the influence of Macmillan, with its role in structuring the deliberations that took place and in translating these into a managerially effective output. Again, this role derived not from the explicit policy statements it put forward about the purpose of user involvement, but from pragmatic considerations about how involvement might best be deployed, given the organization's place in the pilot programme, its broader remit for user involvement, and its need to be seen by a range of stakeholders as fulfilling its mandate (a point discussed further in the next section). As I argued in Chapter 7, the NURG meetings could not be understood in terms of an imposition of rules on involved users by Macmillan, or as a process whereby the views of involved users were selectively interpreted, black-boxed and managerialized by the organization. What they did seem to involve, however, was a process whereby involvement was collaboratively fashioned into something instrumentally useful, and broadly agreeable to Macmillan staff and users. As such, its form was determined by the exigencies of the situation, the developing place of involvement in the pilot programme, the ideas of 'partnership' emerging from site-level interactions: function and form did not precede these but were constructed through them.

This was a process, then, whereby very vague prior notions of the user were transformed into something both concrete and purposive. The involved user as defined in Macmillan's loose rationale was something of a hollow identity, and such an identity offers, as Davies *et al.* (2006: 162-165) note in relation to the construction of the status of 'citizen' put forward by NICE for its Citizens Council, a poor basis from which to deliberate in pursuit of a collective view:

> The citizen is disinterested, impartial and unbiased compared to the interested expert or lobbyist. The citizen is also typically 'down to earth' while the health professional or academic engages in ivory towers mystification. The citizen possesses common sense as opposed to abstruse rationality. […] The identity of the down-to-earth, commonsense, disinterested adjudicator does not seem to be a sufficient foundation for building a collective citizen view. A community of practice like the Citizens Council becomes defined simply as a collective of the sensible. All the councillors come to have in common is their difference from the experts, marginalising any of the other interests and priorities a collective group of citizens might have in democratic deliberation.

As with the Citizens Councillors in Davies *et al.*'s study, the involved users in the NURG had to work from a minimalistic understanding of the role they were to fulfil, endowing it with characteristics that were determined in the context of an emergent set of relationships in the pilot programme.

Barnes *et al.* (2004b) see the public of public-participation initiatives as constituted through policy determinations of who to consult, through the legitimating claims to representation and representativeness of those involved, and through the changes in identities and newly formed alliances that develop in the course of the process. The findings from this study indicate a relative inconsequentiality of the first of these, and the importance of the contingencies of the field in determining the outcome of the latter two. Just as the 'unhyphenated citizen' identity proffered upon Citizens Councillors in Davies *et al.*'s study provided a poor basis for action, so the identity of 'involved user' offered only a starting point to the involved users here, from which those involved variously stressed their status as patients, citizens, professionals in other fields, knowledgeable members of communities of identity or interest and so on, in accordance with the exigencies of the negotiations with staff in which they found themselves (cf. also Kerr *et al.*, 2007, on the contingently 'shifting subject positions' they find adopted by laypeople in interacting with scientific experts).

This, however, suggests certain difficulties with a number of models of public participation and user involvement that specify clear and distinctive roles for these different, constituted, publics. Charles and DeMaio's (1993) well known framework makes the putative division between the collectively minded input of 'citizens' and the more particular input of 'patients'. Such a distinction seems unsustainable in practice, as do arguments that construct different roles for the public as 'taxpayers', 'voters' and 'patients' in public-participation initiatives (e.g. Lomas, 1997; Martin *et al.*, 2002). User involvement in practice seems to float between justifications pragmatically (cf. Barnes *et al.*, 2007), and as Contandriopoulos *et al.* (2004) argue from their explicitly constructivist position, a more reflexive approach to defining and delimiting these roles would not necessarily be a virtue, since it might encourage more instrumental claims to occupy a particular subject position, compared to the relatively 'naïve' manner in which shifts in identity occur now. These findings also suggest certain difficulties with the way in which motivations and identities are seen to develop through involvement (Simmons & Birchall, 2005; Barnes *et al.*, 2007), which are frequently viewed in a positive light as the realization of a collective identity and the transformation of individualized motivation into something more expansive and productive. As I suggest in the next section, contemporary modes of governance seem increasingly to include public-participation initiatives in their spheres of influence from the start, and so such transformations are likely, as here, to occur in the context of and in relation to the exigencies of the wider field of stakeholders.

Finally, as Barnes *et al.* (2003) anticipate, there is a sense in which presence at outlets for public participation such as this might create a distancing from a clearly demarcated constituency, as identity and role develop and deviate from the original brief (however vaguely set out). This was certainly evident in the multiple identities to which involved users laid claim, but there seemed no easy responses to this in practice. Macmillan's keenness to pre-empt the 'establishment' of a 'user bureaucracy' (Chapter 10) might be understood as an attempt to deal with this issue, but given the need to develop a collective understanding of the user role and identity and the relational nature of this process, a degree of distancing—and the undermining of any democratic justification for involvement it implies—seems inevitable. The flipside to this distancing, however, is the opportunity to cultivate a wider set of capacities that might give rise to more productive, expansive rationales—generating what Davies *et al.* (2006: 222) call an 'expertise space'—although, as discussed in the next section, the place of involvement within wider systems of governance may, as in this case, place important constraints and conditions on this.

The findings and current policy and public-service governance

The second set of questions related involvement to the wider organizational and policy context, asking:

- How does user-involvement policy relate to practice, and how does involvement function within the organizational parameters and governance structures of the pilot programme studied and the wider NHS?
- How is the input of user involvement put into practice?
- How far does the contribution find its legitimacy in democratic, technocratic or other rationales?

The rather tenuous link between Macmillan's vague outline of user involvement and the way it was realized through practice was noted in the previous section, and the same might be said of the link between central-government policy on PPI, explored in Chapter 2, and practice on the ground. As is clear from the analysis presented in Chapter 2, though, this is not for want of policy direction: the policy literature on the matter is extensive, if multifaceted and ambiguous about the role to be played by participation. Thus it does not seem to be the case on the level of policy that, as Rhodes and Nocon (1998) anticipated, involvement has been marginalized in Labour's rhetoric since 1997: on the contrary, it has played a major part in the 'modernization' agenda. However, on the level of implementation, central government's policy in relation to involvement has differed markedly from other facets of NHS modernization, such as professional regulation and clinical governance. Where the rise of EBM and clinical governance, for example, has seen a centralization of power and a scientific logic that has been little resisted by the medical profession (Harrison, 2002; Flynn, 2004), state calls for public participation seem more ambivalent in character. They locate it at the centre of the 'new NHS' and place a statutory responsibility on organizations to do it, but offer multiple, ambiguous ideas about how, with little state management of processes and outcomes. In Harrison and McDonald's (2008: 140) terms, involvement policy has taken the form of a 'bright idea' rather than a 'blueprint', "a rather unspecific vision of how to proceed […] providing for policy to emerge from implementation." Conflict over the remit of participation, pragmatically mediated through practice rather than strategically planned in relation to clear objectives, is a common result, as seen in this study and elsewhere (e.g. Rutter *et al.*, 2004; Fudge *et al.*, 2008).

In these terms, it seems, as Salter (2004) argues, that the state is rather less interested in setting up an unambiguous mandate for involvement, which might create new lines of accountability, than in pursuing a more managerialist form of modernization, through projects such as EBM, that centralizes power. The translation of PPI policy into local practice, then, diverges intriguingly from the characterization of 'modernized' NHS governance put forward by Greener and Powell (2008). They argue that stronger central direction combines with an increased focus on local accountability in the NHS give rise to a situation where "the state appears to be attempting to extract itself from taking any blame for the delivery of healthcare at exactly the same time as it takes greater control over the goals and day-to-day running of the NHS" (Greener & Powell, 2008: 631). In the case of user involvement—with its potential, as Salter argues, to pluralize relations of accountability rather than strengthen state control—the situation seems more ambivalent, with a broad central 'bright idea' left to local determination. At most, the state maintains control through its more directive mechanisms, whilst pluralizing stakeholder arrangements, the efficacy of which depends on the success or otherwise of those stakeholders in wielding further influence (Kuhlmann & Allsop, 2008). The result is what Clarke *et al.* (2007: 143; citing Bode, 2007) term 'disorganized governance', which keeps professionals and managers on their toes with a range of competing expectations and constraints.

In this study, implementation was co-ordinated through the lateral, non-directive approach to governance taken by Macmillan, which further devolved responsibility for the form taken by involvement to site-level actors. The result was the pragmatic negotiation of user involvement noted in the previous section and explored in the empirical chapters. The ideas of involvement put forward by involved users and pilot staff each could each find justification in policy. Involved users' notions of the form that involvement should take mirrored what Barnes *et al.* (2007: 15) call the 'stakeholder public' discourse in Labour policy, "built around the idea of the public […] having a stake in the good governance of the public realm." Staff's views seemed to conform more to the 'consuming public' discourse, "focused on the expectations and experiences of individuals in their use of public services" (Barnes *et al.*, 2007: 13), and adapted to professional interests in a fashion similar to that noted by Newman and Vidler (2006) in professionals' reconfiguration of policy rhetoric about 'choice'. Neither of these policy-level discourses, however, could be said to have 'driven' user involvement, even as they offered *post hoc* discursive justificatory resources for the actors as they negotiated its realization.

So the approach of Macmillan, with its emphasis on bottom-up development and the creation of synergistic local partnerships between users and staff, seemed to exacerbate these challenges of implementation. Its efforts at 'imbuing partnership', as I called it in Chapter 9, emphasised the need for those involved in the process to approach it voluntarily, on account of its intrinsic worth, rather than because of compulsion. But the absence of clear prior rationales for involvement held by users and staff—and moreover the lack of synergy between their emergent ideas—meant that the lateral, network governance of involvement envisaged by Macmillan seemed a poor mechanism for realizing this vision. To this extent, the points made by Milewa (2004), Reddel and Woolcock (2004) and Newman *et al.* (2004), about the need for alignment of participation initiatives with vertical governance arrangements, seem well founded. However, the difficulties of implementing involvement were not just attributable to Macmillan's emphases on 'influence rather than direction' and 'voluntarism rather than compulsion'. Wider structural impediments in an NHS characterized by parallel modes of governance seemed to militate against a more expansive contribution for user involvement, despite the explicit weight attached in the Kenilworth model to joined-up working and thinking between sectors of the NHS. For example, as we saw in Chapter 9, ideas put forward by Ava about the need to improve knowledge of cancer genetics in primary care—very much in line with the spirit of the Kenilworth model—were ignored by Site A's lead, whose focus was primarily on patient throughput and the service-delivery aspects of the Kenilworth model. The market, central performance management, and indeed the impenetrability of the barrier between hospital-based care and primary care were important constraining factors in the rest of pilots' work (Martin *et al.*, 2009a), and seemed too to reinforce the marginality of involvement in the pilots. Milewa *et al.* (2002: 807) suggest that policies encouraging networks and partnerships may increase the propensity of reluctant organizations to engage with public-participation initiatives, especially where "partner organizations [...] insist upon degrees of community involvement" and "multi-sectoral initiatives [...] are linked to funding or resource opportunities." However, even where this is the case—as it was here, with Macmillan's expectation and monitoring of involvement—the scope for marginalization if it is not pushed forward proactively is clear (Rummery, 2006; Young, 2006).

