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young adults and citizen participation in health policy.

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### Seeking outsider perspectives in interpretive research: young adults and citizen participation in health policy

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## Seeking outsider perspectives in interpretive research: young adults and citizen participation in health policy

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Policy researchers face a range of pressures to incorporate the perspectives of ‘hard-to-reach’ groups in their research. In the specific case of public involvement policy in health (one example of the growing field of citizen participation initiatives in administrative contexts), researchers have struggled to accomplish this without compelling research participants to enter into a policy discourse that is unfamiliar and may be at odds with their self-understood roles as patients and citizens. This paper presents findings from an interpretive project which sought to understand the perspectives of young adults on local practices of public involvement in a socio-economically deprived area of Scotland. It recounts the researcher’s shifting standpoint in response to silences and absences within young adults’ reaction to the project, and argues that the everyday ‘tactics’ young adults described using in their interactions with health services be reimaged as relevant, albeit challenging forms of citizen participation.

**Keywords:** citizen participation; health policy; Scotland; interpretive policy analysis; hard-to-reach populations

### Introduction

Ensuring that research takes account of diverse populations, and particularly the perspectives of specific ‘hard-to-reach’ or ‘hidden’ groups, is an increasingly important task for researchers internationally (Boote, Wong, and Booth 2012). In health research there is a strong tradition of studying public perspectives (Popay and Williams 1996, Entwistle et al. 1998, Popay et al. 1998). This is further strengthened by external pressure (from research funders and government) to incorporate consideration of public acceptability or support into research on health policy: in England, the Department of Health’s 2005 *Research Governance Framework* specifically states that ‘Research, and those pursuing it, should respect the diversity of human society and conditions and the multicultural nature of society...The body of research evidence available to policy makers should reflect the diversity of the population.’(Department of Health 2005, 8). Although there is some literature concerning the difficulties (and ethics) of engaging ‘hard-to-reach’ groups in research, difficulties in recruitment are often considered as logistical issues for the methods section (Miller and Salkind 2002, Gilbert 2008). This article describes a more holistic approach to the challenges of accessing ‘outsider’ perspectives within research on public perspectives on complex policy. I draw on the example of an interpretive research project seeking the perspectives of young adults on ‘public involvement’ with local health care organizations in Scotland. This highlights the challenges of pursuing outsider views, the

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ways in which such views can challenge the standpoint of both research and researchers, and the potential benefits where outsider views are included in interpretive research.

In common with the international prominence of new modes of citizen participation in administrative contexts (Warren 2009), participation in the planning and organization of health services (often described as ‘public involvement’ in the UK health policy context) has been a declared international priority for decades (World Health Organisation 1978, Tenbenschel 2010). However, the take-up of opportunities is a recurring issue and concerns are often raised that the participants who put themselves forward are not descriptively representative of the wider citizenry, meaning that opportunities are dominated by individuals derogatively known as ‘the usual suspects’ (House of Commons – Health Committee 1997, Martin 2008a). In Scotland, as in other parts of the UK, the engagement of a broad demographic range of the population in health decision-making has been a challenge (FMR Research 2008). Concerns have been raised about consistently under-represented groups including working class people and those from minority ethnic populations. Young adults are also under-represented in most mainstream forums for participation in health, yet the limited engagement of this group has been subject to far less research. Cutler and Frost (2001) state that young people’s participation in the National Health Service (NHS) is commonly limited to issues of health promotion, with less involvement in the shaping of health services. Lightfoot and Sloper (2003) likewise note that initiatives which involve young people often emerge separately from organizational strategies for public involvement.

Accordingly, the study in question sought to incorporate the perspectives of young adults as an interesting and (in this area of policy) under-researched population within a broader project investigating the implementation of policies for public involvement in one locale in Scotland. Previous research has highlighted a tendency for literature on public involvement to idealize the public, and understand ‘it’ as a singular entity (Martin 2008b, Clarke 2013). Selecting a group likely to be in relatively good health (Furlong and Cartmel 2007), and often censured for its health-relevant lifestyle choices might, I suspected, disaggregate this easy evocation of ‘the public’ and shed fresh light on the persistent search within public involvement for what Martin (2008b) describes as ‘ordinary’ community members.

Within my case study site, young people (as a demographic group) were identified by staff and other public participants as ‘hard-to-reach’. This reflected the perception that, despite significant organizational efforts, this group were particularly difficult to engage. The terminology of ‘hard-to-reach’ populations has been widely critiqued (Milbourne 2002, Brackertz et al. 2005), and these debates hold relevance for the role my research with young adults played within the wider study (as well as within local debates about public involvement in my case study site). Researchers (and policy actors such as Equality and Human Rights Commission 2012) have argued that the term hard-to-reach ‘is poorly defined and insufficiently problematized’ (Mackenzie et al. 2012, 517) and ‘defines the groups in question as problematic, rather than the approach used to involve them’ (Brackertz et al. 2005, 163). In a sense this call to turn the focus around mirrors the change in focus described in this article: as a researcher, I moved from frustration at the difficulties of recruiting and engaging interviewees, to a more reflexive questioning of the orientation of the goals and methods of the research project. I use the term ‘outsider perspectives’ to highlight that my interviewees spoke with little or no existing knowledge of the specific policy in question.

