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Does NHS Direct empower patients?

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Abstract

NHS Direct is a 24 h telephone helpline established in England and Wales, UK to offer advice and information for people about health, illness and the National Health Service (NHS) so that they are better able to care for themselves and their families. In 2001/2002 we undertook in-depth home interviews with 60 users of the service in two NHS Direct sites in England. In this paper we consider the extent to which NHS Direct facilitates patient empowerment in terms of helping people to be in control of their health and health care interactions. Our research suggests that NHS Direct facilitates patient empowerment by enabling patients to self care and to access health advice and services. It is also seen to offer the prerequisites for empowerment perceived to be lacking in the wider NHS, including time, respect, listening, support, and information. The service also functions by offering an alternative contact point for people seeking to avoid being labelled 'time wasters' by other busy health care providers. In the context of a wider health service which appears to problematise individuals' ability to make decisions about the appropriateness of seeking health care, NHS Direct legitimises help-seeking actions. Empowerment in the context of NHS Direct has been associated with self care as a way of reducing 'unnecessary' demand on health services. However, health professional and patient perspectives on what is considered necessary demand differ, and in certain contexts, patient empowerment may involve service use as well as self care. Further, our data reveal the context-dependent nature of a concept like empowerment. For example, when people are ill, in pain, or anxious about a loved one, they may value being cared for more than being empowered. Our research suggests that, in addition to its other functions, NHS Direct is also valued as contributing to a sense of being

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Introduction

NHS Direct is a 24 h telephone helpline established to offer "easier and faster advice and information for

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people about health, illness and the National Health Service so that they are better able to care for themselves and their families" (Department of Health, 1997). It began in three pilot sites in England in 1998 and by 2002 had expanded to 23 sites covering the population of England and Wales, with a similar service 'NHS24' in Scotland. The general public can telephone the service for health information or advice. They speak to a call

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handler, who may be able to deal with their request or who may pass the caller to a health information advisor or a nurse advisor. Nurses use computerised decision support software to triage callers to emergency care, primary care or self care as necessary. In addition, the service triages calls on behalf of some general practice out-of-hours services such as general practice cooperatives.

NHS Direct is based on research evidence from international experience of telephone triage. For example, general practitioners triaging patients by telephone in their out-of-hours services in Denmark (Christensen & Olesen, 1998), and nurses using telephone triage in an after-hours paediatric service in the United States (Poole, Schmitt, Carruth, Peterson-Smith, & Slusarski, 1993), and a province-wide helpline in Canada (Robb, 1996). Nurse telephone triage has been shown to be safe, capable of reducing general practitioner workload outof-hours (Lattimer et al., 1998), and has been received favourably by patients (Poole et al., 1993). However, NHS Direct is an innovative service because it has been established on a national basis, is available 24h a day, and deals with all health problems across all age groups. Thus it has generated international interest as similar services develop around the world, including Australia (Turner et al., 2002) and New Zealand (St George & Cullen, 2001).

This innovative service was one of a number of services, including walk-in centres and minor injury units, introduced to deal with increasing demand on traditional NHS services such as general practice and accident and emergency departments. Access to general practitioners outside normal working hours was seen as particularly problematic, and recommendations were made for more graduated access to the health care system through a single point of entry such as NHS Direct (Rogers, Entwistle, & Pencheon, 1998). Thus an aim of NHS Direct when first established was to help over-stretched health services by dealing with some of the people who did not need to contact or use those services (Calman, 1997). There has been minor success to date in meeting this aim in that it has halted the upward trend in demand for out-of-hours general practice while having no effect on attendances to accident and emergency services (Munro, Nicholl, O'Cathain, & Knowles, 2000). A further aim was to help people to manage problems at home or know where to turn for appropriate care (NHS Direct, 2001). There is evidence that this occurs, with 23% of callers finding the advice helpful because they learnt to deal with their problem themselves and 35% because it helped them to contact the right service (O'Cathain et al., 2000).

Patient empowerment has been a common theme associated with NHS Direct. Providers of NHS Direct have described the service as a response to the desire for increased patient empowerment, having the specific

objectives of helping people manage problems at home, reducing unnecessary demands on other services, and allowing professionals to enable patients to be partners in self care (NHS Direct, 2001). A commentator on the policy has heralded the service as "a fundamental shift in the NHS where more public participation in health care can happen closer to home", where access to interactive sources of information would empower patients, and noting that there was a need for the NHS to empower self care given the limited resources available to it (Pencheon, 1998, p. 215). In interviews conducted when NHS Direct was first established, a range of health service professionals sensed the opportunity for NHS Direct to empower callers to undertake self care, whereas others felt threatened by the risk of creating a population which would seek professional advice for the most minor of problems (Munro, Nicholl, O'Cathain, Knowles, & Morgan, 2001, p. 55). Thus patient empowerment has been variously implicated in both aiding and threatening demand management, but with a focus on the empowered individual caring for themselves rather than making unnecessary demands on

Given that patient empowerment was part of the intention of and policy commentary around NHS Direct we might ask whether this new service does indeed empower patients. The Economic and Social Research Council and the Medical Research Council, as part of the *Innovative Health Technologies* programme, funded empirical research to explore empowerment in NHS Direct from the perspective of the patient. Here we begin by examining the ways in which the concept of empowerment has been used before going on to describe how we conducted the research, and then presenting our findings. Finally, we discuss the implications of these findings for NHS Direct itself and for the notions of patient empowerment in health care more broadly.

