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CITIZENS, THEIR AGENTS AND HEALTH CARE RATIONING: AN EXPLORATORY STUDY USING QUALITATIVE METHODS

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INTRODUCTION

A number of health economists are beginning to express concern about the narrowness of economic attempts to define rationing policies. Until recently, economists' research efforts in relation to health care rationing have been concentrated in one specific area: that of developing technical rationing methods based upon efficiency.¹ This has been to the detriment of the rationing debate in general as economists' analytical methods and concepts of utility could conceivably contribute to other important issues concerning the

process of health care rationing. One of these issues is the application of the theoretical notion of a principal-agent relationship to societal health care decision making. The principal-agent relationship was originally developed in mainstream economics to model situations in which the consumer is ill-informed, but can use an agent to make decisions on his or her behalf. Utility functions of these two individuals are assumed to be independent,² conform to expected utility theory³ and show risk-aversion.⁴ Theoretically, contracts are devised between principal and agent to provide an optimal outcome.^{3, 2} In health care the agency relationship has been applied to the doctor-patient relationship although it has mainly been used as a description of the relationship rather than to devise the type of complex fee schedules characteristic of the theoretical analyses within mainstream economics.⁵ The focus of the description is on the asymmetry of information between well-informed doctors and ill-informed patients which can have the potential for exploitation of the patient.⁶ Understanding of this patient-doctor principal-agent relationship is still relatively limited,⁷ although it is suggested that it differs considerably from that described in the mainstream literature, in particular because of the interdependence of the utility functions of the two main actors,² as well as the social context in which health care decision making takes place.⁸ There are other difficulties, concerning the extent to which the doctor acts solely as the patient's agent and the extent to which s/he also acts as an agent for society. Greater understanding of the patient-doctor agency relationship may be important to ensure that incentives exist for doctors to maximise patient utility,⁷ although, again, such a conclusion is limited by the extent to which it is desirable for doctors to act on behalf of society as well as by the extensive information that doctors would require to fulfil the role of perfect agent.⁹ There has been some extension of the notion of agency to the relationship between citizens and those making health care decisions on their behalf. A form of societal agency relationship is envisaged where the aim is to maximise social welfare rather than the utility of the individual patient.^{7; 10} There has been only a small amount of work with respect to this citizen-agent relationship and this has not reached even the descriptive level of the patient-doctor agency relationship. Certainly there has been no discussion of the incentives that might be required to ensure that citizens' agents work to maximise the utility of citizens. Discussion of the citizen-agent relationship has been concentrated in the work of Mooney, but has tended to be exclusively of a theoretical/discursive nature. Mooney has proposed that policy makers should act as agents for citizens but that citizens should be involved in developing principles upon which these agents should act.¹⁰ He then advocates no further involvement for citizens unless agents are not acting according to the principles developed by the citizenry.¹⁰ More generally, there have been various suggestions for identifying agents for citizens which have included administrators/bureaucrats,^{7; 10} policy makers,^{7; 10} politicians,⁷ and public health doctors.⁷ Among economists there is general acceptance that doctors should not take on the role of citizens' agent.^{7; 11-15} It is suggested that clinicians are no better informed than citizens in relation to the operation of health care systems and so the nature of the information gap is not one in which the poor information of the citizen can be provided for by clinical knowledge.^{7; 12; 14} Most of the debate around whether doctors should act as agents for citizens, however, concerns the "dual agency" that this role would imply.¹⁵ Conflict between the (implicit) role of societal agent and the (explicit)

role of patient advocate is intrinsic to the doctor's role,^{7; 11-16} and can be expected to increase as the oft-quoted 'gap' between demand and supply widens. If doctors are to act as both the patient's and the citizen's agent they may be left with moral and ethical problems¹⁷ preventing them from making disinterested rationing decisions.¹⁸ Empirical evidence about the citizen-agent relationship is limited. Survey evidence suggests that although citizens wish to be consulted, they do not want to make rationing decisions directly,¹⁹⁻²⁴ and that the public views doctors as the most appropriate group to take these decisions on behalf of society.^{19; 20; 25; 26} This suggests that citizens may favour a citizen-doctor agency role, in direct contrast to the views of economists. There is no information about whether the current process of decision making takes the form of a citizen-agent relationship and, if so, who acts as agent on behalf of the citizen. The research reported here has two purposes. First, it examines citizens', and their potential agents', preferences for an agent to make decisions on behalf of citizens. Second, it explores the current system of decision making, to see how closely it resembles the sort of citizen-agent relationship postulated by economists. Qualitative research methods were used as the intention was to explore a potentially complex relationship about which there is currently little empirical information.²⁷