This article uses the example of public involvement policy in health to argue for the particular benefits of an interpretive approach to policy implementation which is rooted in

what ‘outsider’ interviewees know, rather than an approach which insists that interviewees enter into a policy discourse which may be unfamiliar and uncomfortable for them. It begins by reflecting on the methods by which researchers have incorporated ‘outsider’ public perspectives on public involvement policies. It then introduces the background and methods of an interpretive approach to outsider perspectives on public involvement, and presents findings from the project. Finally, it identifies key lessons from these findings for policy, before concluding by considering the advantages and pitfalls of this approach to researching public perspectives on policy.

### **An interpretive approach for researching outsider views on public involvement policy**

Since the public involvement agenda rose to prominence in the UK in the late 1990s, a remarkable evolution has taken place in the importance accorded to outsider views in the research literature, and in the approach taken to researching them. What we might term the first wave of post-1997 literature on public involvement policies examined the fora, committees and meetings at which public involvement was ‘done’ in health-care organizations (Anderson and Florin 2000, Alborz, Wilkin, and Smith 2002, Harrison, Dowswell, and Milewa 2002, Milewa et al. 2002, Callaghan and Wistow 2006). As part of this, research with existing participants was often used as a proxy for knowledge about ‘public’ perspectives. Not surprisingly, the resulting conclusion was that the public were motivated to get involved in decision-making and frequently frustrated by the lack of power available through public involvement opportunities. A ‘second generation’ of public involvement research grew out of the occasionally ill-defined but nonetheless prevalent critique that public involvement engaged (and thus empowered) only the ‘usual suspects’ (House of Commons – Health Committee 1997, Martin 2008b). Reflecting on this, researchers (including myself) found themselves in search of the perspectives of the ‘uninvolved’ public: a chimerical task was born.

This challenge has prompted a cluster of studies seeking non-participants’ views on involvement through surveys, focus groups and interviews with sampled members of the public (Litva et al. 2002, 2009, Abelson et al. 2003, Wiseman et al. 2003). The difficulty with these approaches lies in making the opaque terminology of ‘public involvement’ meaningful to research participants with little or no prior awareness of it. Recruiting ‘uninvolved’ people to respond to questions about public involvement is challenging enough (a problem faced by all three approaches outlined here), but eliciting meaningful ‘outsider’ perspectives on a topic that is itself vague, intangible and unfamiliar renders the task near insurmountable. Solutions to this tended to avoid imposing a definition on the term ‘public involvement’, leaving interviewees, focus group participants or survey respondents to define it for themselves: ‘The term “involvement” was deliberately chosen because it is broad enough to encompass all rungs of Arnstein’s ladder and would allow informants to discuss its meaning in relation to each particular decision making context’ (Litva et al. 2002, p. 1827). ‘The concepts of “clinical governance” and “public involvement” were not easily accessible to most lay informants. Thus focus groups were used to allow lay informants to discuss their perceptions about public involvement in three key aspects of clinical governance.’ (Litva et al. 2009, 84) However, this solution – encouraging research participants to talk around an amorphous topic which is potentially entirely new to them – risks generating superficial responses to which researchers then attach great weight. For Eliasoph, this is a major drawback of *all* formalized interviewing in social research, as ‘respondents ... speak in uncharacteristically serious ways about issues that they usually treat flippantly, or ironically, or do not discuss at all’ (Eliasoph 1998, 19).

The research discussed in this article draws on interpretive approaches to policy analysis (Yanow 2000, Wagenaar 2011) and institutional ethnography (Smith 1997, 1999, 2005). Where alternative approaches seek to elicit (and at times generate) perspectives on policy, institutional ethnographers start an enquiry from within the material or social worlds of their research participants. In interviews, this entails finding a starting point in the interviewee's known world and experiences: 'The reach of inquiry goes from where actual people are in their own lives, activities, and experiences to open up relations and organization that are, in a sense, actually *present* in them but are not observable' (Smith 2006, 3). When opening up research to alternative starting points (in this case, everyday experiences of health and health services, rather than 'public involvement' *per se*), the balancing act becomes what McCoy (2006) has termed 'keeping the institution in view' (engaging fully with interviewees' accounts while learning something of the broader structures shaping their experiences; in this case the policy under investigation). The remainder of this article discusses the application of this approach to investigating young people's perspectives on public involvement in the NHS in Scotland.

### **The case study: young adult perspectives on public involvement in the Scottish NHS**

Data discussed in this paper is drawn from an interpretive case study of practices of public involvement in one Community Health Partnership (CHP) in Scotland. NHS policy in Scotland has emphasized 'voice' over 'choice', and the Scottish NHS has, since devolution in 1999, become a less marketized system (Greer 2004, BMA Health Policy and Economics Research Unit 2010). Accordingly, patient choice of provider is rarely a feature of the secondary care system and, while patients can move between primary care practices where alternatives are available (as is the case across the UK), this is not encouraged by policy. Instead, policy has emphasized 'mutualism' and community ownership of services (Stewart 2013a). Opportunities for voice vary between territorial areas, but Public Partnership Forums, groups of self-selected citizens who meet to discuss and advise on services at the local level (Anton et al. 2007), are a statutory requirement. Public involvement in the NHS has been a recurring political priority, but the intrinsic appeal of the agenda is rarely matched by clear, galvanizing policy proposals: in the UK context Klein (2010, 234) describes policymaking in this area as 'a stutteringly inconsistent process'. Previous research has found it difficult to recruit participants to studies seeking 'uninvolved' views on options for public involvement (Litva et al. 2002, Thompson 2003).