Defining empowerment

Patient empowerment is a commonly used term within health care, but there is little consensus regarding its definition (Johnson Roberts, 1999). The meaning of empowerment more generally is far from clear (Mitcheson & Cowley, 2003), appears across a diverse literature (Rodwell, 1996), and changes depending on the context in which it is used (Kuokkanen & Leino-Kilpi, 2000). If we are to consider whether NHS Direct empowers patients, then we must first consider different definitions, and identify those relevant to NHS Direct.

Empowerment can be considered in the contexts of critical social theory, organisational theory, and social psychology theory (Kuokkanen & Leino-Kilpi, 2000). In critical social theory, empowerment refers to people uniting to achieve common goals and may involve citizen power and the emancipation of oppressed

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ntexts of nd social 2000). In o people involve ppressed groups. Although patients might in some circumstances be considered as an oppressed group, this is not relevant to NHS Direct where the focus is on individuals rather than groups. In organisational theory, empowerment refers to delegation of power so that employees assume responsibility and act in line with the organisation's goals. This is relevant to the nurse advisors in NHS Direct rather than callers to the service. Social psychology theory, therefore, with its focus on individual development, and where empowerment refers to individuals gaining control over their own lives (Kuokkanen & Leino-Kilpi, 2000), is relevant to our study of NHS Direct.

Within this literature, empowerment has been defined by its absence, for example in terms of helplessness, paternalism and dependency, as well as more actively, as a feeling of having greater control over one's life (Anderson, 1996). This issue of control is a common theme within the patient empowerment literature, where the patient takes charge of their own health and their interactions with health care professionals (Johnson Roberts, 1999). Empowerment in this sense might manifest itself through individuals undertaking self care, gaining access to the services they want, and challenging health professionals (Johnson Roberts, 1999). Patients are considered as active agents (Salmon & Hall, 2003) who are free to make choices (Rodwell, 1996). Further, the concepts of responsibility and accountability are associated with freedom to make choices (Rodwell. 1996). People cannot be given empowerment, but health professionals can work with people in empowering ways (Starkey, 2003) and enable patients by making things possible (Mitcheson & Cowley, 2003; Rodwell, 1996). This entails a redistribution of power between patients and health professionals, with patients participating in decision-making about their own care (Paterson, 2001; Mitcheson & Cowley, 2003). The necessary conditions for such participation include health professionals showing respect and empathy, giving information, educating, spending time with, listening to, and offering emotional support to patients (Mitcheson & Cowley, 2003; Paterson, 2001; Rodwell, 1996; Starkey, 2003). Patients also need material resources to participate in decision-making about their individual health care in terms of money to spend on child care and travel when they attend appointments with health professionals (Paterson, 2001).

In all the above, empowerment has positive associations, and is considered to be something to be strived for. However, these positive associations can obscure the ways in which power operates (Anderson, 1996; Grace, 1991; Petersen & Lupton, 1996), and the way in which health professionals have an agenda which they wish people to follow (Grace, 1991; Johnson Roberts, 1999). Much of the discourse of the new public health seeks to shift responsibility to the population themselves (An-

derson, 1996; Petersen & Lupton, 1996), and self care, a central tenet of the discourse of empowerment through NHS Direct, can be viewed as a way of managing demand (Chapple & Rogers, 1999) and simply being a cheaper option than reliance on health care (Rodwell, 1996).

In the context of patient interactions with health professionals, empowerment can disguise paternalism or even justify it (Paterson, 2001). Interventions aimed at empowering patients can result in professionals controlling the nature of interactions in health care (Mitcheson & Cowley, 2003) and can more accurately be regarded as disempowering if patients feel the burden of responsibility rather than experiencing enhanced control (Salmon & Hall, 2003). Additionally, an emphasis on self care can overlook the barriers to effective health care which people face (Chapple & Rogers, 1999). For example, patients may feel disempowered through previous experiences or lack of social support networks (Houston & Pickering, 2000); illness may make people less able to meet their own needs (Anderson, 1996) or participate in decisions about their health care (Salmon & Hall, 2003); and the focus on the individual ignores structural issues such as poverty, or institutional constraints (Anderson, 1996). Finally, there can be conflict between the caring and empowerment roles of health professionals (Rodwell, 1996) and between the notion of self reliance and the dignity of dependency which can be seen as one of the defining characteristics of humanity (Sennett, 2003). This highlights the rather narrow focus of empowerment in NHS Direct on self care, which is assumed to be good for patients by allowing them self efficacy, and good for the health service by reducing demand, but lacks acknowledgement of the problematic nature of empowerment.