METHODS

This study was conducted alongside a broader project whose intention was to explore public and professional views about public participation in health care decision making. Thus, initial fieldwork was undertaken in the form of focus groups with 'citizens' and 'agents' living and/or working in one UK county. 'Citizens' are defined here as those obtained through sampling strategies aimed at identifying members of the public or their representatives. Sampling strategies for the broader project included random sampling from the electoral roll (in both middle and working class areas), random sampling of interest groups, selecting existing interest groups and selecting the entire population of elected representatives within particular localities. 'Agents' were defined as those sampled on the basis of their health service role. Groups of general practitioners, hospital clinicians, managers and professionals allied to medicine, board representatives and Community Health Council representatives were identified via key informants and asked to participate. This broader project provided access to a sample of individuals for interview.

Interviewees were purposively selected, based on their comments in the focus group, with the intentions of obtaining a broad range of views about the extent to which individuals appeared to want to participate in health care decision making (citizens), and to obtain a variety of viewpoints about different roles in health care decision making (agents). Because interviewees were drawn from focus groups in which the author had participated, a degree of rapport had already been established with informants before the interview took place. Further, these individuals had already begun to think about issues relating to the rationing of health care as a result of their participation in the focus group, and had therefore had opportunity for both discussion and reflection as recommended in the literature on deliberation.²⁸⁻³¹

Semi-structured interviews were conducted to explore citizen and agent views about health care decision making and rationing in health care. Topics were discussed as they

arose during the interview and covered: the role of the informant and others in health care rationing (in the case of health informants); whether the informant would want to participate in health care decision making (in the case of citizens); who should make choices in health care and why; important aspects of health care; whether the informant perceived health care as being rationed and how such rationing should take place; and whether the informant would want to know about any rationing of their own care. All interviews were tape recorded, fully transcribed using a clear standard based on Poland³² and each transcript checked for accuracy. Analysis used the method of constant comparison.^{33;34} Categories and sub-categories were developed, modified and extended on the basis of emerging themes as the analysis was conducted and detailed descriptive accounts were formed for each informant. Matrices were then used to facilitate comparison and contrast between informants.³⁵ Separate matrices were developed for citizen and health informants and major themes were described across the two groups. Data from the focus groups were concerned primarily with public participation in the rationing process but provided a valuable source of triangulation. Detailed notes relating to the interview-derived themes were made from the transcripts of each focus groups and this information was then integrated into each of the overall citizen and agent descriptive accounts.

This paper presents findings relating to the citizen-agent relationship. The findings do not seek to be statistically representative and cannot be generalised quantitatively. Instead they explore perceptions of citizens and agents about making rationing decisions in health care. Verbatim quotes from informants illustrate the findings. Comments were made during interviews unless otherwise indicated. Ellipses are used to denote missing speech; ‘umm’, ‘err’, ‘you know’, ‘I mean’ and repeats of words which do not add to meaning are removed without use of ellipsis.

Ethics approval for the entire project was granted by two of the relevant three Local Ethics Committees. The third stated that the nature of the project was such that ethics approval was not required. Written consent was obtained from all informants.

FINDINGS

Semi-structured interviews were conducted with 13 citizens and 11 agents between July 1997 and October 1998. Interviews lasted between 30 minutes and one hour 30 minutes. Table 1 contains basic information about citizen and health interviewees. All interviewees (except one agent) had previously attended one of twelve focus groups. Table 2 contains basic information about focus group participants.

Findings are discussed in three sections. The first two examine, respectively, citizens’ and agents’ preferences for use of an agent. The third section explores the current system of decision-making. It should be noted that the views of citizen informants are developed in a very different context to those of the agents. Whilst agents had very extensive experience of health care provision, many of the citizen informants were extremely reliant upon the media for much of their information about health care.

Citizen preferences for use of an agent

Citizen informants spoke extensively about whether they wanted to be involved in health care rationing decisions and very different views were apparent. Three factors appeared particularly important in determining citizens’ preferences for the use of an agent: beliefs

about the knowledge needed for decision making; beliefs about the objectivity needed for decision making and perceptions about how they would feel about denying care to others.