Community Health Partnerships are responsible for planning and delivery of primary care services at the local level in Scotland. They were created in 2004 and tasked with a range of functions including integration of services, partnership with local authorities and involving patients and the public (Scottish Executive 2003). Later guidance required the creation of a 'Public Partnership Forum' in every CHP, to act as 'the main mechanism by which the CHP engages, communicates and maintains a meaningful dialogue with the people of the communities it serves' (Scottish Executive 2004, 4). Findings reported in this article are drawn from a wider research project which included interviewing staff and observing a range of involvement activities, as well as observing meetings of the Public Partnership Forum for a year (Stewart 2012). To protect the anonymity of research participants I call the CHP by a pseudonym, 'Rivermouth', and the names of all participants, and the doctors they mention, have been changed. Ethical approval was gained through the researcher's university, and an application was made to the appropriate NHS Medical Research Ethics Committee, who confirmed that the project did not require medical research ethics approval.

Within this project, my interviews with young adults sat apart from the observational approach, and snowballing of ‘key informant’ interviewees which characterized the rest of the research. In terms of participant recruitment, interpretive analyses of policy (although a broad church) generally direct attention towards ‘what a policy means to the people who are affected by it, how they experience the concerted efforts of a state agency to improve their lives’ (Wagenaar 2011, 3). Yanow (2000, 38–39) emphasizes observation and the informal identification of ‘policy-relevant’ interviewees, alongside documentary analysis and participation in the life of the community being studied. My interviews with young adults sought to answer the research question: what are the reasons for limited or non-use of public involvement mechanisms by young adults? This required the study of the absence of interaction with a policy, and accordingly interviewees could not be informally identified and recruited within the spaces of involvement which I observed. I, therefore, adopted a formal recruitment process more conventional in projects with a more positivist orientation.

Purposive sampling was used to select two primary care practices in Rivermouth. All primary care practices in the CHP were approached, and five practices responded. I selected two which varied most in terms of practice location (urban or rural) and population deprivation by using profiles available at [www.isdscotland.org](http://www.isdscotland.org). This was intended to maximize the potential diversity within my sample. A sample of around 200 18–25-year-old patients was created by staff at each practice. This list was checked by all partners to remove patients who should not be approached for reasons of capacity to give informed consent or take part in an interview. Practice A removed 15 patients and practice B less than 5. A recruitment pack was then sent to those remaining on the list. Interviewees were paid for their time (with a £10 supermarket voucher). Interviews took place in Winter 2009/2010 in the interviewees’ homes and in one case in their workplace. Table 1 sets out some characteristics of my interviewees.

This table demonstrates some of the challenges with this sample (including its small size, and gender composition), but obscures much of the work which went into achieving it. I had hoped for a higher number of interviewees: my research design named 25 as a goal. In total, 22 responses were received, and after attrition, semi-structured interviews were conducted with 14 individuals. The self-selecting mode of recruitment means that interviewees might be expected to have unusually strong views – whether negative or positive – on health services. (In practice, only three interviewees described having any specific grievances against health services. The supermarket voucher for participation may have contributed to less ‘partial’ responses, but also to the disproportionately high number of interviewees who were unemployed or on a Government training scheme for the long-term unemployed.)

Table 1. Interviewee characteristics.

	Number
Men	3
Women	11
In work	7
In full-time education	1
Unemployed	3
On a Government training scheme	3
<b>Total interviews</b>	<b>14</b>



While the total number of interviewees in this research is low, the recruitment was designed to, and succeeded in, reaching young people who cannot be easily recruited through the conventional routes of educational establishments or youth groups. Given the acknowledged difficulties of recruiting young adults for research studies, researchers commonly rely on trusted gatekeepers and on the relatively small numbers of young adults who populate youth groups (see, for example, Curtis et al. 2004, Marsh, O'Toole, and Jones 2007). The interviewees in this study are experientially far closer to the 'ordinary' service user whom I sought to encounter. Research textbooks offer a range of suggestions to increase response rate (often designed for survey research, see, for example, Miller and Salkind 2002, Gilbert 2008), and strategies such as Heckathorne's (1997) respondent-driven sampling offer a more qualitative approach to maximizing the size of (and reducing the bias within) a sample. While this literature had informed my decisions to offer a financial incentive for participation, and the careful wording of the recruitment pack, other options, such as snowballing from interviewees, including focus groups, or advertising the opportunity more widely, were rejected. In this project, low response rates were not merely a practical or methodological challenge to be overcome by technical fixes, but a significant finding with wider implications for the orientation of the research.