Methods

The research was undertaken in two NHS Direct sites in England, one in London providing a service to a diverse ethnic population, and one covering a mixture of urban and rural areas. Ethics committee approval was gained for both sites. The methods included observation in the two sites, involving one of the authors (JG) making day-long visits to each site and training as a callhandler in one site; in-depth interviews with 33 NHS Direct staff chosen purposively to include a range of nurse advisors, call handlers and health information advisors; in-depth interviews with 60 service users; and conversation analysis of 120 calls. This paper draws formally on the in-depth interviews with service users only. However, the analysis was informed by frequent discussion within the research team based on all data sources.

During three separate weekly periods in 2001/2, covering winter/spring, summer and autumn, NHS Direct nurses asked callers, at the end of a call, to give informed consent for their call to be transcribed and for a researcher to contact them with a view to being interviewed. Over 1000 consents were collected in the first time period. Nurses also noted why they had not sought consent from some callers; the top two exclusions were people needing an emergency ambulance and needing to attend accident and emergency. We chose callers purposively for interview to include general practice 'in-hours' (weekdays during the day) and 'outof-hours' (evenings and weekends) calls; males and females; young and old; and those calling for themselves and on behalf of children or other adults. In the subsequent data collection time periods, we asked nurses not to exclude some types of callers they had tended to exclude previously. In the final time period, a small number of nurses were asked to gain consent from particular types of callers who may not have been included in the previous time periods, such as those where there had been conflict between the nurse and the caller.

All callers selected for interview were written to, offered a further explanation of the study, and asked to complete a written consent form. Then they were contacted and interviewed by one of the research team (JG) mainly in their own homes, within three weeks of the call to NHS Direct. Interviewees were not asked directly about whether and how they felt empowered by NHS Direct, but were asked about their experiences of using NHS Direct within the wider health service. The interviews covered: how they had heard about NHS Direct; perceptions of its functions; patterns of service use; and how they had experienced the service, including how it compared with their experiences of more conventional medical encounters, their awareness and experience of the technology being used, and what they did as a result of the information and advice given, both in specific call events and at other times. Lasting between an hour and an hour and a half, interviews were tape-recorded and transcribed verbatim.

Analysis

In the early stages of analysis, the research team read transcripts and noted themes of empowerment around self care and use of services. Whilst discussing the transcripts in team meetings we identified themes which did not fit the model of 'empowerment as a good thing'. For example, we identified interviewees' accounts of the burden of responsibility, and their desire to take responsibility in some circumstances but not others. Reading the literature on empowerment helped us to identify aspects of empowerment which were present in interviewees' accounts but which we had not considered

in the context of empowerment, in particular the prerequisites for empowerment such as being given time by health professionals. We developed a thematic framework based on definitions of empowerment used by NHS Direct service providers and policy commentators, the literature, and issues emerging from the transcripts pertaining to the concept. Transcripts were selected from each sampling period in turn, reread, and coded using the thematic framework. Themes were further refined during this process and sub-themes identified. After 21 transcripts had been systematically coded, AOC noted that no further sub-themes or refinements were emerging. A further 6 transcripts were coded to ensure that saturation had been obtained.

Findings

The interviewees

JG undertook 53 caller interviews, some of which were undertaken jointly with the caller and patient, resulting in interviews with 60 NHS Direct users. Joint interviews were not part of the study design but were undertaken in seven cases because the patient as well as the caller was present when the interviewer arrived and responded positively to negotiations around joint participation in the interview. In the sample, approximately a third of calls were from each sampling time period. Presenting symptoms included fever, abdominal pain, cystitis, chest pain, back pain, insect bite, cough, and headache. The sample is described in Table 1 and was diverse in all aspects except that only two callers were from minority ethnic groups and only two were recommended by NHS Direct to go to accident and emergency. Our sample did not allow us to comment on empowerment in minority ethnic groups. However, because interviewees discussed previous calls as well as the one selected, we did have accounts of NHS Direct recommendations to attend accident and emergency.