On the level of the programme, rather than the individual pilots, Macmillan did seem somewhat more willing to sponsor involvement more proactively in this way, putting the views of the NURG forward through mechanisms including the narratives, the guidance it provided to user-involvement leads, and the prominent place it gave to user involvement at Pilots Together events. Its support for the NURG gave the users time and space to develop an increasingly coherent rationale and involved-user identity, which they drew upon in relating to the pilots, albeit with limited success. To this extent, the organization did provide the kind of support that might empower involved users in their efforts to gain leverage at pilot and programme level. However, as we have also seen, this support was provided in accordance with wider concerns relating to Macmillan's position within the pilot programme (as a sponsor), within the policy network (as a partner to the DH in formulating and implementing cancer-related policy), and within wider society (as a charity dependent on private and corporate donations, and thus conscious of its image). Macmillan thus occupied the position of what Davies (2007) calls a 'dialogic intermediary organization', which must constantly demonstrate its integrity according to the divergent criteria of a variety of stakeholders. On the whole, as we have seen, involved users accepted and even endorsed the managerial concerns expressed by Macmillan staff, for example in relation to the need for instrumentalization of the outputs of the NURG. Nevertheless, this does draw attention to the need to acknowledge the role of institutional pressures in governance networks in creating "a unique set of possibilities and tensions for partnerships in developing democratic governance" (Sterling, 2005: 147), and in particular the positioning of third-sector organizations in such governance arrangements. Barnes *et al.* (2006; 2007) advocate the possibilities offered by 'parallel discursive arenas' to allow open deliberation among involved publics, away from the 'invited spaces' of participatory governance, which they see as increasing "the potential that both the agenda for and the rules of deliberation will be constructed jointly, rather than imposed by officials" (Barnes *et al.*, 2007: 50). Here, though, Macmillan's position within the pilot programme meant that the NURG could not be characterized so straightforwardly as a parallel arena: rather it was *always already* drawn into the programme's rationality, so that the contribution, role and identity formulated through the NURG did not precede the exigencies of the programme, but were rather defined in relation to them, as discussed in the previous section. Thus there seemed a thin and unstable line between the autonomy of the NURG and its dependency on the programme, on account of the way in which it was "discursively constituted as a 'partner'" (Barnes *et al.*, 2007: 154) within the pilot programme. This point seems particularly pertinent in a context where many third-sector organizations, including some smaller than Macmillan, are being incorporated into networks of public-service governance, whether as 'dialogic intermediary organizations' at the level of policy formulation, or in implementing public services on the ground, as providers, consultants or conduits through which 'user voices' are articulated and imparted. While Beresford and Branfield (2006) see possible worth in such partnership arrangements, their potential to bring previously autonomous groups of users closer to the nexus of governmental power, such that distinctions between 'parallel discursive arenas' and the 'invited spaces of governance' (and the users and contributions they construct) become problematic, should also be recognized.

The realities of the practice of involvement at programme and pilot level, then, tended to result in the more expansive contributions of involved users being 'crowded out' by other concerns. While involved users occasionally invoked democratically founded justifications for their involvement, these seemed contingent on the negotiations in which they were engaged. Regardless of how far these claims were defensible, democratic rationales for involvement tended in practice anyway not to be the basis for involvement. Rather, user involvement seemed to be more about meeting the emergent needs of the governance arrangement, the pilots and Macmillan. This was exemplified in the way in which involved users' roles came to be defined largely as those of 'quasi-professionals' and 'pseudo-patients', as I called them, deliberately provocatively, in Chapter 10. Certain technocratically oriented contributions were welcomed, but only, on the whole, if these did not threaten to shift control away from clinical professionals. Rather than opening up professionally bounded expertise to outside influence through user involvement, this was about a (limited) pluralization of the knowledges seen as relevant to the contemporary governance of the health service, secured at pilot level through ongoing professional control of agenda, and at programme level by the interdependencies between the three groups.

The findings, social theory and contemporary society-state relationships

The final set of research questions put forward in Chapter 3 sought to relate the empirical findings back—perhaps tentatively—to the social-theoretical narratives of change explored in Chapter 1:

- What does the practice of user involvement have to say about the relationship between the individual, the state, society and knowledge in late modernity?

- Who or what is being governed through user involvement?
- How far do theories of reflexive modernization and governmentality provide a useful lens through which to understand changing processes 'on the ground'?

On the one hand, the motivation, drive and tenacity of the users whose involvement in the cancer-genetics programme is documented in this thesis seems to point towards the rise of a kind of subjectivity that might be understood in terms of 'active citizenship' or 'life politics' (Giddens, 1991; Rose & Novas, 2005; Novas, 2006; Rabinow & Rose, 2006), or 'becoming' a certain kind of citizen with a productive contribution to give (Campbell, 2005). Their willingness to challenge expert and state authority on account of their own experience and acquisition of knowledge reflects the sceptical, challenging disposition of the individual in late modernity; their sense of a community of interest and efforts in articulating its viewpoint embody an organization of agency from below that might pose challenges to the rationality of unreflexively modern loci of power.

On the other hand, as the previous sections of this chapter stress, such agency was always mediated by the concerns of various actors in a complex system of governance. Its contribution was thus structured by these concerns, and furthermore, as we have seen, the motivations of those involved, and even the involved-user identity, were constituted relationally in this context. As Barnes *et al.* (2007: 185) argue in a governmentality vein, this highlights the importance of noting

> what happens over time, stressing the importance of understanding why and how initiatives that start out with good intentions—the 'empowerment' of new social actors, the inclusion of new voices in the shaping of policy, or a shift in power relationships between public bodies and the public they serve—often end up as a process in which participants become captured in governmental fields of power.

Of course, as Rabinow and Rose (2006) suggest, 'bottom-up' and 'top-down' constitution of collective forms of action are not mutually exclusive, and there was certainly a sense in which the NURG offered a welcome space for involved users to clarify their purpose and identity, and make it operational and relevant in relation to the field of services they were seeking to influence. This was an opportunity, then, for those drawn into these governmental fields of power to become 'active subjects', as Taylor (2007) has it. Yet in terms of the practice of involvement, as it was translated from these spaces into concrete contributions within the pilots and at the programme level, the 'active' aspects of what involved users were seeking to offer seemed to be lost. This was signalled in the kinds of knowledge valued by pilot staff, as documented in Chapters 8 and 9. Involved users frequently offered 'knowledge about' a given topic, for example the barriers faced by those from marginal, 'hard-to-reach' groups in accessing care, which both Chanan and Dawn sought to provide to their pilots. What staff wanted, however, was not 'knowledge about' such subjects but more direct 'experience of' them, derived from membership of these groups. As we saw, this posited a rather different relationship with the involved users, and a rather different construction of the validity of their contributions. It emphasised 'being' over 'becoming': the involved users sought were not the active but the passive. Pilot staff's construction, then, of the relationship between the public and professional expertise was rather more traditional than the active-citizenship model would suggest—even if in practice it seemed to involve certain contradictions, as I suggested in Chapter 9 in characterizing the desire for a passive, yet involved, service user as a search for a chimaera.

One could certainly understand this situation within the framings of governmentality. It chimes with the analysis put forward, for example, by Enticott and Entwistle (2007), who discuss how the more expansive and original perspectives put forward by the actors engaged by more networked forms of governance are constrained in practice by narrower, conventional understandings of their role put forward by the state. In this understanding, governmentality in practice in user involvement would seem to be less about the productive harnessing of a range of social identities—'experts in laity' and the like, discussed in the light of the analysis of policy documents in Chapter 2—in pursuit of the better governance of public services, and more about the means by which dominant actors, such as the state and powerful professional groups, retain power over governance, despite giving the appearance of dispersing power to a wider range of actors, including involved users.

This is a well rehearsed understanding of the operation of governmentality, and of the ongoing primacy of the central state in an era of network governance. But there are difficulties in pursuing this argument in relation to the data and analysis presented in this thesis. For a start, this is evidently not a matter of overt efforts by the state to retain control and deliberately impede user involvement, for as we have seen, on a rhetorical level, central policy advocates a range of new roles for PPI that seem to be about harnessing, rather than marginalizing, the rationality of the public, while on a practical level, the role of policy in centralizing or dispersing power seemed to be minimal. It merely set the stage for the local negotiation of user involvement, providing certain discursive prompts that were drawn on by the actors in justifying their roles, but without offering a clear script. There was, then, continuing the metaphor, no centrally determined plot of the kind that might inform a more state-centred interpretation of governmentality's operation in this field, such as those put forward by Marinetto (2003) and Enticott and Entwistle (2007).

Perhaps, then, the role of user involvement might be understood in the more distributed descriptions of governmentality offered by authors such as Rose (1996; Rose & Miller, 1992). This more nuanced account of 'government at a distance' would place the state less centrally, and put greater emphasis on the role of societal discourses in providing a governmental rationality that informed the behaviour of the actors involved, pilot staff, users and Macmillan staff alike. The state, then, is seen as entrusting responsibility to a range of actors whose interactions ensure the effective development and delivery of services through their aggregate rationality. This might be seen in the way in which the NURG developed its relatively conservative, managerial contributions to the programme not through coercion or a managerializing 'black boxing' of the discussions by Macmillan respondents, but via those involved accepting and responding to the needs of the pilot programme. Similarly, it might be seen in the way in which a role for involved users as 'pseudo-patients' or 'quasi-professionals', with contributions that fitted the governance needs of the programme and the pilots, came to be established through the intentions, actions and interactions of the three groups. Perhaps most explicitly, it might be seen in the concerted efforts of Macmillan to 'imbue' partnership through efforts to act on the subjectivity of those involved, prioritizing instilling the right mindset in users and staff over efforts to put forward models of appropriate approaches to involvement or put in place structures that might assist its progress—even though the success of this approach was, at best, mixed. This account, then, would highlight the success of the devolved governance of the pilot programme as an example of 'government at a distance' in fashioning a constrained but governmentally useful set of contributions from user involvement: a prime example of the machinations of advanced-liberal governmentality.

Yet I have difficulties with prosecuting such an account in relation to my study. To connect the behaviours of those I talked to and observed to the constitutive power of large-scale socially determining governmental discourses seems to me problematic. The actions and interactions that gave rise to user involvement in this study had their own, local, rationales and logics, and I have doubts over how far these can be accounted for in terms of the constitutive power of governmental discourse. The motivations of involved users as these were developed through the NURG; the concerns of Macmillan about the need to instrumentalize the products of user involvement whilst ensuring 'freshness' rather than 'professionalization'; the 'commonsense' understanding of user involvement held by staff, and the way this linked into organizational and professional interests and exigencies: each of these could, certainly, derive in the final instance from powerful discourses that secure the reproduction of advanced-liberal society. But each, too, has its own more local logic, and to claim a determining relationship between societal-level discourses and these logics seems to me to be to extrapolate well beyond the scope of my empirical evidence. Certainly, I cannot trace an empirical operationalization of governmentality of the kind put forward by, for example, Schofield (2002: 675), in his account of how "the discourse of community becomes overtly governmental." It seems to me, then, that, as Newman (2005b: 13) has it, "general theories of the constitutive power of discourse fail to capture the complexity and diversity of the ways in which conceptions of the public are negotiated and remade." There is, then, a gap between empirical reality and grand narratives of social change (among which I would count theories of governmentality) which herald the importance of new subjectivities. As Clarke *et al.* (2007: 153-154) put it:

> [The] theories with which we began have tended to assume that the subjects implied in the dominant trends materialise in practice. […] There are both analytical and political problems about such assumptions that persistently short-circuit the empirical question of whether any of these new subjects actually materialise and deliver their performances.