The small sample size and problems of attrition discussed above were experienced as major, unsettling stumbling blocks in the research process. The impersonal language of attrition does not capture the frustration of being 'stood up' on a stranger's doorstep on a cold winter's evening. However, I found a standpoint perspective (Smith 2005) encouraged me to engage with potential interviewees' rejection of the interview as something more meaningful than a personal disappointment. In an analysis of the difficulties of meaningfully researching the 'service user experience' of people living with HIV/Aids, Huby (1997, 1153) describes one interviewee's repeated avoidance of planned interviews as 'strong statements about a person's experience of the services or the research as intruding and controlling'. Similarly, that my invitation of payment in return for an interview about public involvement was so unappealing, suggests a disconnect between the empowering 'opportunity talk' of the policy rhetoric, and how it is received by its target publics.

Once in a room with an interviewee, the difficulty of engaging them in discussion of public involvement policies was a further challenge. None of my interviewees considered themselves experts on health services, even where they had something that they wanted to tell me about their experiences. The topic seemed to risk alienating or intimidating participants. Several interviewees expressed concern that they did not have enough experience, or that they did not have sufficiently 'interesting' experiences, to be worth interviewing. My approach to interviews initially involved asking interviewees what they would do, or who they would talk to, if they were unhappy about any health service interaction and then I introduced a more hypothetical discussion about potential for agency within the NHS: complaining about problems, joining a Public Partnership Forum or choosing an alternative service provider. Almost any question which sought to place my interviewees in the role of 'empowered citizen' (e.g. 'how happy are you with your experiences of NHS services here?') yielded reluctant, brief answers ('I don't know', 'it's okay'). When probed, answers broadly supported the availability of opportunities for public involvement, but largely as an activity practised by some 'other' group of people. However, spurred on by one telling quote in a pilot interview ('That [joining a PPF] would just seem like a really strange thing for me to do'), I began to move the interviews beyond specific questions about public involvement opportunities to a broader discussion

about young adults' health service use in the context of their lives, focusing on what did seem to be meaningful and relevant to them.

### Shifting standpoint: avoidance, resistance and everyday creativity

Instead of seeing my interviewees from the perspective of public involvement policy (as disengaged or hard-to-reach young adults), I began to attend to the everyday processes of their health. In order to take these seriously, I had to shift away from a standpoint located within policy. Instead of focusing on my interviewees' absence from the formal mechanisms of public involvement in the NHS, I began to listen to and probe their everyday, ostensibly mundane tales of service use. My interpretation of the accounts I heard from my young adult interviewees is that they firstly *avoided* playing a public role within health services, and secondly, exercised their agency through *everyday creativity* in interactions with health services. I repeatedly heard about (what I describe as) tactics used by my interviewees in their interactions with the NHS. In understanding these as relevant and important (and not merely a distraction from the 'real' aims of the interview), the work of scholars including De Certeau (1984) and Scott (1990) was invaluable.

Scott's (1990) 'weapons of the weak' and De Certeau's (1984) account of everyday creativity take as their starting points, respectively, the domination of a group by repressive landlords in non-democratic contexts, and 'contemporary culture and its consumption' (De Certeau 1984, xxi). Despite the diversity of subject matter, there is common ground in their interest in opposition to hegemonic power. Scott's (1990) ethnographic study of peasant culture argued that in non-democratic contexts where overt displays of political power are impossible, marginalized groups are not passive, but merely express politics in ways that political science struggles to recognize: 'The realities of power for subordinate groups means that much of their political action requires interpretation precisely because it is intended to be cryptic and opaque' (Scott 1990, 21). Scott identifies a number of 'weapons of the weak', grouped under headings of anonymity, euphemism, grumbling and collective representations, including folktales. I feel his work, described by Tilly (1991, 596) as being about 'carv[ing] out little areas of autonomy in the midst of fierce discipline', chimes with elements of young adults' management of their own health. De Certeau (1984, xi) offers us his focus on everyday life as a realm where 'users – commonly assumed to be passive and guided by established rules – operate'. He proposes that attention to practices assumed to be passive (for example, reading and watching television) can illuminate the subtle ways in which 'consumers' exert their agency in the world around them. His concept of 'anti-discipline' draws heavily on Foucault's (1979) understanding of tightening discipline within society:

'If it is true that the grid of 'discipline' is everywhere becoming clearer and more extensive, it is all the more urgent to discover how an entire society resists being reduced to it, what popular procedures (also 'miniscule' and quotidian) manipulate the mechanisms of discipline and conform to them only in order to evade them, and finally, what 'ways of operating' form the counterpart, on the consumer's ... side, of the mute processes that organise the establishment of the socioeconomic order.' (De Certeau 1984, xiv)

For de Certeau, consumers have no terrain of their own ('There is no longer an elsewhere' 1984, p. 40) but exist within a space defined by elites. Here, 'tricks' and 'ruses' allow some 'elbow-room' or 'space for manoeuvre'.