This study is based on a purposive rather than a representative sample and thus it is inappropriate to describe the frequency with which any issues were reported by interviewees. However, it is important to know how our sample compared with NHS Direct users more generally, in order to consider the transferability of the study findings. Our sample had a similar make-up to NHS Direct users in general (Table 1). However, we sampled fewer people who had been recommended to attend accident and emergency departments than we had intended (see above). Also, although we made efforts to include calls where there had been conflict between the nurse and caller, and interviewees discussed calls to NHS Direct which they had been unhappy about, we recognise that callers may have been more likely to agree

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Table 1 Description of sample and comparison with data on NHS Direct use

Characteristic	Number in sample	Percentag	ge of sample (%)	Comparative data for NHS Direct	
Calls					
Time of call					
Week day	38	72		71% at weekends and evenings	
Weekend	15	28			
Day time	33	62			
Evening	20	38			
Call on behalf of	¥1				
Self	29	55		44%	
Other	24	45		56%	
NHS Direct recommendation					
A&E or ambulance	2	4		7-39%	
GP	31	58		28-58%	
Self care	11	21		20-37%	
Health information/other	9	17		6-28%	
Callers					
Gender					
Male	12	23		20%	
Female	41	77		80%	
Age					
18–29	8	15			
30-49	30	57			
50-65	10	19			
65+	5	9			
Ethnic status					
White	- 51	96		97%	
Other	2	4		3%	
Educational level					
Degree	17	32		57% left school aged 16 or under	
A level/further education	12	. 23		er se sue viennied de se	
GCSE	14	26			
No qualifications	10	19.			

^aBased on data from Munro, Nicholl, O'Cathain, and Knowles (1998) and Payne and Jessopp (2001).

to participate in the study if they were generally happy with the service provided.

NHS Direct—facilitating empowerment?

Whilst it is not possible for NHS Direct to 'give empowerment' to patients, it can enable their access to effective care, and establish a relationship which is experienced as empowering. The ways in which these occurred, or not, in interviewees' accounts of their interactions with NHS Direct are presented below.

Self care

Interviewees discussed episodes where NHS Direct had enabled them to look after themselves and their families in their own homes without recourse to primary or secondary care. For example, a woman felt that her health problem was minor and did not want to bother her GP about it but did not know how best to care for it herself. NHS Direct gave her advice about the action to take. NHS Direct also helped while patients were awaiting their appointment with their GP in a few days time. For example, a woman had cystitis and had a three day wait for a GP appointment. She was in discomfort and NHS Direct gave her self care advice in the meantime.

The way I use it is to stop me going down the doctor's surgery every five minutes or down the hospital every two minutes. (Interviewee 48, F)¹

I had a feeling I could relieve the symptoms by doing particular things myself rather than actually having to see a GP and get medication for it [..] because I didn't really want to call my GP out on a Sunday if it wasn't necessary [....] They advised me what to do

¹indicates unique identifier, gender, and age (if known) of interviewee.

and it really helped. I didn't actually realise you can get stuff over the pharmacy" (Interviewee 47, F, 21)

As well as helping with their current problem, there were episodes when interviewees felt able to apply prior self care advice to subsequent problems, sometimes by replicating the computer algorithms in their own heads to decide how serious a problem might be, or by following the self care advice given for a similar problem. The detailed explanations given about a health problem and how to deal with it educated callers to the extent that they could reapply this learning. However, they did not always feel able to simply apply their learning from one situation to the next because of subtle differences between two episodes, which led them on some occasions to seek professional advice for the subsequent episode.

Access to health services

Callers' learning was not focused solely on self care, but included understanding when it was in fact necessary to seek contact with a health professional. NHS Direct facilitated access to health services in a context where callers were unsure about whether a health problem was serious enough to seek contact with a service, by advising on the necessity of contacting a service and on which service was the most appropriate to contact. It could also help patients obtain an emergency appointment with their general practitioner.

I then called my doctor but the clinic wouldn't, they didn't think it was necessary for me to see anybody because I'd seen a doctor that morning and I said to them "well he's got worse and the NHS Direct has recommended that I see you" and after a bit of hesitation they then let me see a doctor. (Interviewee 34, F, 27)

The immediacy of access to health advice was particularly appreciated:

I was actually very very thankful that there was somebody that I could speak to and get information immediately and I think that's really important [...] That's one of the frustrations with phoning up a doctor's surgery and being told 'well he might be able to squeeze you in some time next month' and you're going 'crikey I could be dead by then' (Interviewee 53, F, 47)

However, as well as facilitating access, NHS Direct itself was viewed in other circumstances as obstructing access. Whereas some interviewees recounted being impressed by the relative speed with which the nurse called them back, for example comparing a wait of 45 min favourably with a potential wait of 4h in accident and emergency, there were also accounts of having to wait

1 or 2h for a nurse to call back. This created a loss of trust in the service, leading interviewees on some occasions to by-pass the system by attending an accident and emergency department in order to get faster access to care.