Some citizens felt very strongly that they had insufficient expertise to make decisions whilst others felt that acquiring the necessary knowledge was possible. Further, some informants felt that the expertise that they were able to offer as a citizen would be of value in itself:

As [husband] said, I'm not, we're not qualified, so what right would we have to decide?... it wouldn't be up to me or [husband] to decide, I don't think so.

(Citizen, female, aged 50)

I would be handicapped, in as much as I wouldn't have any really expert knowledge about any particular health situation. (Citizen, male, aged 71)

When I say well look we've made this decision ... because of these facts and if it's clear cut like that then it's easy isn't it, it's not pleasant, but it's easy. (Citizen, male, aged 65)

'I'm a mother with six kids and these are the problems that I've had.' That's what you really want to be hearing from... (Citizen, male, aged 63)

Whilst most citizens suggested that objectivity or neutrality was important for making decisions, there were very different views about the extent to which different groups could be objective. Many citizens felt that members of the public would not be able to take an objective view, that they would have difficulty maintaining a citizen perspective and would revert to a patient perspective. Others, however, were equally (or more) concerned about the lack of objectivity which would be experienced by health professionals:

I think really... the public will take a personal view, but with the... fully qualified surgeon or professor, that's their job so it wouldn't be a personal view... (Citizen, male, aged 48)

I think that decisions like this have to be made by people who are not emotionally involved because as we were saying it's very easy to make these decisions when you're not emotionally involved but once you become emotionally involved you would see a very different perspective (Citizen, female, aged 68)

They wouldn't be able to be objective anyway, you know, the general GP, I don't think they would be able to be objective enough (Citizen, female, aged 62)

The desire to avoid personal responsibility for denying care was apparent among all citizen informants. For some citizens this preference was particularly strong, and among all informants the desire to avoid personal responsibility for denying care was most notable where specific individuals were denied, and, particularly, where specific individuals were denied what was perceived to be life saving care. It was suggested that taking part in the denial of care to others would cause distress to the person denying that care:

It is just so hard to say 'no' to somebody really that's in need of some treatment. If they are going to be terribly affected... and if you're saying 'well we can't offer you that', then you would feel awful if you knew that you were turning that one person down (Citizen, female, aged 29)

... after I've made the decision, even then I'll be still thinking to myself 'should I have done this?' and two or three months down the line, I'll be thinking 'now was

that decision right? ... you know how's it going?' it wouldn't be a case of making that decision and walking away from it. (Citizen, female, aged 50)

I would hate to be in any position to turn to turn a person down ... I wouldn't like to be in that position (Citizen, male, aged 31)

Some citizens were therefore adamant that they would not want to have any involvement in making rationing decisions:

Because maybe I can't cope with it. I think there are some situations in life that you feel you don't want to know about well certainly I've learned this, perhaps its self-protection in a way. No I don't honestly- don't want to be no, no, definitely not, no. (Citizen, female, aged 68)

I wouldn't like the responsibility ... that's just the way I feel, there's no right or wrong I know that, I just don't feel that I could I could make a decision like that. (Citizen, female, aged 50)

Even where citizens were apparently keen to be involved in decision making, strategems were used to avoid or minimise the distress associated with denial, for example by believing that absolute denials of care would not take place even where rationing occurred or by limiting discussion of rationing decisions to those extreme cases where denial of care could in some way be deemed acceptable, for example where care is needed only for cosmetic reasons or where a 'tiny' benefit is achieved at 'huge' cost:³⁶

You are not saying that some people will never get treatment, you are not going to have a list of, now these will be treated, these will never be treated, it is not going to work like that. They will just be lower down in the priority. (Citizen, female, aged 62)

... a choice made between two patients... one could've been a heart problem, the other could be cosmetic, so it's obvious what you do. (Citizen, male, aged 65)

If there's no chance, definitely no chance with one, and there is with the other then you shouldn't really have to make too much of a decision. (Citizen, male, aged 65)

Of all these factors, citizens' perceptions about the extent to which they personally would be distressed by having to deny care to others appeared to exert the greatest influence over whether they wanted an agent to make decisions on their behalf. Those who were most keen to avoid the denial of care were more likely to suggest that health professionals should make these decisions:

It is up to the person to say, or the surgeons, they're there, hands on... they know, the thing is the hospital might not have any day beds, it might have one cancer bed vacant... The same [as] with anything else... when you pays in for the pension or whatever... you don't tell them exactly where you want that money in... after you're 65 you're going to get that pension out, it doesn't matter where you put it in the meanwhile, do you see what I mean? As long as it comes out when you needs it all well and good, you can do what you like with it, and its the same with the National Health Service (Citizen, male, aged 48)

Other informants were very aware that health professionals might also wish to avoid the responsibility for denying care, and made a number of suggestions about ways in which decisions might be made which would avoid the need for any individual to take responsibility for the decisions:

I think it is very difficult to put somebody in that situation because then it would be like they were playing God. And I don't think anybody should be ... put in that situation really because it's a lot to carry about with you isn't it? (Citizen, female, aged 37)

The doctors have got to act like God I suppose at times.... It must be terrible for them. (Citizen, male, aged 73)

Maybe the public can have an opinion on how to structure a criteria ... so instead of being consulted each time they would have some, well it sounds bad though don't it really... (Focus group comment, citizen, male, aged 31)

I would prefer it to be one step back and say that this service would be available/not available on the NHS. (Citizen, female, aged 29)

It goes back to that computer, pressing a button and... it comes out with 'yes' or 'no', well maybe it is easier to use a computer cos I don't know if one individual person could do that (Citizen, female, aged 33)

Set a computer to it, the machine could do it for you, you gotta take away the emotion (Focus group comment, citizen, male, aged 63)

Yet others felt that citizens should be directly involved in decision making:

I don't want to see a group of so-called professionals sitting down and doing it. I think it has got to be something that is arrived at by rather more consensus than that. (Citizen, female, aged 62)

In summary, there appear to be three main factors influencing the desire of citizen informants to 'employ' an agent to make societal rationing decisions: knowledge, objectivity and the potential for distress to result from involvement in the denial of care. The three factors tended to be aligned within individual informants, so that those who were most distressed by the potential denial of care were also those who felt that it was difficult to not become emotionally involved in the decision and that they had insufficient knowledge to be involved.

Agent preferences for use of an agent

Remarkably consistent and clear views emerged from the agent informants concerning the extent to which citizens are perceived to need to 'employ' an agent for health care decision making. Most informants suggested that members of the public do not have sufficient expertise to take part in decision making:

It's very difficult for them to grasp the complexities of health services because any group of people you get together... you're talking about things which by and large they have very little experience of... they get very quickly befuddled, bemused. (Agent, female, aged 47)

I wonder how the people think that they're going to participate in top level decisions except at a sort of extremely general way. Because in order to understand the issues you have to read and listen to an enormous amount of stuff. (Agent, male, aged 70)

The whole problem about information and its availability, how you make judgements, which even the experts haven't got a reliable way of doing so how on earth you can expect consistent views from the public, you can't. (Agent, male, aged 62)

Similarly, most agent informants were concerned about the problem of lack of neutrality among the public. They suggested that citizens essentially comprise patients with vested

interests, concerned only with those issues which affect them directly. Whilst emotional involvement was perceived as justifiable for patients, it was not considered so for making decisions at a societal level:

And if they do come to the public meetings it's because they are part of a pressure group that wants their particular disease put to the top of the priorities... it won't be Joe Public who's interested in everyone's health. They'll be there for their own disease. (Agent, male, aged 44)

People complain... when they have a personal interest. And that's fine. But that means there is an emotional interest. People don't sit there on the train going to work and think 'I think I'll write to the Health Authority and complain about their policy on beta interferon' out of the blue... that just doesn't happen. (Agent, male, aged 39)

Hence this group saw a very definite role for the agent in making health care decisions on behalf of society:

I think it's got to be made by those with the knowledge and I won't say the experts, so it's got to be the medics, public health, the academics... and I think it has to be shared explicitly in terms that everybody would understand with the general public. I don't think [the public] can by and large make the rationing decisions. They can't possibly... I don't think they can make the decisions. (Agent, female, age missing)

It's a collective decision making process, that is very complicated. I guess we set up structures that allow others to make those decisions for us. Other examples are schools, you could think of a whole range of examples where you say, 'I don't know we don't know. We haven't got the time, sort it out'. (Agent, male, aged 39)

although there was some awareness that the decisions made by any agent would only imperfectly represent the views of citizens:

All of us do our damndest to try and achieve what we believe is in the best interest of the local population. I really do think we all try and do that, but recognise that what we think... is in the best interest of the public, may not always be what the public thinks is their best interest. (Agent, male, aged 62)

Current health care decision making

Among the entire 'agent' group of informants it was indicated that the health authority currently takes the main role in acting for the local population/citizen/society, ideally taking objective decisions on society's behalf:

I would see it as a role that [the health authority] have, to have a wider perspective... (Agent, female, aged 35)

One of the key issues is about trying to be as objective as possible and avoid making decisions on an emotional base. (Agent, male, aged 39)

Even as health authorities attempt to make those initial objective societal decisions, however, a number of obstacles intrude suggesting that they are limited in the extent to which they can act entirely as agents for citizens. Perhaps the most important is that the health authority has a dual accountability which additionally involves acting for the Secretary of State for Health. Although some discomfort was expressed at this dual accountability (particularly given the perception that politicians are primarily concerned with their chances of re-election), it also provides the health authority with one means of avoiding total responsibility for decisions:

There are all sorts of problems about pretending that an individual health authority can make significant changes to what is being dictated from above, it's all an illusion. (Focus group comment, agent, male, aged over 50)

Because of the system of finance, it is a national service, it is financed by parliament through the Secretary of State, clearly it has got to be accountable through the Secretary of State. And I find that absence of local democracy and the national accountability a rather uncomfortable position. (Agent, male, aged 62)

Politicians on the whole are very bad at accepting responsibility for unpleasant things. Because they know that next time, people being irrational are going to vote against them, they may have imposed it because it's the only thing to do, but people are going to blame them. (Agent, male, aged 70)

There's no point, I don't think, in holding on so strongly to principles, that you get your head chopped off... So is it better to say 'well, we'd like to do that but we can't. So lets try and do something firstly that doesn't go against that direction and, ideally, takes us at least part of the way there' and then try and move the debate on in stages. (Agent, male, aged 39)

Politicians, however, are not the only obstacle which the health authority faces in acting for society. Others include clinicians (particularly shroud-waving clinicians), the Trusts, pressure groups and general practitioners. Each of these 'vested interests' influences the decisions that are made by the health authority as societal agent, generally by introducing emotion to decisions:

Consultants would prefer to do life saving operations that they see as medically urgent... we would expect the doctors on medical committees, directors of public health, to be advising the Health Authority... there is a route. And we recognise that and not infrequently, the clinical directors will be involved in purchasing new things... a lot of us have met with the purchasers, we've sat down and discussed what things should be advised. (Agent, male, aged 44)

A lot of it from, particularly clinicians, is around the individuals who are individuals, not the aggregate individuals, but it tends to be presented as this is life or death, the classic sort of shroud waving types. And unfortunately we do... give in to them. We give into it, because it's a feature. We allow that to influence our decisions, perhaps more than we ought to. (Agent, male, aged 39)

These obstacles, then, interfere with the role of the health authority as agent for the citizen. Equally important, however, is the subsequent dilution of the impact of decisions as the somewhat theoretical, societal choices of the health authority are translated into practical decisions and, frequently, reinterpreted at lower levels within the health care system. This dilution of decisions is carried out with the implicit collusion of the health authority, with informants from this group suggesting that difficult decisions are deliberately passed from one group to another:

And then occasionally things come out like [treatment]. And [trusts] say 'we must have more money to deal with this' and our response is... usually 'if you clinicians think that this is a better way of using your resources you have at your disposal than something else you're doing then, by all means, do it'. So we pass the buck... (Agent, male, aged 39)

We don't say to the [clinicians] you may not prescribe [treatment], what we've said is we are not able to provide additional funds for the [clinical] service in recognition of the increased costs that would arise if you did prescribe [treatment]... But if you can do it within your budget, that is your business not ours. (Agent, male, aged 62)

The first dilution of decisions occurs at trust level. Trusts appear to reallocate the funding that they receive according to a set of priorities that do not necessarily match the objective societal health authority decisions. In particular, reallocation of resources towards 'life saving' care appears to occur. In essence, this reallocation realigns priorities away from the view of the 'objective citizen' and towards the view of the emotionally involved, where the greater emphasis is on saving the lives of individuals at all costs. Such reallocation reduces the distress associated with denial that falls on any one group: the health authority "fudges" and passes on the final decision to another group, whilst the trust board alters the decision of the health authority so that the perceived harm of the decision is reduced.