In the context of the NHS, I argue that the moments of agency my interviewees described, while never engaging with the structures of ‘invited participation’, are relevant to an understanding of patterns of citizen participation. Here, I briefly describe the three most commonly described tactics: avoiding ‘bad’ doctors, negotiating an acceptable diagnosis and ‘transforming’ emergency appointments, before considering their implications for a policy of public involvement.

### *Avoiding ‘bad’ doctors*

Most interviewees said they had preferences to see, or avoid, particular general practitioners (GPs) within their practice. Everyone who expressed a preference primarily justified it with reference to interpersonal factors – the doctor’s smile, demeanour, relative youth or their gender – but framed it in ways which suggested these factors informed relationships of trust. Crucially, and in contrast to their assumed apathy, several of my interviewees described often acting on these preferences. To varying degrees, everyone who expressed a preference for or against one GP had tactics for seeing or avoiding that person. Most said they would ask the receptionist for an appointment with a named GP. Several were a little more pro-active, and guarded. Rebecca described her tactics for avoiding appointments with one particularly unpopular GP (Dr Jones):

Rebecca: *If I phone, I dinnae<sup>1</sup> want to say ‘I dinnae want Dr Jones or Dr Stevens.’ I’ll just say, and if she says ‘Dr Jones’ then I’ll just say ‘oh no that’s no’ any good’... Make an excuse. You dinnae want them to make it out eh that you’re no’ actually wanting them, cause then they might say ‘oh what are you no’ wanting them for?’ So I just say ‘have you got another time?’*

Int: *And would you not like the opportunity to say?*

Rebecca: *Nuh.*

Int: *Nah?*

Rebecca: *Nuh. [Laughs]. I’ll just avoid them.*

Rebecca was willing to go to some lengths to avoid two doctors she disliked, but also to avoid this being registered as feedback. Other interviewees remarked that the unpopular doctors were generally those with whom one could get an appointment at short notice: suggesting the possibility that individual ‘sink GPs’ can develop within a practice, in the same way that ‘sink hospitals’ may within a marketized system (Paton 2007).

Interviewees not only had service preferences, and acted on them, but in some cases also took steps to avoid these preferences being utilized as constructive feedback. They described themselves as unwilling to play the role of ‘responsible citizen’ whose ‘voice’ drives up the efficiency and effectiveness of a public service. This knowledge and the resulting tactics are not, however, likely to be accommodated or furthered by policy, which seeks instead to harness service user preferences for managerial goals (Le Grand 2007). Even where patient choice is being embraced in the UK (primarily in the English NHS), it remains concerned with choosing between service providers and organizations, not between individual health professionals.

### *Negotiating diagnosis*

Diagnosis constituted the main focus of my interviewee’s accounts of health service interaction. It was this stage that interviewees seemed to find most worrying, and it was

mostly here that negative experiences were recounted. Once a diagnosis is reached, health service users can draw on resources of information and support from services and fellow sufferers, and may be reassured about the legitimacy of their worries (Clarke 2000). However in the uncertain terrain pre-diagnosis, my interviewees either negotiated a solution (drawing on resources of family knowledge and the internet, and making repeat visits to different individual health professionals until they felt the problem was solved) or disengaged from this process (perhaps worrying quietly about an ongoing symptom, or perhaps giving it little further thought until the moment of our interview).

Several interviewees described resisting their GP's initial diagnosis. Lisa described the process of getting a diagnosis of gallstones, involving making three visits to different GPs within her practice, each of whom offered a different account relating to her 'unhealthy' lifestyle. Later in the interview, Lisa revealed that she had guessed this eventual diagnosis earlier in the process:

*Lisa: My auntie had a gallbladder out in the summer, and this is when my pain started coming and causing me nothing but trouble, so my auntie was like 'I'm telling you it's gallbladder, it's gall stones', so I'm on the computer, googling 'pains in my side' and that's one of the things that came up was gall stones, so I read about that and I went to the doctors and she said 'no it's not gall stones', this is when I was told I was obese. 'No it's nothing like that, it's just because you're clinically obese, you're needing to lose weight.'*

When I asked her how she felt about the process of getting this diagnosis, Lisa's response illustrated the way in which she had used this combination of family knowledge and online medical information, not to assertively make her point but instead as a reason to keep returning to the doctors.

*Int: How did you feel about all this?*

*Lisa: Annoyed. Because I was telling them the symptoms and the symptoms I've got are the symptoms that I'm reading off the computer. At one point I was actually going to print it off and take it to him and say look, there you go, that's what I've got. But, I never done that.*

*Int: Why not?*

*Lisa: I, cause I didnae want, I didnae want to be coming across as being cheeky, and trying to show them to do their job. Because [laughs] I could have been reading anything. Ken?<sup>2</sup> The internet's no' that a fair place, so.*

Lisa was aware of managing the impression the doctors had of her, and of the unreliable nature of some of the information available on the internet. However, she was convinced that she was right about her diagnosis, and eventually, by persistently making appointments with different GPs, achieved the outcome she wanted. While this can be seen as an exertion of agency, it was interpersonal, informal and frustrating for my interviewees.