I thought 'why am I being referred to a nurse now'. When I've already told him I need [help...] I just automatically thought I'd ring this number and get an appointment with a doctor, but then I had to wait another hour for the nurse to phone you see [...] [.My friend] actually asked her doctor if there's a number she can phone rather than go through all that, you see. But she said now she just goes to casualty with him, with her husband. (Interviewee 4, F, 34)

I see it as a means to get to a GP [...] it used to be easier to get to speak to a GP and it used to take less time [...] you feel like you are wading through all these layers to get to a doctor [...] it has felt frustrating [...] they are trying to rule out lots of different conditions, which I know damn well I haven't got, but I'm having to answer their questions (Interviewee 5, F)

Challenging health professionals

As detailed above, NHS Direct was used to gain access to a service to which there were perceived barriers. Accounts suggested that NHS Direct also encouraged people to engage more assertively with health services so that they could obtain the information they required from doctors, nurses and administrative staff, or question the advice they were given. They could check issues they were concerned about and return to the appropriate part of the system with this newly acquired knowledge.

Then you'd be able to go to your GP with [a] slightly more objective outlook, and you might be able to pressure more for something that they wouldn't normally refer [...] rather than just taking their opinion straight away. (Interviewee 36, M, 29)

However, interviewees who discussed challenging health professionals said that they did so with care for fear of jeopardising their treatment or their long-term relationships with health professionals.

Nobody wants to be hated. I wouldn't want to think that when they [the GP receptionist] put down the phone they think 'that bloody woman again'. (Interviewee 16, F)

The availability of choices

Callers felt pleased to have NHS Direct as an alternative to their GP to save them bothering the

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doctor. NHS Direct could also offer advice on alternative sources of treatment which patients had not considered, for example being advised to attend accident and emergency for relief of dental pain whilst waiting to locate another dentist.

If you can't get hold of your doctor or if it's out-of-hours [...] I've also used it when my own doctor's surgery I've felt that they haven't given me very good advice or the information I need, so I've resulted in ringing NHS Direct. [....] They gave me an alternative that was totally fine. (Interviewee 32, F)

However, sometimes callers felt that NHS Direct limited the options available, in that they had no choice about using the new service because it was their *only* route to gaining access to a GP out of hours.

So in some respects you're forced to use it if you seek that type of advice. (Interviewee 24, M, 34)

Participation in decision-making

NHS Direct nurses use a computerised decision support system which presents them with a set of questions to ask patients and which recommends actions for patients. In other settings, structured guidelines have been shown to get in the way of patients participating in decision-making (Mitcheson & Cowley, 2003). Our interviewees did not tend to notice or object to the presence of the software in NHS Direct, rarely identifying it as an asset or a barrier. There was little evidence of patients participating in making the decision about which service, if any, to contact. If NHS Direct was in a position to grant access to a service, in particular a home visit from a GP, then interviewees gave accounts of challenging any recommendation they disagreed with until they obtained access to the service they wanted. Otherwise any disagreement could be handled by simply not following the recommendation given.

I just said alright but I don't think I had any intentions [to go to the doctors]. (Interviewee 45, F, 69)

Where there was participation in decisions, interviewees could recognise the responsibility involved. For example, a mother was told by NHS Direct that her baby was not seriously ill, but that nevertheless she was an expert in the baby's health, and could decide to take the baby to the GP herself if she felt the need to. She felt frightened by this level of responsibility for the decision but at the same time she appreciated the sharing of expertise between the nurse and herself.

And she was very good at explaining to me [...] and she actually said [...] 'actually you are probably the best person to judge whether you need to take her somewhere or not' [...] Doctors [...] try and provide all the answers. (Interviewee 35, F, 39)

Much more commonly than discussing participation in the actual decision, interviewees described NHS Direct as offering what we identified earlier as the *prerequisites* for patient empowerment. They appreciated being given time, being listened to so that their opinion was taken into consideration rather than ignored, and being given emotional support.

I felt like they cared, I was suffering and felt like they cared. And that's what I wanted, a bit of sympathy I think. (Interviewee 45, F, 69)

They considered time, and explanations, to be in short supply in the wider NHS, a perception highlighted elsewhere around primary care in the UK (Rogers, Chapple, & Sergison, 1999).

I get the sense that a lot of them are just rushed off their feet, just completely rushed off their feet to the point where [...] its almost like you're a number [...] doctors don't have enough time to sit and explain what's going on. (Interviewee 20, F)

Detailed explanations supplied by NHS Direct about a health problem, and how to deal with it, educated callers to the extent that they felt they could reapply this learning. This educational approach has been advocated to empower parents to care for their young children in the context of calling doctors outside normal working hours (Houston & Pickering, 2000).

And even now when he has a cold I still follow all the steps that they told me to[...] But it was nice just to have a checklist to go through and actually when he gets a cold now I still follow all those steps. (Interviewee 34, F, 27)

Given that patients need resources such as time and money when participating in decision-making with health professionals, because of the costs attached to travelling and waiting, NHS Direct sometimes helped callers to control the amount of effort they needed to make when contacting services. Callers wanted to know that it was absolutely necessary to visit the GP or accident and emergency department before making the effort to travel and wait, especially if they felt very ill themselves or had sick children whom they did not want to remove from home unnecessarily.