There is, of course, a crucial difference between the empirical social science that I am pursuing, and the broad-brush, textually based, genealogical accounts of the character of contemporary society put forward in theoretical expositions of governmentality. As Rose (1999: 274) himself acknowledges, a viable criticism of theories of governmentality is that they "deny the polycentric, multi-vocal, heterogeneous and messy realities of power relations as they are enacted and resisted in a multitude of micro-locales." The disjuncture between social theory and the 'messiness' of social practice is thus an inevitable one. To fail to at least note apparent points of alignment between social reality and social-theoretical explanations, then, would be to run the risk of underanalysis. However, it seems to me that the risk of overanalysis is also great, and its consequence is an approach to explanation which writes out particularity, exception and contingency in favour of a reductionism that involves incautious causational 'leaps of faith' rather than critical evaluation of available evidence. The result is a 'metasocial' level of analysis which can lose sight of more localized logics and rationales that account for social phenomena, seeking to explain these in terms of powerful discourses which, although constituted through social processes, are endowed by such analyses with a determining authority that goes beyond the social. Such analyses offer powerful starting points for understanding the condition of contemporary social action, but for me it is important to avoid merely reproducing their claims by reducing the contingencies of empirical work to their frameworks. This implies instead a more modest level of analysis and explanation, which recognizes particularities, exceptions and contingencies as important, irreducible elements of social process which need to be incorporated into empirical and theoretical understandings.

Thus whilst highlighting above the ways in which the practice of user involvement does seem to conform with some of the points made in the literature about the operation of advanced-liberal governmentality, I am not convinced that it would be defensible to seek to explain it wholly or even primarily in these terms. This would be to imbue my findings with an ultimate coherence, a unifying determining logic, which cannot be empirically sustained. Rather, I would seek to understand my data in terms of an analysis which locates agency more firmly in the local decisions made by individual actors, rather than understanding these in terms of the enactment, reproduction and contestation of determinant governmental discourses. To locate my analysis at this abstract level of social causality would not only be unsustainable in terms of my empirical evidence, but would also fail to do justice to the multifaceted nature of the micro-level processes that gave me my dataset.

This is not to say that my findings are incompatible with a governmentality-based account of contemporary developments in the governance of the NHS and public services. Indeed, there are certain further congruencies that should be highlighted, even whilst avoiding empirical extrapolation. In particular, two possible hypotheses that are generated—but untested—by the findings suggest themselves. Firstly, the 'disorganized governance' discussed in the previous section, resulting from the ambivalent policy mandate and challenges of implementation, might represent a kind of 'governmentality by neglect'. In an area of relatively marginal importance (at least in the context of the wider challenges faced in NHS modernization, from the ageing population to the prickly question of medical regulation), perhaps the very lack of explicit frameworks, clear incentives and managerial accountability generates exactly the kinds of agency and action desired. Those responsible for operationalizing user involvement locally are charged with the task of negotiating their own order, producing settlements that "depend on how various stakeholders exercise their powers" (Kuhlmann & Allsop, 2008: 185). Government can thus demonstrate commitment to greater involvement, accountability and democratization, provide an outlet for user activism, and quietly abdicate responsibility for the forms that subsequently emerge, whilst confidently relying on the countervailing forces of professional self-interest and organizational inertia to ensure that the 'right', productive kind of involvement is realized. Meanwhile, more intensive effort is devoted to the more pressing issues of public-service governance and modernization, involving much more meticulous alignments of governmental rationality with influential authorities and the subjectivities of professional staff, as described, for example, by Flynn (2004) in relation to clinical governance.

A second—alternative—hypothesis is that involvement of this kind represents a failure of governmentality. The 'bright ideas' encapsulated in recent participation policy, with their incitements to action but lack of prescription, and the enactment of this *modus operandi* in the efforts of Macmillan in this case to 'imbue' partnership by seeking to work at the subjectivities of those involved, come up against impenetrable barriers on account of structural, institutional and cultural impediments to change. In other words, this study is one that illustrates the major challenges faced by 'government at (such) a distance', through subjectification, without the support of more direct and directive policies emanating from some level (be it the state, the meso-level complex of quasi-governmental and non-governmental organizations, or a more local source). There is some wider evidence that might support such a hypothesis. The plethora of recent policy on public involvement has been accompanied by considerable institutional turbulence, as noted in Chapter 2, with the creation and subsequent abolition of the CPPIH and the succession of CHCs by PPI Forums by LINks. As Harrison and McDonald (2008) point out, this volatility might be explained, in part, by apparently genuine concern among policymakers about the failure of PPI to surmount the 'brick wall' between involvement activities and tangible results (Department of Health, 2004). With the introduction of LINks, there are signs of a slightly more directive approach to public involvement, for example in commissioning processes (Harrison & McDonald, 2008; Martin, 2009c), suggesting perhaps a withdrawal from quite such a singular reliance on subjectivity and agency in securing a place for involvement, and maybe even a commitment to ensuring more pervasive forms of involvement in the future.

These, though, are little more than possible congruencies with governmentality, and given the malleability of the theory, as hypotheses they tend towards the unfalsifiable. This, perhaps, is a crucial point. The grand theories of governmentality and reflexive modernization are not ones which can be subject to 'verification' or 'validation' as such (Mythen, 2007). However, there is also the risk that uncritical application of their insights to empirical work may lead to unthinking reproduction of their premises rather than a more careful, critical contribution to understanding of social processes. Whilst not arguing for the redundancy of higher-level analytical accounts, then, efforts to construct empirical studies in relation to them must avoid sacrificing the details, contingencies and contradictions of social reality for an explanatory coherence of dubious defensibility. Thus even whilst acknowledging certain points of alignment, I prefer in accounting for my findings to point towards the more 'mundane', local rationales and logics of behaviour that gave rise to the way user involvement played out in my study. As we have seen, in some ways these are specific to the cases concerned, but there are also important generalizations to be made: in relation to the relative unimportance of policy determinations in the practice of user involvement; in relation to the way in which 'commonsense' professional views about involvement were reinforced by institutional constraints and by the way in which user involvement was practised; and in relation to how the position of Macmillan, as a third-sector organization implicated in the governance of the pilot programme, both constrained and facilitated the realization of the particular form of user involvement that developed, to give three examples. These analyses do not preclude a social-theoretically informed understanding of the field; indeed, each could certainly be constructed in terms of governmentality. But I prefer to aim my contribution principally at this more modest, practical and policy-relevant level, rather than engage in the extrapolation necessary to reduce my study to the terms of a higher-level theory which may or may not provide it with a valid explanatory framework.

CONCLUSION

In Chapter 11, I offer an analysis of my findings on three levels, from the micro-level scale of practice in public participation, through meso-scale questions of policy and its implementation, to a discussion of the findings in relation to macro-level theories of contemporary society. As acknowledged at the start of that chapter, this meant abstracting from the specific analyses of the previous five empirical chapters. This concluding chapter begins, therefore, by reprising the specific and general findings from the empirical chapters, and bringing these together to highlight the key contributions of the thesis empirically and theoretically.

Chapter 6 introduced the empirical field by considering the expectations of the three key groups of actors—Macmillan staff, pilot staff and the involved users themselves—about the nature and purpose of involvement, and recounting the testimony of users on their reasons for becoming involved in the pilot programme. On a discursive level, there was unity about the importance of user involvement, and its utility for a programme like this. Below the surface, though, I suggested that there was considerable doubt and uncertainty about what user involvement was to involve. Furthermore, an unwillingness on the part of Macmillan to provide a user-involvement 'blueprint', alongside the competing demands faced by pilot staff and the status of involved users as newcomers to the pilots, resulted in what I termed an 'implementation gap', with each party unwilling or unable—for the moment—to impose its expectations of user involvement on local practice. The developments from this situation are covered in subsequent chapters; what was apparent already, however, was that implementation of the outline of user involvement presented in Chapters 4 and 6 was likely to face plentiful challenges, especially given the lack of direction from above and lack of 'push' from below. Policy discourses of the kind discussed in Chapter 2, then, with their ambiguous but powerful constructions of the potential of participation, were starting to seem a long way from practice on the ground.

At the programme and pilot levels respectively, Chapters 7 and 8 discussed the ways in which involved users (and, on the pilot level, staff) began to deal with this implementation gap. Chapter 7 focused on the National User Reference Group, which brought involved users together with facilitation from an assembly of Macmillan staff, in order to support and develop user involvement and strengthen its role in the pilots. This afforded users the opportunity to construct an increasingly coherent and persuasive vision of their identity and purpose, but as my sustained observational work at the NURG meetings revealed, this process took place under circumstances characterized by certain endogenous power relationships, exogenous pressures and the inevitable constraint of time. Despite these exigencies, I stressed, the NURG did not operate in a way that marginalized or co-opted user involvement to managerial intentions, and many users found it an empowering space. Nevertheless, it was important to highlight how aspects of the conduct of the NURG meetings—such as the construction of a involved-user identity that was endorsed by the majority but which excluded a minority of users, the effort to produce an output that was managerially useful by Macmillan staff (an effort which was transparent and open, and accepted as necessary by most involved users), and the prioritization, through time, of subscription to the group's ethos over status as a service user in determining 'contributory rights'—meant that it was a very particular vision of users, involvement and its potential that was developed. This analysis, then, adds to previous work (e.g. Thompson & Hoggett, 2001; Barnes *et al.*, 2006; Davies *et al.*, 2006) on the reality of deliberation in involvement processes, highlighting that instrumentalization, exclusion and managerialization can operate through much more subtle group dynamics, as well as through the crude managerialism that previous research has tended to emphasise (Mort *et al.*, 1996; Harrison & Mort, 1998; Milewa *et al.*, 1998; Williams, 2004).

Chapter 8, meanwhile, considered the clash between this developing construction of user involvement proffered by (most) users and the rather different ideas held by (most) pilot staff. In particular, I sought to argue that these differences seemed to arise from a substantive divergence in beliefs about the role of 'lay' publics and users in the management and delivery of health services. Through their interactions in the NURG and elsewhere, users were articulating an increasingly thoroughgoing and skills-based role for user involvement, premised as much on their professional and personal backgrounds as on their status as service users. Staff, in the main, saw the justification for involvement as deriving from the very laity of users, or from their experiences as patients, and this construction suggested a much more conservative role for involvement. Users saw their contributions as autonomous and irreducible to professional frames of understanding; staff members drew on a 'commonsense' (and occasionally more nuanced, reasoned) notion of lay and patient contributions as subordinate to their own priorities and those of the NHS. Moreover, this divergence seemed to reflect more than just the instrumental interests of the two parties, but arose from conflicting understandings of the relationship between the 'lay' public, professional expertise and state service provision. While these conflicting understandings could both be justified in terms of policy discourses of 'stakeholder' and 'consumer' publics (Barnes *et al.*, 2007), they seemed also to 'trump' these, taking precedence over the loose prescriptions of national or programme-level policy, as Chapter 11 explores further.