### ***Transforming 'emergency' appointments***

At both the practices I recruited through, the practice information states that a number of appointments are held back each day for emergencies, and allocated to patients who phone at as soon as the practice opens each morning. On websites and in leaflets, patients are encouraged to make responsible use of this option: for example, 'Please try not to ask for

an urgent appointment unless you feel this is absolutely necessary.’ By contrast, in my interviewees’ accounts, phoning on the day was presented as the main, ‘normal’ way of making an appointment.

Rebecca: *If you really need an appointment if you phone at 8 o’clock, as soon as you get up in the morning, usually they do have some sort of cancellation that day. Might no’ always be the doctor you want, but, if you really needed the appointment you could get an appointment, wi’ another doctor eh.*

Other interviewees could not call in the morning because of their shift patterns at work, but this was still a familiar option. Rachel recounted an anecdote which suggested the tension between practice staff trying to maintain a system of emergency appointments through unofficial ‘triage’ (a process where reception staff who are not medically trained will filter requests for appointments; see, for example, Coulter and Elwyn 2002), and patients trying to use this as the main appointment system.

Rachel: *Well I got up at 8 that morning and I phoned and I got an appointment, I think it was in the afternoon.*

Int: *And how do you find the reception?*

Rachel: *The reception, it, it depends I think. Because sometimes, you could phone in the morning and you wait a long time on getting on the phone. And sometimes, it depends what receptionist’s on, they’ll maybe ask you why are you wanting an appointment, is it urgent, you know. Like you get a whole list of questions fired at you eh, ‘cause when you’d rather just like get your appointment and see the doctors. Ken even if it’s just like to ask the doctors a question, you ken, it’s, it’s no’ a case if it’s an emergency, if somebody’s wanting to see a doctor, they’re wanting to see them for a reason eh.*

The system of emergency appointments can be seen as reflecting an organizational preference for its users’ problems to be manageable (and for their reactions to be measured, patient, ‘responsible’) as well as national level policy pressure to offer timely access to a GP (The Scottish Government 2010). In using emergency appointments simply because they fit in with one’s schedule, my interviewees were (from a system perspective) not living up to their ‘responsibilities’ as patients. However, it is important to recognize the muted character of this disobedience. My interviewees described not protesting about the appointment booking system, or going ‘inappropriately’ to Accident and Emergency, but working within the confines of the system. Avoiding confrontation and patiently dialling and redialling at 8am until all the ‘emergency’ appointments were filled had to some extent transformed ‘emergency’ appointments into a standard way to see the doctor.

### **‘Keeping the institution in view’: implications for policy**

Despite the absence of what is conventionally recognized as ‘public involvement’ with the NHS, the young adults in my study were not passive users of health services. There are clear similarities between the tactics revealed in these interviews and those explored for decades by sociologists of health and illness. Researchers have explored the ways in which service users assert themselves within the medical encounter: moving from the notion of a powerless patient trapped in a web of social control (see, for example, Parsons 1951) to an often asymmetrical but nonetheless active engagement with the medical system (see, for example, Friedson 1980). Likewise, Locker’s (1981) *Symptoms and Illness* explores how his interviewees make active decisions about whether to attend the

doctor, and includes reference to irritation at gate-keeping receptionists. McCoy's (2006) study of HIV patients coins the term 'patient's triage work' to highlight the active role played by patients in making choices not between providers competing in a market, but between specialist care, primary care and emergency care.

However, it is not commonplace to draw these observations into a study of policy to 'involve' patients and the public within health systems. While interesting conceptual avenues are developing within health services research (for example, the concept of 'candidacy' bringing together individual choices, social contexts and macro-influences (see Dixon-Woods et al. 2006)), much of the mainstream health policy literature continues to neglect individual accounts of experience. In a review of contributions to the journal *Sociology of Health and Illness*, Davies (2003, 178) argues that 'The gulf between writers on health policy and organization and sociologists of health and illness has undoubtedly widened in recent years'. In this research project, it was important that I fully attended to the experiences described by my interviewees, without losing focus on the policy under investigation.

Within the heavily normative bent of much literature and policy on participation (Moini 2011, Clarke 2013), there could be a temptation to discount my interviewees' reported actions as simply examples of non-participation. Citizen participation is often uncritically presented as 'a good thing' in the literature on public services: with the potential benefits of effective participation often conflated into simple rationales: 'public participation is essential if health policy processes are to be accountable and transparent to the general public' (Tenbenschel 2010, 1537). Theoretical models of citizen participation – most notably Arnstein's (1969) influential 'ladder of participation' – rank types of participation by the degree of empowerment achieved.