Well the advantage of NHS Direct is you don't have to go down to the surgery and make an appointment and sit and wait in the waiting room and wait for your turn and hope they're not too busy [...] not having to put a child in the car and drive them and sit and wait and all that (Interviewee 52, F, 55)

Enabling or authorising?

NHS Direct not only enabled people to self care, access services and challenge health professionals, but also authorised their actions and legitimised their concerns.

If you've gone through NHS Direct they can authorise you to turn up at the out-of-hours centre [...] you can't just turn up [..] so that it would sort of justify my visit if I phoned [...] That gave me the authority to go the next morning and say "I've been through to NHS Direct" so there wasn't a scene with the receptionist saying "oh you're not going to turn up here are you, you have to join the queue" (Interviewee 52, F, 55)

Patients felt that they needed authorisation to access health services because their view of the wider NHS was of a service under pressure, where access was restricted. They did not feel free to make choices around accessing services, and sometimes consciously resorted to tactics to gain access.

You have to make it sound as though the child is dying, what else do you do? So that frustrates me. (Interviewee 34, F, 27)

They felt a responsibility to avoid wasting the time of busy health professionals (Rogers et al., 1999), but also wanted to avoid being labelled as time wasters (Goode et al., 2004). The need to avoid this label often required considerable work by individuals.

When I went [to hospital] I could say at least I've waited so many days, and the doctors aren't open, and I have rung NHS Direct, and they said to come down. (Interviewee 32, F).

Having 'heard' messages in the wider NHS not to contact services unless their problem was serious, people needed confirmation that their problem was serious enough for contact with a health professional, or that their choice to self care was correct. This dilemma of whether or not to call the doctor has been found elsewhere in the context of sick children (Houston & Pickering, 2000), with patients resorting to self-rationing of care (Rogers et al., 1999). The need for a service like NHS Direct was less apparent when interviewees felt confident about the urgency of a health problem, and in this respect could be viewed as a barrier to the service which people knew they wanted to access. However, uncertainties around entitlement caused problems in that interviewees did not have confidence in their own ability to make the right decision. This is a significant part of the context in which patients turn to NHS Direct to share the responsibility for the decision, or even to make the decision on their behalf. One could argue

therefore that rather than being in control of their health care interactions, some patients become unable to act without permission to do so. One could also argue that at other times it was having their concerns legitimised that enabled patients to take action.

The problem of equating low service use with empowerment

As described earlier, there was a hope when NHS Direct was first established that it would empower people to self care and thereby make less use of busy health services. However, it may not be possible to label an individual as empowered or not by the extent to which they use services. Health professionals and patients can make different judgements about the necessity of contact with a service. Some newly recruited NHS Direct call handlers for example expressed surprise that people called the service about minor problems such as 'having the flu', and also speculated about a degree of 'parental paranoia' around the health of children. Callers who were also health professionals themselves echoed this characterisation of 'dependence' on professional advice generally in the NHS.

We find that people come and make an appointment for advice about things which in the past somebody in the family would have given you help or advice with.[...] I think we expect a lot more from health professionals. (Interviewee 2, F)

Yet these same health professionals, whom we might assume to be empowered by their insider status when it came to their own health and health care, called NHS Direct because they did not necessarily feel that their own professional knowledge equipped them to make accurate assessments of their children's symptoms. Additionally, some interviewees themselves felt that they might be over-reliant on health services-"I class myself as a very anxious parent" (Interviewee 48, F, 33), whilst for others their language hinted at possible overuse-"Everything that the lady told me from NHS Direct is precisely what the GP told me twice since then. because I've seen two of them". (Interviewee 46, F, 49). However, there were also callers who talked about occasions when they had made multiple visits to a range of services about an episode of illness which turned out to be a serious health problem. Further, some patients identified contacting a service as empowering, viewing it as a way of being in control of their lives, for example enabling them to meet their work commitments. A young woman with a mental illness, who made frequent contact with a range of health services as well as family and friends, felt empowered by this because she felt that she was being active in seeking out the help she needed

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to deal with a chronic condition, the early signs of which she was learning to detect—"I'm working on it, my main priority is me identifying it" (Interviewee 33, F, 22). She saw NHS Direct as playing a crucial role in accessing help out of hours at the point at which she identified the onset of another episode.

The importance of caring

Interviewees did not necessarily react positively, in their interactions with the NHS in general, to potential manifestations of empowerment. Some experienced the message that it was their responsibility to look after themselves and their family as burdensome, while others reluctantly took on an assertive role because they felt let down by the health service. In these circumstances 'being active' felt forced upon them; they were seeking advice, information, and access to services which they felt that the health service should have been more proactive in delivering. Their language revealed the hard work that they saw as necessary to obtain something like a piece of information or a prescription from the NHS-"That took a bit of sorting out. I got [...] all ready and geared up" (Interviewee 31, M, 59 seeking health information) and "I get into gear" (Interviewee 4, F, 34 when discussing her determination to access a GP).