Where Chapters 7 and 8 were concerned primarily with the developing visions of public participation of the three groups, Chapters 9 and 10 focused more on the negotiation of these ideas on pilot and programme levels, and their outcome in terms of the practice of user involvement on the ground. The first half of Chapter 9 took a tour of the seven pilot sites, adding local detail to the themes identified in the previous chapters, and expanding on some of these. It noted, for example, how the conflicting visions of involvement illuminated in Chapter 8 gave rise to different expectations about what users could contribute, with staff expecting users with *experience-derived* knowledge *of* an issue, and users often offering knowledge *about* an issue, based not on experience but on their own reflections and analysis. Staff wanted subjective, insider knowledge; users usually provided an abstracted, objectivised perspective. User involvement in practice thus frequently failed to bridge the gap in expectations between the two groups (though there was some progress towards such a reconciliation, as Chapter 10 records). The second half of Chapter 9 considered how, on the programme level, Macmillan responded to this situation, and to concern from the NURG members that pilots were failing to take involvement seriously and engage with it appropriately. Macmillan was somewhat more directive about involvement and sought through various methods to promote a more partnership-based notion of involvement, in which the views and ideas of users would be given greater precedence than in the superordinate-subordinate relationship imagined by most staff. However, for two reasons in particular, these efforts of Macmillan staff were always tinged with ambiguity. Firstly, as the chapter highlights, there was the concern that to enforce partnership would be to undermine its very essence: true partnership required a belief in its worth, an intrinsic motivation, from both partners, not imposition from above. Secondly, as Chapter 11 subsequently explores in more detail, Macmillan's preference for lateral persuasion rather than top-down diktat, and its position as co-sponsor of the pilots, meant that its staff were reluctant to hold up partnership as *the* model for involvement, in the process denigrating the efforts of the majority of pilots in which involvement fell short of this ideal. Consequently, Macmillan's approach to nurturing involvement in the pilots took a number of subtle forms, 'imbuing' rather than imposing partnership, and seeking to value other modes of involvement as valid alternatives rather than deficient substitutes. This chapter, then, presents an intriguing empirical examination of the challenges facing public participation in network governance (Newman *et al.*, 2004), and of the constraints on the actions of a third-sector organization such as Macmillan when it is given such a multifaceted role in the management and delivery of public services and the representation and participation of service users.

Chapter 10 returned to the pilot level to consider how a number of institutional, organizational and interpersonal factors seemed to reinforce the divided picture of user involvement that had been drawn in the preceding pages. In most sites, expedient recruitment, the presence of more pressing priorities and the lack of any formal vetting or selection of users by staff combined to preclude the development of anything approaching a partnership in which users felt encouraged to make the contributions they wanted. This situation was exacerbated by the fact that there was little informal contact between users and staff of the kind which might promote trust, mutual respect and the development of a mutual agenda. In many sites, users only came into contact with staff at formal steering-group meetings, tightly bound by preset agenda, which represented the least auspicious opportunities for putting forward the kinds of wideranging and novel ideas harboured by users. The absence of opportunities to develop the social, transactional aspects of partnership (trust, reciprocity, ongoing working relationships) thus combined with wider forces to preclude the development of the functional aspects of partnership (shared power, equality of influence, joint decision making). In contrast, the one site in which some form of partnership could be said to have developed was characterized by much greater formal and informal integration of the involved users within the professional team. I also noted, though, that this resulted in an evolution of partnership that seemed to result in an increasingly professionalized role for user involvement, straying somewhat from the spirit of the (admittedly loose) guidance initially issued by Macmillan. On the programme level, meanwhile, users were increasingly involved in the discourse of the national meetings of the pilots, but not in quite the way they had anticipated. Rather, I argued that they had to fashion their contributions in ways that meant that they acted either as 'pseudo-patients'—giving a 'universal patient perspective' that drew little on their actual experiences and ideas—or as 'quasi-professionals'—adopting the language and preoccupations of staff by acquiring a professionalized knowledge of the organizational intricacies of the NHS. As at the local level, then, my work in this chapter revealed the empirical details on the pilot level that make the practical realization of involvement so complicated.

The discussion in Chapter 11 sought to draw on these five empirical chapters, and relate their findings back to the three levels of questions posed at the end of Chapter 3. On a practical level, I emphasised in particular how the forms of user involvement produced in the programme seemed to depend much more on the contingencies of the process than on any policy or theoretical direction. Despite the flurry of guidance and direction in relation to public participation, some of which I examined in Chapter 2, policy was at most a *post hoc* resource on which involved users and professionals drew in seeking to justify their divergent visions. That neither government policy nor Macmillan offered a 'blueprint' for participation meant that the identity of 'involved user' was something of a hollow one that participants had to fill (cf. Davies *et al.*, 2006). This led to something of a distancing of user involvement from the publics 'represented', but it also offered a creative space in which users could develop their own, innovative ideas about the kinds of contributions they could offer—though when it came to realizing these ideas in practice, there were multiple obstacles that arose from diverse institutional, organizational and interpersonal factors. On the meso-level of policy and implementation, I returned to the point that despite its volume, the copious government rhetoric on public participation does not seem to amount to detailed guidance on involvement in practice, noting that Macmillan, too, for reasons described in the empirical chapters, was reluctant to produce a clear mandate about what involvement should be and how it should be done. The ambivalence, I argued, seemed to suit a government eager not to legitimize new, localized relationships of accountability given the centralizing tendencies of much of the rest of the modernization agenda, and suited Macmillan given the multifaceted position in which it found itself in relation to the programme, the 'user voice' and the wider governance of the NHS. There were, furthermore, limits to the viability of network governance of user involvement, given the pressures of performance management facing pilots, and this entanglement of Macmillan in relationships with various stakeholders with divergent interests and wishes. Other third-sector organizations will find themselves in similar positions to that of Macmillan, and this means that the gap between Barnes *et al.*'s (2007) notions of autonomous 'parallel discursive arenas' for public participation, and the 'invited spaces of governance' is not as clear-cut as it may appear. Finally, returning to the macro-level questions posed by the theories of contemporary society and social change with which Chapter 1 began, I noted what I consider to be the explanatory limitations of high-level social theory in relation to empirical practice 'on the ground'. More modest explanations should not be lost in a rush to reduce findings to such frameworks of understanding, losing sight of more visible and verifiable causal mechanisms. However, I also posited two particular hypotheses that were generated, but untested, by the empirical work, around the idea that user involvement represents a 'failure of governmentality' or a case of (to some extent successful) 'governmentality by neglect'.

The findings presented in the empirical chapters and the overarching discussion chapter rest, of course, on analysis of involvement as it unfolded in one particular pilot programme over a certain period of time. Nevertheless, certain points do seem generalizable to the wider field of public-involvement initiatives in health services and other areas of public-service provision, as highlighted throughout the empirical chapters and in Chapter 11 in particular. The lack of certainty over the role and remit of involvement, for example, might be seen as resulting indirectly from the policy-level ambiguities about what public participation is for (as explored in Chapter 2), and the results of this—the competing rationales for involvement discussed in Chapter 8, for example—are reflected in other recent studies of involvement processes (e.g. Rutter *et al.*, 2004; Fudge *et al.*, 2008). Similarly, the ambivalent status of the NURG as an kind of 'parallel discursive arena', but one which seemed always already to be drawn into certain rationalities and exigencies of the governance of the wider pilot programme, draws on and extends the analysis of other authors (e.g. Barnes *et al.*, 2006) in relation to an empirical case that seems to exemplify the challenges facing involvement more generally in complex contemporary governance networks.

The methods deployed in order to answer the set of questions put forward in Chapter 3 have their strengths and limitations, in many ways inextricably linked to each other. The centrality of in-depth interviews to the study allowed intensive time with key protagonists in the field discussing the issues at stake. This permitted considerable insights into the differing constructions of user involvement held by different parties, though the reconstitutive nature of one-to-one interviews should never be forgotten.

Indeed, it was starkly evident at times—for example, in the tension between a keenness among pilot staff to record how they valued user involvement, and their difficulties in describing its influence on their work. Nevertheless, interviews were crucial in assisting my understanding of the key differences between groups' and individuals' understandings of involvement, of the status of the users, and of how this seemed to reflect wider constructions of the relationship between professionally led service provision and the public it serves. Similarly, my approach to participant observation was a pragmatic and bounded one, in which the nature of the meetings and my role within them, my position as a sole researcher and the lack of recording equipment—as well as the nature of the questions I was seeking to answer—dictated the limits of what I could record. Nevertheless, my notes on the ebbs and flows of the meetings—as well as the more tacit knowledge I acquired from just 'being there'—were formative in my understanding of the field and the analysis which followed.

While the strengths and weaknesses of the approach, and thus the validity and many of the limitations of the research, were inextricably linked, certain aspects of the study could have been improved. I noted in Chapter 5 how overcautiousness in making interview requests meant that I failed to obtain interviews with two potentially important respondents. Due to NHS research-governance requirements, I was unable to attend and observe site-level meetings as early as I would have liked. There were also certain national-level meetings—the programme steering-group meeting, and the events for user-involvement leads—at which attendance may have enriched my analysis, especially in terms of my understanding of dynamics within Macmillan. One particularity of the study that should be noted, especially in relation to the question of generalizability, is its focus on those users who stayed the course of the pilots, attended multiple meetings of the NURG in London, and were generally the most committed among those who got involved. As noted in Chapter 5, in most pilots there were, besides the users I came into contact with, more 'occasional' users who were perhaps involved early on before drifting away, or maintained contact without attending meetings. Rather different accounts of motivation and contribution might have derived from research focusing on this group, and the flipside to the depth of understanding of the views of the users who 'lasted the distance' is the neglect of the rather different group that did not.

The study threw up certain issues of note which might benefit from closer examination in future research. In particular, certain aspects of the organizational and governance arrangements in the programme, and my findings in relation to them, reflect wider developments in the field of public participation. The most recent set of reforms to public involvement in health, which saw the abolition of the CPPIH and the replacement of PPI Forums with LINks, would seem to offer somewhat more directiveness about the role and place of involvement, as intimated in the last chapter. LINks are intended to draw together various different forums for involvement in given localities, to reduce overlap, sharpen the focus of involvement efforts, and increase influence. They are also—if the rhetoric is to be believed—to be endowed with a central role in NHS commissioning decisions, providing "a means for the collective voice of people to be heard" and "a view of health and social care in the round" (Secretary of State for Health, 2006: 159; see also Martin, 2009c). Although the precise institutional arrangements for securing it are not yet clear, the role of LINks—notably their place within the newly remarketized NHS, and their task of reconciling the views of multiplicitous publics to come to a "collective voice"—is a fascinating one. Their efforts to fulfil it, in light of the kinds of tensions around representativeness, relationships with NHS staff, and the constitutive effects of incorporation into wider governance processes, offers an interesting topic of future inquiry, as does the increasingly complex set of roles being granted to third-sector organizations, and the publics they claim to represent, in public-service policy, planning and delivery.