However in doing so, they offer no space for either strategic 'refusal' or for assertive outsider tactics. While Lipsky's (1980) seminal work on the discretionary work of 'street-level bureaucrats' has inspired many to attend to how policy is negotiated at the frontline (Maynard-Moody and Musheno 2000, Durose 2007), there has been less scholarly interest in the roles played by citizens at this interface. In the context of the US, Soss (2000, 1) directed attention towards 'the quieter politics of everyday life in the welfare system', and Dubois (2010) has done similar work in the French benefits system. Both identified a range of tactics used by citizens in their interactions with this facet of the state, and both declared them to be political acts. Acknowledging that there is scope for citizens to subvert and resist policy intentions in these spaces, raises further questions. My interviewees' subversion of the rationing of resources (in the form of the emergency appointments system) was largely based on their own convenience. There was no sense in their descriptions of 'going to the doctors' that they acknowledged the collective systemic consequences of their individual decisions, nor that they sought to achieve systemic change by continuing to make appointments in the way that worked best for them. This resonates with Prior and Barnes (2009, 191) argument that we should avoid 'identify[ing] subversion as a heroic, revolutionary or necessarily even conscious act deliberately intended to undermine a particular purpose or outcome of public policy'. Likewise, Abu-Lughod (1990) cautions against the 'romanticisation' of resistance, advocating instead careful engagement with the 'analytic dilemmas' tactics generate.

In this case the tactics described by my interviewees revealed two related analytic dilemmas regarding public involvement in health services in Scotland. First, the shift in standpoint highlights how narrowly policy debates conceive of citizen agency. Debates in health policy between 'choice and voice' (Greener 2008) direct our attention towards a pre-defined range of acts, and away from agency more broadly conceived, as governments

‘explicitly recognize, and attempt to influence and utilize, the agency of subjects’ (Prior and Barnes 2011, 269). Approaching research with the public from a policy perspective deems patient choices between competing providers interesting, and patient choices between non-competing providers invisible (except where patients make ‘inappropriate’ choices, thus overburdening emergency care (see, for example, Philips et al. 2010)). In the assumptive world of this policy, power is held by NHS organizations, to be handed over (in prescribed ways and venues) to members of the public. A genuine concern to ensure the involvement of members of the public in the governance of public services – as repeatedly stated in the policy rhetoric of a ‘mutual NHS’ in Scotland (The Scottish Government 2007) – needs to acknowledge existing modes of agency, and not simply prescribe policy-sanctioned routes of influence and then bemoan their low take-up.

Second, the depth of my interviewees’ puzzlement (and discomfort) at my questions about their role as citizens (and in current Scottish policy ‘co-owners’ of the NHS) demonstrates that the formal opportunities available for influence are onerous and at odds with the self-understandings of my interviewees. The occasional ‘everyday creativity’ (De Certeau, Jameson, and Lovitt 1980) or resistance I discerned within the lives of my young adult interviewees is oppositional in its evasion of responsibility for health service governance. The doctors, nurses and receptionists who form the bulk of their interaction with the NHS are often helpful and occasionally essential to their lives. While describing appreciation when things go well (as they mostly had for most of my interviewees), when the organization, or individuals within it falter or fail their reaction is not that of a confident ‘co-owner’ but that of an anonymous outsider. I argue that my interviewees are describing an orientation to local health services which, instead of embracing the ‘partnership and collaboration’ which policy aspires to, is more adversarial and critical. As discussed above, these acts are unlikely to have a broader influence because examples of ostensibly poor service from health professionals remain unregistered at an organizational level. I would argue that they are, nonetheless, a problematic omission from current conceptual and policy models of participation.

Locating the project of policy analysis within this standpoint can offer a new analytic perspective on policies of public involvement in the NHS, as one manifestation of a wider project of ‘governance-driven democratisation’ (Warren 2009). Acknowledging a more adversarial relationship between a public service and (sections of) its publics – and rejecting the vision of an apathetic public ignoring the ‘participatory’ opportunities that local institutions offer – might allow us to exploit the inevitably ‘unsettled’ nature of Government policies. Public involvement is, like many areas of public policy, ill-defined and indistinct (Stewart 2013b). If we accept that ‘the policy process [is] an ongoing struggle to establish settled meanings’ (Prior and Barnes 2009), then there is potential to emphasize the ‘challenge’ function of public involvement so that the energies evident in some campaigning activity within health systems (see, for example, Moon and Brown 2001, Barnett and Barnett 2003, Oborn 2008) can be channelled into NHS decision-making more widely.

## Conclusion

Existing academic literature has highlighted the way in which opportunities intended to promote citizen participation summon particular types of public, and exclude other sections of the population (Barnes et al. 2007). However in trying to move beyond simple statements of ‘community apathy’ (see, for example, Wright et al. 2011) to point out the failings of formal participatory projects, scholars have risked neglecting the alternative

tactics by which members of the public assert themselves in their interactions with public services and the state. This article has sought to redress this balance, offering a critical perspective on participatory practice in public services without painting non-participants as passive recipients of public services. Given the sophistication of accounts of the discretionary tactics of front-line workers at local level (Lipsky 1980, Maynard-Moody and Musheno 2000, Durose 2007), this article contributes to a small but growing body of work which highlights the parallel active work of ‘street-level service users’ (Soss 2000, Dubois 2010), within a literature more accustomed to exploring the discretionary work of front-line staff and professionals. Crucially, this work goes beyond policy-sanctioned ‘co-production’ (Needham 2008) to encompass oppositional tactics which, while falling outside the frame of public involvement policy, are nonetheless meaningful expressions of agency.