So in terms of my well being and looking after myself as I get older, I've got to make the provision [...] I've got to work it out for myself" (Interviewee 1, M, 35).—I think you really have to watch out for yourself [...] that you're not really in their care, that you have to constantly ask for their help and assistance [...] you have to stand up for yourself, you have to demand things [...] I wouldn't say they are begrudging, but yes I guess begrudging [...] of their time. (Interviewee 20, F)

In contrast to this experience of the wider NHS, NHS Direct was welcomed by the interviewees because they did not have to make the same level of effort to obtain the help they wanted. In the discourse of empowerment, there seems to be no place for the ill, vulnerable, and anxious, who are expected to take responsibility regardless of their circumstances (Anderson, 1996), a point developed in a more general context by Sennett (2003) who takes issue with the unproblematic assumption in western societies that to be dependent is to occupy a negative state, and is to be avoided at all costs. This resonated in our interviews when callers expressed the need to share the burden of responsibility, and on some occasions give total responsibility to health professionals in situations when they were acutely anxious or in pain. Interviewees found it difficult to be assertive when ill, or to think rationally when a loved one was ill. For

example, a parent of a baby who ended up being hospitalised for 6 days talked about being "in a state of panic because everything we had tried just wasn't calming him down at all [...] we were just in despair" (Interviewee 24, M, 34). The same interviewees also talked about other occasions when they had been assertive and in control of their health care interactions with professionals. Thus empowerment is not something that an individual possesses or not, but is dependent on context (Anderson, 1996).

Echoing Sennett's (2003) point that the act or state of being dependent is part of what it is to belong to a community, marking out and defining humanity, callers felt reassured that NHS Direct was there for them, when they could not get hold of a doctor or when they needed support in a distressing situation. The 24 h availability of the service seemed of particular value to them. They expressed trust in a service they described as caring, but also something they could rely on, and that offered robust advice—"It just makes you feel that there's somebody there, medically trained" (Interviewee 32, F). Even a caller who viewed the service as a barrier to her GP on some occasions felt that it had given her support on another occasion when she really wanted someone 'to be there' for her.

Discussion

We have shown the range of ways in which NHS Direct can facilitate patient empowerment by enabling people to self care, and to access health services. However, NHS Direct also authorises them to take one or other course of action as they grapple with the challenge of determining when their health problems are serious enough not to be seen to be wasting the time of busy health professionals. Thus NHS Direct can be used to legitimise contact with health services in a context of the delegitimation of the lay person's ability to make judgements about their own health and illness, and their use of health services. People have come to need recourse to one health professional to determine whether they need to see another health professional. This need for legitimation has also been identified for patients with chronic disease, where people's knowledge and experience of their illness is delegitimised (Paterson, 2001). The delegitimation of back pain, for example, can lead to a reliance on the medical profession to confirm the suffering of the patient, to offer credibility, and thus to allow access to social benefits (Glenton, 2003). At the same time, however, NHS Direct offers patients the prerequisites of empowerment, such as time, listening, information and support, which they value and consider largely to be lacking in the wider NHS.

The empowerment movement can serve a number of agendas, including both enhancing patient choice and

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control, and resource allocation (Anderson, 1996). Both agendas operate in NHS Direct. Patient empowerment in terms of enabling self care may aid demand management, whereas patient empowerment in terms of legitimising access to services may not. But there are, in any case, problems when empowerment is defined in quantitative terms, for example in relation to levels of health services utilisation. Negative labels such as 'time waster' reveal the assigner's priorities rather than the patient's, and from the perspective of the patient, frequent service use may be a manifestation of their own empowerment rather than a demand management problem.

Moreover, it is easy to think of individuals as either empowered or not. This view of empowerment as an outcome rather than a process precludes people from moving in and out of settings which act as disempowering (Starkey, 2003; Johnson Roberts, 1999). Individuals can be assertive in some interactions with health professionals and on other occasions give responsibility over to health professionals when they are in pain, or highly anxious about the safety of a loved one. At these times they may value 'being cared for' more highly than being 'empowered'. Rather than viewing the need to be cared for as a weakness, or associating it with childhood (Sennett, 2003), it could be viewed as a human state which different people occupy at different times. Too often it is left out of discourses of empowerment, yet was a vital component of what our interviewees valued about NHS Direct.

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References

- Anderson, J. M. (1996). Empowering patients: Issues and strategies. Social Science & Medicine, 43(5), 697–705.
- Calman, K. (1997). Developing Emergency Services in the Community. The final report. London: NHS Executive.
- Chapple, A., & Rogers, A. (1999). 'Self-care' and its relevance to developing demand management strategies: A review of qualitative research. *Health and Social Care in the Commu*nity, 7(6), 445–454.
- Christensen, M. B., & Olesen, F. (1998). Out of hours service in Denmark: Evaluation five years after reform. British Medical Journal, 316, 1502-1505.
- Department of Health. (1997). The New NHS: Modern, dependable. Cmd 3807. London: The Stationery Office.
- Glenton, C. (2003). Chronic back pain sufferers—striving for the sick role. Social Science & Medicine, 57, 2243–2252.