Whether LINks stand the test of time better than their immediate predecessors remains to be seen. What seems surer, though, is that the ambiguities, tensions and opportunities presented by new formations of involvement in the complex webs of public-service governance will remain a productive area in which to further understanding of the changing relationship between the public, the state and public servants. The research reported in this thesis offers a contribution to this understanding which, whilst based on one initiative with its own particularities, nevertheless points towards some important generalizable themes. The findings relating to the gap between policy intentions around involvement and the pragmatic determination of identities, roles and contributions by users and staff on the ground highlight the ongoing importance of local negotiation in the nature of involvement in practice, in an NHS where central control of parallel processes seems to be on the rise. The relatively limited determining power of policy in this field presents opportunities as well as challenges to the parties involved, and the chance to enact diverse interpretations of citizenship and consumerism to those putting themselves forward as users or involved members of the public. Yet the research also highlights the ongoing power of professionals in delineating these roles and, more intriguingly, the way in which the incorporation of third-sector organizations into governance processes creates compromised spaces for such enactment, where the negotiation of involvement has primacy over any theoretical or even policy-level definitions of the purpose of user involvement. It is in these compromised spaces that the encounters between the state and the public seem to be increasingly played out.

This situation should not be contrasted unfavourably with some idealized earlier age of citizenship in which individuals held their own, unpolluted, prior preferences and could put these forward through their interactions with the agents of the welfare state, or where civil society occupied a discursive space insulated from the managerializing influence of welfare-state governance. However, whether understood in the grand terms of social theory or the more modest language of empirical social research, this study does cast light on the contextual conditions that govern the interface between the state, public servants and the public in the changing social and political circumstances of the contemporary UK, and the expectations, norms and pressures influencing those from both sides of the interface in their efforts to make public participation real.

REFERENCES

Abelson, J., Forest, P.-G., Eyles, J., Smith, P., Martin, E. & Gauvin, F.-P. (2003) Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science & Medicine* **57**(2): 239-51

Addicott, R., McGivern, G. & Ferlie, E. (2007) The distortion of a managerial technique? The case of clinical networks in UK health care. *British Journal of Management* **18**(1): 93-105

Adonis, A. & Mulgan, G. (1994) Back to Greece: the scope for direct democracy. *Demos Quarterly* **3**: 1-28

Anderson, W. & Gillam, S. (2001) The elusive NHS consumer: 1948 to the NHS Plan. *Economic Affairs* **21**(4): 14-18

Axworthy, D., Brock, D.J.H., Bobrow, M. & Marteau, T.M. (1996) Psychological impact of population-based carrier testing for cystic fibrosis: 3-year follow-up. *The Lancet* **347**: 1443-6

Babbie, E. (1992) *The practice of social research.* Wadsworth, Belmont

Baggott, R. (2005) A funny thing happened on the way to the forum? Reforming patient and public involvement in the NHS in England. *Public Administration* **83**(3): 533-51

Barnes, M. (1999a) Researching public participation. *Local Government Studies* **25**(4): 60-75

Barnes, M. (1999b) Users as citizens: collective action and the local governance of welfare. *Social Policy & Administration* **33**(1): 73-90

Barnes, M. (2002) Bringing difference into deliberation? Disabled people, survivors and local governance. *Policy & Politics* **30**(3): 319-31

Barnes, M. (2004) Affect, anecdote and diverse debates: user challenges to scientific rationality. In A. Gray & S. Harrison (eds) *Governing medicine: theory and practice.* Open University Press, Maidenhead: 122-31

Barnes, M., Knops, A., Newman, J. & Sullivan, H. (2004a) The micro-politics of deliberation: case studies in public participation. *Contemporary Politics* **10**(2): 93-110

Barnes, M., Newman, J., Knops, A. & Sullivan, H. (2003) Constituting 'the public' in public participation. *Public Administration* **81**(2): 379-99

Barnes, M., Newman, J. & Sullivan, H. (2004b) Power, participation, and political renewal: theoretical perspectives on public participation under New Labour in Britain. *Social Politics* **11**(2): 267-79

Barnes, M., Newman, J. & Sullivan, H. (2006) Discursive arenas: deliberation and the construction of identity in public participation at a local level. *Social Movement Studies* **5**(3): 193-207

Barnes, M., Newman, J. & Sullivan, H. (2007) *Power, participation and political renewal: case studies in public participation.* Policy Press, Bristol

Barry, A., Osborne, T. & Rose, N. (1996) Introduction. In A. Barry, T. Osborne & N. Rose (eds) *Foucault and political reason: liberalism, neo-liberalism and rationalities of government.* UCL Press, London: 1-17

Bauman, Z. (1995) *Life in fragments: essays in postmodern morality.* Blackwell, Oxford

Bauman, Z. (1996) On communitarians and human freedom: or, how to square the circle. *Theory, Culture & Society* **13**(2): 79-90

Beck, U. (1991) *Risk society: towards a new modernity.* Sage, London

Beck, U. (1998) Politics of risk society. In J. Franklin (ed.) *The politics of risk society.* Cambridge, Polity Press: 9-22

Beck, U. (2000) The cosmopolitan perspective: sociology of the second age of modernity. *British Journal of Sociology* **51**(1): 79-105

Beck, U. (2008) Reframing power in the globalized world. *Organization Studies* **29**(5): 793-804

Beck, U. & Beck-Gernsheim, E. (2001) *Individualization.* Sage, London

Beck, U. & Lau, C. (2005) Second modernity as a research agenda: theoretical and empirical explorations in the 'meta-change' of modern society. *British Journal of Sociology* **56**(4): 525-57

Beresford, P. & Branfield, F. (2006) Developing inclusive partnerships: user-defined outcomes, networking and knowledge - a case study. *Health & Social Care in the Community* **14**(5): 436-44

Beresford, P. & Campbell, J. (1994) Disabled people, service users, user involvement and representation. *Disability & Society* **9**(3): 315-25

Bishop, P. & Davis, G. (2002) Mapping public participation in policy choices. *Australian Journal of Public Administration* **61**(1): 14-29

Blair, T. (1998) *The Third Way: new politics for the new century.* Fabian Society, London

Bode, I. (2007) New moral economies of welfare: the case of domiciliary elder care in Germany, France and Britain. *European Societies* **9**(2): 201-27

Bourdieu, P. (1973) Public opinion does not exist. Reprinted in P. Bourdieu (1993) *Sociology in question.* Sage, London: 149-57

Bourdieu, P. (1981) Political representation: elements for a theory of the political field. Reprinted in P. Bourdieu (1991) *Language and symbolic power.* Polity Press, Cambridge: 171-202

Bourdieu, P. (1984) Delegation and political fetishism. Reprinted in P. Bourdieu (1991) *Language and symbolic power.* Polity Press, Cambridge: 203-19

Bowl, R. (1996) Involving service users in mental health services: social services departments and the National Health Service and Community Care Act 1990. *Journal of Mental Health* **5**(3): 287-303

Bristol Royal Infirmary Inquiry (2001) *Learning from Bristol.* HMSO, London

Brown, H. (2002) Interview: Peter Cardy - Macmillan Cancer Relief. *The Lancet Oncology* **3**(3): 188-92

Brown, I. (2001) Organizational values in general practice and public involvement: case studies in an urban district. *Health & Social Care in the Community* **9**(3): 159-67

Brownlea, A. (1987) Participation: myths, realities and prognosis. *Social Science & Medicine* **25**(6): 605-14

Bungay, H. (2005) Cancer and health policy: the postcode lottery of care. *Social Policy & Administration* **39**(1): 35-48

Callaghan, G. & Wistow, G. (2006) Governance and public involvement in the British National Health Service: understanding difficulties and developments. *Social Science & Medicine* **63**(9): 2289-300

Campbell, B., Darke, M., Davis, T., Green, D., De Groot, J., Halverson, R., Hart, S., Jacques, M., Leadbeater, C., Pearce, B., Rodrigues, J., Stuart, M. & Temple, N. (1989) Realignment of politics. In S. Hall & M. Jacques (eds) *New times: the changing face of politics in the 1990s.* Lawrence & Wishart, London: 448-53

Campbell, K.B. (2005) Theorizing the authentic: identity, engagement, and public space. *Administration & Society* **36**(6): 688-705

Carr, S. (2007) Participation, power, conflict and change: theorizing dynamics of service user participation in the social care system of England and Wales. *Critical Social Policy* **27**(2): 266-76

Catt, H. & Murphy, M. (2003) What voice for the people? Categorising methods of public consultation. *Australian Journal of Political Science* **38**(3): 407-21

Chadderton, H. (1995) An analysis of the concept of participation within the context of health care planning. *Journal of Nursing Management* **3**(5): 221-8

Chandler, D. (2001) Active citizens and the therapeutic state: the role of democratic participation in local government reform. *Policy & Politics* **29**(1): 3-14

Charles, C. & DeMaio, S. (1993) Lay participation in health care decision making: a conceptual framework. *Journal of Health Politics, Policy and Law* **18**(4): 881-904

Church, J., Saunders, D., Wanke, M., Pong, R., Spooner, C. & Dorgan, M. (2002) Citizen participation in health decision-making: past experience and future prospects. *Journal of Public Health Policy* **23**(1): 12-32

Clarke, J. (2005) New Labour's citizens: activated, empowered, responsibilized, abandoned? *Critical Social Policy* **25**(4): 447-63

Clarke, J., Newman, J., Smith, N., Vidler, E. & Westmarland, L. (2007) *Creating citizen-consumers: changing publics and changing public services.* Sage, London

Collins, H.M. & Evans, R. (2002) The third wave of science studies: studies of expertise and experience. *Social Studies of Science* **32**(2): 235-96

Contandriopoulos, D. (2004) A sociological perspective on public participation in health care. *Social Science & Medicine* **58**(2): 321-30

Contandriopoulos, D., Denis, J.-L. & Langley, A. (2004) Defining the 'public' in a public healthcare system. *Human Relations* **57**(12): 1573-96

Cook, D. (2002) Consultation, for a change? Engaging users and communities in the policy process. *Social Policy & Administration* **36**(5): 516-31

Cooke, M. (2000) Five arguments for deliberative democracy. *Political Studies* **48**(5): 947-69

CPPIH (2004) *Handbook for PPI Forum members (Issue 7).* CPPIH, Birmingham

Crawford, M., Rutter, D. & Thelwall, S. (2003) *User involvement in change management: a review of the literature.* NCCSDO, London

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. *British Medical Journal* **325**: 1263-7

Croft, S. & Beresford, P. (1992) The politics of participation. *Critical Social Policy* **12**(2): 20-44

Currie, G., Finn, R. & Martin, G. (2007) Spanning boundaries in pursuit of effective knowledge sharing within healthcare networks in the NHS. *Journal of Health Organization and Management* **21**(4/5): 406-17

Currie, G., Finn, R. & Martin, G. (2008) Accounting for the 'dark side' of new organizational forms: the case of healthcare professionals. *Human Relations* **61**(4): 539-64