This paper outlines one approach to include the perspectives of ‘outsider’ populations who appear, at first, to have little to say to researchers interesting in improving policy. The findings above came from a process in which I (1) practiced reflexivity in the face of difficulties in recruitment and engagement, (2) reoriented the standpoint of the research to make space for what my interviewees *were* willing to talk to me about and (3) ‘kept the institution in view’, resisting the temptation to turn the analytic lens of the project onto my interviewee’s reported behaviour, and away from the policy which I had set out to investigate.

When it comes to policy-relevant research, our predefined questions are almost inevitably located within the standpoint of that policy. Huby (1997, 1158–1159) argues that ‘Service providers participating in evaluation research often expect clear and unambiguous statements of service user experience. The dilemma facing researchers is that the language of policy and action is precisely the language which often masks or distorts a service user perspective’. Survey research deliberately limits opportunities for researcher or participants to reshape the orientation of an enquiry during data collection. Boehm, Bowman, and Zinn (2013, 311) argue that ‘by imposing a predefinition of an issue and its causes, surveys not only enact a reality, they also tend to reinforce the disempowerment of those who experience disadvantage’. More structured approaches to qualitative research similarly have the potential to take an ‘extractive’ approach to data collection in ways which, as one critical article described it, can seem ‘redolent of the criminal justice system’ (Sinha and Back 2013, 2). By contrast, an interpretive approach, rooting research in the everyday experiences of interviewees even where they do not recognize (or claim) the value of their own experience of a policy, can provide a valuable, albeit not straightforward, antidote to research rooted within a given policy discourse.

Inevitably, this approach to incorporating public perspectives into studies of policy brings its own risks and challenges. This approach does not offer a solution to the recruitment challenges facing projects which do not immediately capture public imagination (although in this case interviewees seemed more comfortable discussing their own experiences than attempting to formulate views on an unfamiliar policy). On a pragmatic level, the findings of the interpretive, dialogic type of research reported here may be poorly matched to the questions researchers are paid to answer (or that policymakers want to be answered). This is particularly the case given governmental concern that research should demonstrate evidence for ‘measurable’ outcomes of policy (Cabinet Office 1999, Blunkett 2000), which tends to encourage quantitative, large-scale studies (Boehm, Bowman, and Zinn 2013). Thus far, attempts by the Scottish Government to ascertain citizens’ views on the NHS have relied on highly structured questionnaires, the collection of ‘patient stories’ volunteered by members of the public, and a limited amount of



qualitative research, usually undertaken with hospital inpatients or regular attendees (e.g. those suffering from long-term health conditions) (McKissock 2008, Reeves 2008). In an era in which researchers are experiencing increasing pressure to be able to demonstrate research ‘impact’ (Smith 2010), it may be difficult for researchers to justify pursuing an approach which risks yielding findings that do not neatly answer questions of pressing policy concern.

More fundamentally this approach entails that the researcher does much of the work of making connections between described experiences and policy after, and separately, from the interview. In contrast to the co-productive dynamics outlined in participatory research (Beebeejaun et al. 2013), the model of data analysis here is unilateral, and interaction with my interviewees was fleeting. While respondent validation offers some reassurance – and my interviewees were offered the option of, and expressed no interest in, playing a slightly more active role within the research –, this remains a non-participatory approach. Sinha and Back (2013, 5) critique non-participatory research for assuming that ‘researchers have an expertise in relating participant’s observations or accounts to research objectives and public affairs, with participants positioned as knowledgeable about their own lives and what their world means to them’. They advocate involving research participants in all stages of the process, including topic selection. However in the project discussed here, this would likely have directed the research to topics which interested the young adults I spoke to, and thus excluded their ‘uninterested’ perspectives on this policy. While some researchers suggest that participatory action research is the only acceptable ‘bottom-up’ approach (see, for example, Shdaimah, Stahl, and Schram 2009), I would argue that there is both scope and a need for researcher-initiated *and* participatory research projects in order to ensure that less immediately engaging areas of policy do not become under-researched.

Dialogic, interpretive research with citizens who do not see themselves as key ‘stakeholders’ or experts on a policy can elicit findings from research participants who may otherwise be unheard, on topics with which many would not otherwise engage. Injecting these new perspectives into policy debates may, without necessarily neatly answering the questions policymakers ask about a given policy, contribute to what Weiss (1979) described as the enlightenment function of social science research for policy. If it is indeed ‘ideas’ and not ‘evidence’ that are translated into policy from social research (Smith 2007), then encouraging research participants to speak on their own terms, from their own experiences, (being frank, or even impolite about the policy under discussion) may (in a gradual way) prompt more fundamental reconsideration of the basis of a policy. Starting from the ostensibly mundane lived experience of citizens can provide a valuable space from which to understand and critique the assumptive worlds of policy.

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### **Notes on contributor**

Ellen A. Stewart is a postdoctoral fellow in the Centre for Population Health Sciences, University of Edinburgh. She works in the area of citizen participation in health systems, and is currently funded by the Chief Scientist Office (Scotland) to research public engagement, public protest and evidence use in processes of hospital closure. Research reported in this paper is explored further in a forthcoming (2015) monograph in the series Palgrave Studies in Science, Knowledge and Policy.

## Notes

1. Dinnae: don't.
2. Ken: know (in this case, 'you know?').

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