Goode, J., Hanlon, G., O'Cathain, A., Luff, D., Strangleman, T., & Greatbatch, D. (2004). Risk and the responsible health consumer: The problematics of entitlement among callers to NHS Direct. Critical Social Policy, 24, 210–232. Roc

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- Grace, V. M. (1991). The marketing of empowerment and the construction of the health consumer: A critique of health promotion. *International Journal of Health Services*, 21, 329–343.
- Houston, A. M., & Pickering, A. J. (2000). 'Do I don't I call the doctor': A qualitative study of parental perceptions of calling the GP out-of-hours. *Health Expectations*, 3, 234–242.
- Johnson Roberts, K. (1999). Patient empowerment in the United States: A critical commentary. *Health Expectations*, 2, 82-92.
- Kuokkanen, L., & Leino-Kilpi, H. (2000). Power and empowerment in nursing: Three theoretical approaches. *Journal of Advanced Nursing*, 31, 235–241.
- Lattimer, V., George, S., Thompson, F., Thomas, E., Mullee, M., Turnbull, J., et al. (1998). Safety and effectiveness of nurse telephone consultation in out of hours primary care: Randomised controlled trial. *British Medical Journal*, 317, 1054–1059.
- Mitcheson, J., & Cowley, S. (2003). Empowerment or control? An analysis of the extent to which client participation is enabled during health visitor/client interactions using a structured health needs assessment tool. *International* Journal of Nursing Studies, 40, 413-426.
- Munro, J., Nicholl, J., O'Cathain, A., & Knowles, E. (1998).
 Evaluation of NHS Direct first wave sites. First interim report to the Department of Health. Sheffield: Medical Care Research Unit, University of Sheffield.
- Munro, J. F., Nicholl, J. P., O'Cathain, A., & Knowles, E. (2000). Impact of NHS Direct on demand for immediate care: Observational study. *British Medical Journal*, 321, 150-153.
- Munro, J. F., Nicholl, J. P., O'Cathain, A., Knowles, E., & Morgan, A. (2001). Evaluation of NHS Direct first wave sites. Final Report of the phase 1 research. Sheffield: University of Sheffield, Medical Care Research Unit.
- NHS Direct (2001). NHS Direct—A new gateway to health-care. www.nhsdirect.nhs.uk.
- O'Cathain, A., Munro, J. F., Knowles, E., & Nicholl, J. P. (2000). How helpful is NHS Direct? Postal survey of callers. British Medical Journal, 320, 1035.
- Paterson, B. (2001). Myth of empowerment in chronic illness. Journal of Advanced Nursing, 34(5), 574-581.
- Payne, F., & Jessopp, L. (2001). NHS Direct: Review of activity data for the first year of operation of one site. *Journal of Public Health*, 23, 155–158.
- Pencheon, D. (1998). NHS Direct: Managing demand. British Medical Journal, 316, 215–216.
- Petersen, A., & Lupton, D. (1996). The new public health. Health and self in the age of risk. London: Sage Publications.
- Poole, S. R., Schmitt, B. D., Carruth, T., Peterson-Smith, A., & Slusarski, M. (1993). After-hours telephone coverage: The application of an area-wide telephone triage and advice system for pediatric practices. *Pediatrics*, 92, 670–679.
- Robb, N. (1996). Telecare acting as an "electronic grand-mother" for New Brunswickers. Canadian Medical Association Journal, 154(6), 903–904.

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Rogers, A., Chapple, A., & Sergison, M. (1999). "If a patient is too costly they tend to get rid of you:" The impact of people's perceptions of rationing on the use of primary care. *Health Care Analysis*, 7, 225–237.

Rogers, A., Entwistle, V., & Pencheon, D. (1998). A patient led NHS: Managing demand at the interface between lay and primary care. *British Medical Journal*, 316, 1816–1819.

Salmon, P., & Hall, G. M. (2003). Patient empowerment and control: A psychological discourse in the service of medicine. Social Science & Medicine, 57(10), 1969–1980. Sennett, R. (2003). Respect: The formation of character in an age of inequality. London: Allen Lane.

St George, I. M., & Cullen, M. J. (2001). The Healthline pilot: Call centre triage in New Zealand. New Zealand Medical Journal, 114, 429-430.

Starkey, F. (2003). The 'empowerment debate': Consumerist, professional and liberational perspectives in health and social care. Social Policy & Society, 2(4), 272–284.

Turner, V. F., Bentley, P. J., Hodgson, S. A., Collard, P. J., Drimitis, R., Rabune, C., & Wilson, A. J. (2002). Telephone triage in Western Australia. *Medical Journal of Australia*, 176, 100-103.