Currie, G., Martin, G. & Finn, R. (2009) Professional competition and modernising the clinical workforce in the NHS: possibilities and limits to the development of the specialist generalist in primary care. *Work, Employment & Society* in press

Currie, G. & Suhomlinova, O. (2006) The impact of institutional forces upon knowledge sharing in the UK NHS: the triumph of professional power and the inconsistency of policy. *Public Administration* **84**(1): 1-30

Davies, C. (2007) Grounding governance in dialogue? Discourse, practice and the potential for a new public sector organizational form in Britain. *Public Administration* **85**(1): 47-66

Davies, C., Wetherell, M. & Barnett, E. (2006) *Citizens at the centre: deliberative participation in healthcare decisions.* Policy Press, Bristol

Davies, G. & Burgess, J. (2004) Challenging the 'view from nowhere': citizen reflections on specialist expertise in a deliberative process. *Health & Place* **10**(4): 349-61

Daykin, N., Sanidas, M., Tritter, J., Rimmer, J. & Evans, S. (2004) Developing user involvement in a UK cancer network: professionals' and users' perspectives. *Critical Public Health* **14**(3): 277-94

Delanty, G. (2000) *Citizenship in a global age: society, culture, politics.* Open University Press, Buckingham

Department of Health (1992) *Local voices: the views of local people in purchasing for health.* Department of Health, London

Department of Health (1995) *A policy framework for commissioning cancer services.* Department of Health, London

Department of Health (1996) *Genetics and cancer services.* Department of Health, London

Department of Health (2003a) *Overview and scrutiny of health - guidance.* Department of Health, London

Department of Health (2003b) *Strengthening accountability: involving patients and the public: policy guidance.* Department of Health, London

Department of Health (2003c) *Strengthening accountability: involving patients and the public: practice guidance.* Department of Health, London

Department of Health (2004) *'Getting over the wall': how the NHS is improving the patient's experience.* Department of Health, London

DeSario, J. (1987) Consumers and health planning: mobilization of bias? In J. DeSario & S. Langton (eds) *Citizen participation in public decision making.* Greenwood Press, London: 133-51

Dingwall, R. (1999) 'Risk society': the cult of theory and the millennium? *Social Policy & Administration* **33**(4): 474-91

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth, A. & Jones, D. (2007) Appraising quality of research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy* **12**(1): 42-7

Donaldson, A., Lank, E. & Maher, J. (2007) Sharing experiences of user involvement in shaping new services: the story of a national patient group. *Familial Cancer* **6**(2): 249-56

Donnellon, A. (1996) *Team talk: the power of language in team dynamics.* Harvard Business School Press, Boston

Dryzek, J.S. (2000) *Deliberative democracy and beyond: liberals, critics, contestations.* Oxford University Press, Oxford

Dryzek, J.S. (2001) Legitimacy and economy in deliberative democracy. *Political Theory* **29**(5): 651-69

Eeles, R., Purland, G., Maher, J. & Evans, D.G. (2007) Delivering cancer genetics services - new ways of working. *Familial Cancer* **6**(2): 163-7

Ellison, N. (1997) Towards a new social politics: citizenship and reflexivity in late modernity. *Sociology* **31**(4): 697-717

Emery, J. (2001) Is informed choice in genetic testing a different breed of informed decision-making? A discussion paper. *Health Expectations* **4**(2): 81-6

Enticott, G. & Entwistle, T. (2007) The spaces of modernisation: outcomes, indicators and the local government modernisation agenda. *Geoforum* **38**(5): 999-1011

Epstein, S. (1995) The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology, & Human Values* **20**(4): 408-37

Epstein, S. (1996) *Impure science: AIDS, activism, and the politics of knowledge.* University of California Press, London

Evans, S., Tritter, J., Barley, V., Daykin, N., McNeill, J., Palmer, N., Rimmer, J., Sanidas, M. & Turton, P. (2003) User involvement in UK cancer services: bridging the policy gap. *European Journal of Cancer Care* **12**(4): 331-8

Exworthy, M. & Powell, M. (2004) Big windows and little windows: implementation in the 'congested state'. *Public Administration* **82**(2): 263-81

Eyles, J. & Litva, A. (1998) Place, participation and policy: people in and for health care policy. In R.A. Kearns & W.M. Gesler (eds) *Putting health into place: landscape, identity, and well-being.* Syracuse University Press, New York: 248-69

Field, F. (1995) *Making welfare work: reconstructing welfare for the millennium.* Institute of Community Studies, London

Finn, R. (2008) The language of teamwork: reproducing professional divisions in the operating theatre. *Human Relations* **61**(1): 103-30

Fitzpatrick, T. (2002) The two paradoxes of welfare democracy. *International Journal of Social Welfare* **11**(2): 159-69

Flynn, R. (2004) 'Soft bureaucracy', governmentality and clinical governance: theoretical approaches to emergent policy. In A. Gray & S. Harrison (eds) *Governing medicine: theory and practice.* Open University Press, Maidenhead: 11-26

Foucault, M. (1981) *The history of sexuality: an introduction.* Penguin, Harmondsworth

Foucault, M. (1982) The subject and power. In H.L. Dreyfus & P. Rabinow (eds) *Michel Foucault: beyond structuralism and hermeneutics.* Harvester Wheatsheaf, Hemel Hempstead: 208-26

Foucault, M. (1988) The political technology of individuals. In L.H. Martin, H. Gutman & P.H. Hutton (eds) *Technologies of the self: a seminar with Michel Foucault.* Tavistock, London: 145-62

Foucault, M. (1989) An ethics of pleasure. In S. Lontringer (ed.) *Foucault live.* Semiotext(e), New York: 257-76

Foucault, M. (1991) Governmentality. In G. Burchell, C. Gordon & P. Miller (eds) *The Foucault effect: studies in governmentality.* Harvester Wheatsheaf, Hemel Hempstead: 87-104

Fox, N. & Ward, K. (2006) Health identities: from expert patient to resisting consumer. *Health* **10**(4): 431-79

Frankish, C.J., Kwan, B., Ratner, P.A., Wharf Higgins, J. & Larsen, C. (2002) Challenges of citizen participation in regional health authorities. *Social Science & Medicine* **54**(10): 1471-80

Fraser, N. (1992) Rethinking the public sphere: a contribution to the critique of actually existing democracy. In C. Calhoun (ed.) *Habermas and the public sphere.* MIT Press, London: 109-42

Fudge, N., Wolfe, C.D.A. & McKevitt, C. (2008) Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal* **336**: 313-17

Fung, A. & Wright, E.O. (2003) Countervailing power in empowered participatory governance. In A. Fung & E.O. Wright (eds) *Deepening democracy: institutional innovations in empowered participatory governance.* Verso, London: 259-89

Gersick, C.J.G. (1988) Time and transition in work teams: toward a new model of group development. *Academy of Management Journal* **31**(1): 9-41

Giddens, A. (1990) *Consequences of modernity.* Polity Press, Cambridge

Giddens, A. (1991) *Modernity and self-identity: self and society in the late modern age.* Polity Press, Cambridge

Giddens, A. (1994a) *Beyond left and right: the future of radical politics.* Polity Press, Cambridge

Giddens, A. (1994b) Living in a post-traditional society. In U. Beck, A. Giddens & S. Lash, *Reflexive modernization: politics, tradition and aesthetics in the modern social order.* Stanford University Press, Stanford: 56-109

Giddens, A. (2000) *The Third Way and its critics.* Polity Press, Cambridge

Gilliatt, S., Fenwick, J. & Alford, D. (2000) Public services and the consumer: empowerment or control? *Social Policy & Administration* **34**(3): 333-49

Glaser, B.G. (2001) *The grounded theory perspective: conceptualization contrasted with description.* Sociology Press, Mill Valley

Glaser, B.G. (2002) Constructivist grounded theory? *Forum: Qualitative Social Research* **3**(3): http://www.qualitative-research.net/fqs-texte/3-02/3-02glaser-e.pdf

Glasner, P. & Dunkerley, D. (1999) The new genetics, public involvement, and citizens' juries: a Welsh case study. *Health, Risk & Society* **1**(3): 313-24

Gollust, S.E., Apse, K., Fuller, B.P., Miller, P.S. & Biesecker, B.B. (2005) Community involvement in developing policies for genetic testing: assessing the interests and experiences of individuals affected by genetic conditions. *American Journal of Public Health* **95**(1): 35-41

Gordon, C. (1991) Governmental rationality: an introduction. In G. Burchell, C. Gordon & P. Miller (eds) *The Foucault effect: studies in governmentality.* Harvester Wheatsheaf, Hemel Hempstead: 1-51

Gothill, M. & Armstrong, D. (1999) Dr. No-body: the construction of the doctor as an embodied subject in British general practice 1955-97. *Sociology of Health and Illness* **21**(1): 1-12

Gray, A. (2004) Governing medicine: an introduction. In A. Gray & S. Harrison (eds) *Governing medicine: theory and practice.* Open University Press, Maidenhead: 1-7

Gray, J.A.M. (2001) The public health professional as political activist. In D. Pencheon, C. Guest, D. Melzer & J.A.M. Gray (eds) *Oxford handbook of public health practice.* Oxford University Press, Oxford: 262-7

Gray, J. & Harper, P.S. (2004) Cancer genetics services. *Medicine* **32**(3): 42-4

Green, J. (2005) Professions and community. *New Zealand Sociology* **20**(1): 122-41

Greener, I. & Powell, M. (2008) The changing governance of the NHS: reform in a post-Keynesian health service. *Human Relations* **61**(5): 617-36

Gregory, A. (2003) The ethics of engagement in the UK public sector: a case in point. *Journal of Communication Management* **8**(1): 83-94

Gregory, W.J. & Romm, N.R.A. (2001) Critical facilitation: learning through intervention in group processes. *Management Learning* **32**(4): 453-67

Gustafsson, U. & Driver, S. (2005) Parents, power and public participation: Sure Start, an experiment in New Labour governance. *Social Policy & Administration* **39**(5): 528-43

Gutmann, A. & Thompson, D. (1996) *Democracy and disagreement.* Harvard University Press, London

Gutmann, A. & Thompson, D. (2000) Why deliberative democracy is different. Reprinted in A. Gutmann & D. Thompson (2004) *Why deliberative democracy?*

Princeton University Press, Woodstock: 125-38

Gutmann, A. & Thompson, D. (2002) Just deliberation about health care. Reprinted in A. Gutmann & D. Thompson (2004) *Why deliberative democracy?* Princeton University Press, Woodstock: 139-59

Gutmann, A. & Thompson, D. (2004) *Why deliberative democracy?* Princeton University Press, Woodstock

Habermas, J. (1984) *The theory of communicative action: reason and the rationalization of society.* Polity Press, Cambridge

Habermas, J. (1987) *The theory of communicative action: the critique of functionalist reason.* Polity Press, Cambridge

Habermas, J. (1988) Popular sovereignty as procedure. Reprinted in J. Habermas (1996) *Between facts and norms: contributions to a discourse theory of law and democracy.* MIT Press, Cambridge MA: 463-90

Habermas, J. (1992) Further reflections on the public sphere. In C. Calhoun (ed.) *Habermas and the public sphere.* MIT Press, London: 421-61

Habermas, J. (1996) *Between facts and norms: contributions to a discourse theory of law and democracy.* MIT Press, Cambridge MA

Hallowell, N. & Lawton, J. (2002) Negotiating present and future selves: managing the risk of hereditary ovarian cancer by prophylactic surgery. *Health* **6**(4): 423-43

Hammersley, M. & Atkinson, P. (1995) *Ethnography: principles in practice.* Routledge, London

Harding, S.G. (1991) *Whose science? Whose knowledge? Thinking from women's lives.* Cornell University Press, New York

Harrison, S. (2002) New Labour, modernisation and the medical labour process. *Journal of Social Policy* **31**(3): 465-85

Harrison, S. & McDonald, R. (2008) *The politics of healthcare in Britain.* Sage, London

Harrison, S. & Mort, M. (1998) Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Social Policy & Administration* **32**(1): 60-70

Hasselbladh, H. & Bejerot, E. (2007) Webs of knowledge and circuits of communication: constructing rationalized agency in Swedish health care. *Organization* **14**(2): 175-200

Henwood, F., Wyatt, S., Hart, A. & Smith, J. (2003) 'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health and Illness* **25**(6): 589-607

Hess, D. (2003) Technology, medicine, and modernity: the problem of alternatives. In T.J. Misa, P. Brey & A. Feenberg (eds) *Modernity and technology.* MIT Press, London: 279-302

Higgs, P. (1998) Risk, governmentality and the reconceptualization of citizenship. In G. Scambler & P. Higgs (eds) *Modernity, medicine and health: medical sociology towards 2000.* Routledge, London: 176-97

Hodge, S. (2005) Participation, discourse and power: a case study in service user involvement. *Critical Social Policy* **25**(2): 164-79

Hogg, C. (1996) *Back from the margins: which future for CHCs?* Institute of Health Services Management, London

Hogg, C. (1999) *Patients, power & politics: from patients to citizens.* Sage, London

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

Irwin, A. (2004) Expertise and experience in the governance of science: what is public participation for? In G. Edmond (ed.) *Expertise in regulation and law.* Ashgate, Aldershot: 32-50

Jessop, B. (2007) From micro-powers to governmentality: Foucault's work on statehood, state formation, statecraft and state power. *Political Geography* **26**(1): 34-40

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. *Social Science & Medicine* **59**(1): 93-102

Kelly, T. (2004) Unlocking the iron cage: public administration in the deliberative democratic theory of Jürgen Habermas. *Administration & Society* **36**(1): 38-61

Kerr, A., Cunningham-Burley, S. & Amos, A. (1998) The new genetics and health: mobilizing lay expertise. *Public Understanding of Science* **7**(1): 41-60

Kerr, A., Cunningham-Burley, S. & Tutton, R. (2007) Shifting subject positions: experts and lay people in public dialogue. *Social Studies of Science* **37**(3): 385-411

Kuhlmann, E. & Allsop, J. (2008) Professional self-regulation in a changing architecture of governance: comparing health policy in the UK and Germany. *Policy & Politics* **36**(2): 173-89

Labour Party (1995) *Renewing democracy, rebuilding communities.* Labour Party, London

Lachman, R. (2000) Stepping into the kitchen: lay clients as co-producers of a professional service. *International Journal of Human Resource Management* **11**(3): 617-34

Lambert, H. & Rose, H. (1996) Disembodied knowledge? Making sense of medical science. In A. Irwin & B. Wynne (eds) *Misunderstanding science? The public reconstruction of science and technology.* Cambridge University Press, Cambridge: 65-83

Lash, S. (1994) Expert systems or situated interpretation? Culture and institutions in disorganized capitalism. In U. Beck, A. Giddens & S. Lash, *Reflexive modernization: politics, tradition and aesthetics in the modern social order.* Stanford University Press, Stanford: 198-215

Le Grand, J. (1997) Knights, knaves and pawns: human behaviour and social policy. *Journal of Social Policy* **26**(2): 149-69

Le May, A. (2003) A new year, a new commission: the Commission for Patient and Public Involvement in Health. *Journal of the Royal Society for the Promotion of Health* **123**(1): 10

Leach, S. & Wingfield, M. (1999) Public participation and the democratic renewal agenda: prioritisation or marginalisation? *Local Government Studies* **25**(4): 46-59

Leadbeater, C. & Mulgan, G. (1994) Lean democracy and the leadership vacuum. *Demos Quarterly* **3**(45): 82

Lemke, T. (2001) 'The birth of bio-politics': Michel Foucault's lecture at the Collège de France on neo-liberal governmentality. *Economy and Society* **30**(2): 190-207

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

Lomas, J. (1997) Reluctant rationers: public input into health care priorities. *Journal of Health Services Research & Policy* **2**(2): 103-11

Lowndes, V., Pratchett, L. & Stoker, G. (2001a) Trends in public participation: part 1 - local government perspectives. *Public Administration* **79**(1): 205-22

Lowndes, V., Pratchett, L. & Stoker, G. (2001b) Trends in public participation: part 2 - citizens' perspectives. *Public Administration* **79**(2): 445-55

Lowndes, V. & Sullivan, H. (2004) Like a horse and carriage or a fish on a bicycle: how well do local partnerships and public participation go together? *Local Government Studies* **30**(1): 51-73

Lund, B. (1999) 'Ask not what your community can do for you': obligations, New

Labour and welfare reform. *Critical Social Policy* **19**(4): 447-62

Macdonald, G. (2003) Judge or jury: involving people in decision-making. *Health Promotion International* **13**(4): 273-5

Macmillan (2001) *The 'Kenilworth' group report.* Macmillan, London

Macmillan (2005) *Working brief 5: working partnership with cancer patients and carers to improve cancer services.* Macmillan, London

Marinetto, M. (2003) Who wants to be an active citizen? The politics and practice of community involvement. *Sociology* **37**(1): 103-20

Martin, D., Abelson, J. & Singer, P. (2002) Participation in health care priority-setting through the eyes of the participants. *Journal of Health Services Research & Policy* **7**(4): 222-9

Martin, G.P. (2008a) 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness* **30**(1): 35-54

Martin, G.P. (2008b) Representativeness, legitimacy and power in public involvement in health-care management. *Social Science & Medicine* **67**(11): 1757-65

Martin, G.P. (2008c) Residents, interviewees, class representatives? Reflections on the use of qualitative interviews in knowing the worlds of gentrification. In P.J. Maginn, M. Tonts & S. Thompson (eds) *Qualitative housing analysis: an international perspective.* Elsevier, Oxford: 115-39

Martin, G.P. (2009a) Public and user participation in public-service delivery: tensions in policy and practice. *Sociology Compass* in press

Martin, G.P. (2009b) Public participation in state governance from a social-theoretical perspective. In G. Currie, J. Ford, N. Harding & M. Learmonth (eds) *Public services management: a critical approach.* Routledge, London

Martin, G.P. (2009c) Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements. *Critical Public Health* in press

Martin, G.P., Currie, G. & Finn, R. (2009a) Leadership, service reform, and public-service networks: the case of cancer-genetics pilots in the English NHS. *Journal of Public Administration Research & Theory* in press

Martin, G.P., Currie, G. & Finn, R. (2009b) Reconfiguring or reproducing intra-professional boundaries? Specialist expertise, generalist knowledge and the 'modernization' of the medical workforce. *Social Science & Medicine* in press

Martin, G.P., Finn, R. & Currie, G. (2007) National evaluation of NHS genetics service investments: emerging issues from the cancer genetics pilots. *Familial Cancer* **6**(2): 257-63

Martin, G.P., Phelps, K. & Katbamna, S. (2004) Human motivation and professional practice: of knights, knaves and social workers. *Social Policy & Administration* **38**(5): 470-87

Martin, S. & Boaz, A. (2000) Public participation and citizen-centred local government: lessons from the Best Value and Better Government for Older People pilot programmes. *Public Money & Management* **20**(2): 47-53

Milewa, T. (1997) Community participation and health care priorities: reflections on policy, theatre and reality in Britain. *Health Promotion International* **12**(2): 161-8

Milewa, T. (2004) Local participatory democracy in Britain's health service: innovation or fragmentation of a universal citizenship? *Social Policy & Administration* **38**(3): 240-52

Milewa, T., Dowswell, G. & Harrison, S. (2002) Partnerships, power and the 'new' politics of community participation in British health care. *Social Policy & Administration* **36**(7): 796-809

Milewa, T., Valentine, J. & Calnan, M. (1998) Managerialism and active citizenship in Britain's reformed health service: power and community in an era of decentralization. *Social Science & Medicine* **47**(4): 507-17

Milewa, T., Valentine, J. & Calnan, M. (1999) Community participation and citizenship in British health care planning: narratives of power and involvement in the changing welfare state. *Sociology of Health and Illness* **21**(4): 445-65

Montpetit, É. (2003) Public consultations in policy network environments: the case of assisted reproductive technology in Canada. *Canadian Public Policy - Analyse de Politiques* **29**(1): 95-110

Mort, M., Harrison, S. & Wistow, G. (1996) The user card: picking through the organisational undergrowth in health and social care. *Contemporary Political Studies* **2**: 1133-40

Mullen, P.M. (1999) Public involvement in health care priority setting: an overview of methods for eliciting values. *Health Expectations* **2**(4): 222-34

Munro, A.J. (2001) The Calman-Hine report: its causes and consequences. *European Journal of Cancer Care* **10**(3): 213-20

Murphy, E. & Dingwall, R. (2003) *Qualitative methods and health policy research.* De Gruyter, New York

Mythen, G. (2007) Reappraising the risk society thesis: telescopic sight or myopic vision? *Current Sociology* **55**(6): 793-813

National User Reference Group (2007) Open letter. *Familial Cancer* **6**(2): 169

Nettleton, S. (1997) Governing the risky self: how to become health, wealthy and wise. In A. Petersen & R. Bunton (eds) *Foucault, health and medicine.* Routledge, London: 207-22

Nettleton, S. & Burrows, R. (2003) E-scaped medicine? Information, reflexivity and health. *Critical Social Policy* **23**(2): 165-85

Newman, J. (2001) *Modernising governance: New Labour, policy and society.* Sage, London

Newman, J. (2005a) Conclusion. In J. Newman (ed.) *Remaking governance: peoples, politics and the public sphere.* Policy Press, Bristol: 197-213

Newman, J. (2005b) Introduction. In J. Newman (ed.) *Remaking governance: peoples, politics and the public sphere.* Policy Press, Bristol: 1-15

Newman, J., Barnes, M., Sullivan, H. & Knops, A. (2004) Public participation and collaborative governance. *Journal of Social Policy* **33**(2): 203-23

Newman, J. & Vidler, E. (2006) Discriminating customers, responsible patients, empowered users: consumerism and the modernisation of health care. *Journal of Social Policy* **35**(2): 193-209

Novas, C. (2006) The political economy of hope: patients' organizations, science and biovalue. *BioSocieties* **1**(3): 289-305

Novas, C. & Rose, N. (2000) Genetic risk and the birth of the somatic individual. *Economy and Society* **29**(4): 485-513

Office of Public Services Reform (2002) *Reforming our public services: principles into practice.* Cabinet Office, London

Orr, K. & McAteer, M. (2004) The modernisation of local decision making: public participation and Scottish local government. *Local Government Studies* **30**(2): 131-55

Papadopoulos, Y. (2001) Citizenship through direct democracy? The 'broken promises' of empowerment. In C. Crouch, K. Eder & D. Tambini (eds) *Citizenship, markets, and the state.* Oxford University Press, Oxford: 173-96

Parkinson, J. (2003) Legitimacy problems in deliberative democracy. *Political Studies* **51**(1): 180-96

Parsons, E. & Atkinson, P. (1992) Lay constructions of genetic risk. *Sociology of Health and Illness* **14**(4): 438-55

Payne, M. (2000) *Teamwork in multiprofessional care.* Palgrave, Basingstoke

Pellizzoni, L. (1999) Reflexive modernization and beyond: knowledge and value in the politics of environment and technology. *Theory, Culture & Society* **16**(4): 99-125

Pellizzoni, L. (2001) The myth of the best argument: power, deliberation and reason. *British Journal of Sociology* **52**(1): 59-86

Petersen, A. (1996) The 'healthy' city, expertise, and the regulation of space. *Health & Place* **2**(3): 157-65

Petersen, A. (1997) Risk, governance and the new public health. In A. Petersen & R. Bunton (eds) *Foucault, Health and Medicine.* Routledge, London: 189-206

Petersen, A. & Lupton, D. (1996) *The new public health: health and self in the age of risk.* Sage, London

Porter, S. (1997) The patient and power: sociological perspectives on the consequences of holistic care. *Health & Social Care in the Community* **5**(1): 17-20

Pratchett, L. (1999) New fashions in public participation: towards greater democracy? *Parliamentary Affairs* **52**(4): 616-33

Press, N., Reynolds, S., Pinsky, L., Murthy, V., Leo, M. & Burke, W. (2005) 'That's like chopping off a finger because you're afraid it might get broken': disease and illness in women's views of prophylactic mastectomy. *Social Science & Medicine* **61**(5): 1106-17

Prime Minister & Minister for the Cabinet Office (1999) *Modernising government.* The Stationery Office, London

Prior, D., Stewart, J. & Walsh, K. (1995) *Citizenship: rights, community & participation.* Pitman Publishing, London

Prior, L. (2003) Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health and Illness* **25**(Silver Anniversary Issue): 41-57

Rabinow, P. & Rose, N. (2003) Foucault today. In P. Rabinow & N. Rose (eds) *The essential Foucault: selections from the essential works of Foucault, 1954-1984.* New Press, New York: vii-xxxv

Rabinow, P. & Rose, N. (2006) Biopower today. *BioSocieties* **1**(2): 195-217

Reddel, T. & Woolcock, G. (2004) From consultation to participatory governance? A critical review of citizen engagement strategies in Queensland. *Australian Journal of Public Administration* **63**(3): 75-87

Rhodes, M. (2000) Desperately seeking a solution: social democracy, Thatcherism and the 'Third Way' in British welfare. *West European Politics* **23**(2): 161-86

Rhodes, P. & Nocon, A. (1998) User involvement and the NHS reforms. *Health Expectations* **1**(2): 73-81

Richardson, A., Sitzia, J. & Cotterell, P. (2005) 'Working the system': achieving change through partnership working: an evaluation of cancer partnership groups. *Health Expectations* **8**(3): 210-20

Rose, N. (1993) Government, authority and expertise in advanced liberalism. *Economy and Society* **22**(3): 283-99

Rose, N. (1996) Governing 'advanced' liberal democracies. In A. Barry, T. Osborne & N. Rose (eds) *Foucault and political reason: liberalism, neo-liberalism and rationalities of government.* UCL Press, London: 37-64

Rose, N. (1999) *Powers of freedom: reframing political thought.* Cambridge University Press, Cambridge

Rose, N. & Miller, P. (1992) Political power beyond the State: problematics of government. *British Journal of Sociology* **43**(2): 173-205

Rose, N. & Novas, C. (2005) Biological citizenship. In A. Ong & S.J. Collier (eds) *Global assemblages: technology, politics, and ethics as anthropological problems.* Blackwell, Oxford: 439-63

Rose, N., O'Malley, P. & Valverde, M. (2006) Governmentality. *Annual Review of Law and Social Science* **2**: 83-104

Rowe, R. & Shepherd, M. (2002) Public participation in the new NHS: no closer to citizen control? *Social Policy & Administration* **36**(3): 275-90

Rummery, K. (2006) Partnerships and collaborative governance in welfare: the citizenship challenge. *Social Policy & Society* **5**(2): 293-303

Rutter, D., Manley, C., Weaver, T., Crawford, M.J. & Fulop, N. (2004) Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine* **58**(10): 1973-84

Ryfe, D.M. (2002) The practice of deliberative democracy: a study of 16 deliberative organizations. *Political Communication* **19**(3): 359-77

Salter, B. (2004) *The new politics of medicine.* Palgrave Macmillan, Basingstoke

Sanders, T., Harrison, S. & Checkland, K. (2008) Evidence-based medicine and patient choice: the case of heart failure care. *Journal of Health Services Research & Policy* **13**(2): 103-8

Saward, M. (2003) Enacting democracy. *Political Studies* **51**(1): 161-79

Saward, M. (2005) Governance and the transformation of political representation. In J. Newman (ed.) *Remaking governance: peoples, politics and the public sphere.* Policy Press, Bristol: 179-96

Schofield, B. (2002) Partners in power: governing the self-sustaining community. *Sociology* **36**(3): 663-83

Scott, F.E. (2000) Participative democracy and the transformation of the citizen: some intersections of feminist, postmodernist and critical thought. *American Review of Public Administration* **30**(3): 252-70

Scott, S., Prior, L., Wood, F. & Gray, J. (2005) Repositioning the patient: the implications of being 'at risk'. *Social Science & Medicine* **60**(8): 1869-79

Secretary of State for Health (2000a) *The NHS cancer plan: a plan for investment, a plan for reform.* Department of Health, London

Secretary of State for Health (2000b) *The NHS plan: a plan for investment, a plan for reform.* HMSO, London

Secretary of State for Health (2003) *Our inheritance, our future: realising the potential of genetics in the NHS.* The Stationery Office, London

Secretary of State for Health (2006) *Our health, our care, our say: a new direction for community services.* The Stationery Office, London

Silverman, D. (2001) *Interpreting qualitative data: methods for analysing talk, text and interaction.* Sage, London

Simmons, R. & Birchall, J. (2005) A joined-up approach to user participation in public services: strengthening the 'participation chain'. *Social Policy & Administration* **39**(3): 260-83

Skelcher, C. (1998) *The appointed state: quasi-governmental organizations and democracy.* Open University Press, Buckingham

Spencer, L., Ritchie, J., Lewis, J. & Dillon, L. (2003) *Quality in qualitative research: a framework for assessing research evidence.* Strategy Unit of the Cabinet Office, London

Stenson, K. (1998) Beyond histories of the present. *Economy and Society* **27**(4): 333-52

Sterling, R. (2005) Promoting democratic governance through partnerships? In J. Newman (ed.) *Remaking governance: peoples, politics and the public sphere.* Policy Press, Bristol: 139-57

Stokkom, B. van (2005) Deliberative group dynamics: power, status and affect in interactive policy making. *Policy & Politics* **33**(3): 387-409

Strauss, A., Schatzman, L., Ehrlich, D., Bucher, R. & Sabshin, M. (1963) The hospital and its negotiated order. Reprinted in R. Dingwall (ed.) (2008) *Qualitative health* *research, vol. 3: healthcare organizations*. Sage, London: 13-27

Taylor, M. (2006) Communities in partnership: developing a strategic voice. *Social Policy & Society* **5**(2): 269-79

Taylor, M. (2007) Community participation in the real world: opportunities and pitfalls in new governance spaces. *Urban Studies* **44**(2): 297-317

Thompson, S. & Hoggett, P. (2001) The emotional dynamics of deliberative democracy. *Policy & Politics* **29**(3): 351-64

Thurston, W.E., MacKean, G., Vollman, A., Casebeer, A., Weber, M., Maloff, B. & Bader, J. (2005) Public participation in regional health policy: a theoretical framework. *Health Policy* **73**(3): 237-52

Toth, B. (1996) Public participation: an historical perspective. In J. Coast, J. Donovan & S. Frankel (eds) *Priority setting: the health care debate.* Wiley, Chichester: 169-202

Tovey, P., Atkin, K. & Milewa, T. (2001) The individual and primary care: service user, reflexive choice maker and collective actor. *Critical Public Health* **11**(2): 153-66

Tritter, J.Q., Barley, V., Daykin, N., Evans, S., McNeill, J., Rimmer, J., Sanidas, M. & Turton, P. (2003) Divided care and the Third Way: user involvement in statutory and voluntary sector cancer services. *Sociology of Health and Illness* **25**(5): 429-56

Truman, C. & Raine, P. (2002) Experience and meaning of user involvement: some explorations from a community mental health project. *Health & Social Care in the Community* **10**(3): 136-43

Turner, B.S. (1997) From governmentality to risk: some reflections on Foucault's contribution to medical sociology. In A. Petersen & R. Bunton (eds) *Foucault, health and medicine.* Routledge, London: ix-xxi

Vigoda, E. (2002) From responsiveness to collaboration: governance, citizens, and the next generation of public administration. *Public Administration Review* **62**(5): 527-40

Williams, M. (2004) Discursive democracy and New Labour: five ways in which decision-makers manage citizen agendas in public participation initiatives. *Sociological Research Online* **9**(3)

Williams-Jones, B. & Burgess, M.M. (2004) Social contract theory and just decision making: lessons from genetic testing for the BRCA mutations. *Kennedy Institute of Ethics Journal* **14**(2): 115-42

Wilson, J. (2005) To know or not to know? Genetic ignorance, autonomy and paternalism. *Bioethics* **19**(5-6): 492-504

Wistow, G. & Barnes, M. (1993) User involvement in community care: origins, purposes and applications. *Public Administration* **71**(3): 279-99

Wonderling, D., Hopwood, P., Cull, A., Douglas, F., Watson, M., Burn, J. & McPherson, K. (2001) A descriptive study of UK cancer genetics services: an emerging clinical response to the new genetics. *British Journal of Cancer* **85**(2): 166-70

Wynne, B. (1992) Misunderstood misunderstanding: social identities and public uptake of science. *Public Understanding of Science* **1**(3): 281-304

Wynne, B. (2003) Seasick on the third wave? Subverting the hegemony of propositionalism: response to Collins & Evans (2002). *Social Studies of Science* **33**(3): 401-17

Young, I.M. (2000) *Inclusion and democracy.* Oxford University Press, Oxford

Young, R. (2006) Introducing role and service changes in health and social care: the impact and influence of user involvement in England and Wales. *Social Policy & Society* **5**(2): 249-68

Ziebland, S. (2004) The importance of being expert: the quest for cancer information on the Internet. *Social Science & Medicine* **59**(9): 1783-93