For many years [the health authority] wouldn't fund an adequate level of support for [illness]... And for many years we were having to use funds from elsewhere to support [patients] who should have been paid for by [the health Authority]. (Agent, male, aged 70)

What happens is you transfer money in as legal a way as possible... all hospitals do it... especially if you've got an acute service where people are dying. (Agent, male, aged 70)

The trusts will always develop services they want to develop. Whether we pay for it or not. The money seems to appear from somewhere. (Agent, female, aged 47)

The health authority's but one grouping in a whole constellation of them. We don't make the real decisions about where the money gets spent. The individuals it gets spent on. That's a matter for the trust. (Agent, male, aged 39)

The second stage of dilution occurs with the trust management. Managers responsible for the day to day running of services weigh up the requests of different groups and balance their interests. They have to contend with the narrower perspectives of those who bring pressure to bear on behalf of their individual patient groups and, as with the trust board, the emphasis is on always treating the urgent:

...the manager saying, 'I'm sorry, we're all faced with those exact same problems, we all have to cope with how to do our best, you have to prioritise, you have to do those patients that are the emergencies and the urgents, and yes other people may well have to wait a bit longer for your services, but if they are not the priority then unfortunately, those are the facts of life.' (Agent, female, aged 35)

The third level of dilution happens as priorities are reinterpreted by clinicians. Here the doctor-patient agency relationship is important, with the clinician aiming to do the best for the patient within the available resources, yet also attempting to meet their own objectives, including avoiding the distress which might result from having to deny the patient – particularly having to deny life-saving treatment:

A nurse or a doctor is there to care for an individual and do everything that is necessary. (Agent, female, aged 35)

The Government give you the resources, you have your own personal, professional satisfaction, quality standards. And with those two together, you do what you can for the patient. (Agent, male, aged 44)

And of course there's also the great hope, and we do know that over the years by trying out new treatments, leukaemias, lymphomas, we now actually do cure people. We haven't got that with lung cancer but perhaps the new combination of chemotherapy might work. If you keep trying. And that's undoubtedly one of the doctor's motivations... (Agent, male, aged 44)

One of the tests I run... we've got a long waiting list. The waiting list is going up and I have had to tell the referring clinicians 'don't refer so many or else this is just going to grind to a halt'... what they probably do, though, is not tell the patient 'no, you can't have your [test]', it's just that they don't refer so many patients for the [test]. The patient wouldn't know it was an appropriate test...(Agent, male, aged 44)

I personally and I think most doctors believe it's terribly important that when they sit down in front of the patient or stand by the bedside that that patient can have confidence that they will do their very best for that patient... so I think that it's not at all helpful to that sort of relationship for Doctor Bloggs to say to me 'well I'm sorry but you know I had Mrs Jones in before you and she got the last lot for dialysis this year so you're not gonna get dialysis because I can't afford to pay for it' I think that's very different than saying 'well I'm sorry but you know there has been a decision that only so many patients can be put on dialysis and unfortunately the list is already...' (Focus group comment, agent, male, aged over 50)

Whilst decisions are made by the health authority and are acted upon by the trust boards, trust management and individual clinicians, the health authority does not directly send patients to hospitals. This role is carried out by GPs who, like the hospital doctors, perceive themselves as advocate for the patient within an awareness of resource constraints. A 'subliminal' threshold is determined by the final decisions that are made in the hospital setting, in turn, based on the constrained and diluted decisions of societal agents:

IN2: ... I suppose it is kind of subliminal really isn't it?... it is very interesting if you ask GPs about what they want to improve in the health service then quite often to begin with they are stuck for an answer because you get used to working within a certain set of constraints and I guess that actually applies. After all most rationing in the NHS is not explicit and it is all through sort of waiting lists, and therefore GPs basically just have got used to working with that so if you've got a patient who you think needs referral, then obviously it's in, very much in the back of your mind that there is a very long waiting time to see a consultant and that might influence whether you make a referral or whether you decide to leave it a bit longer or explore some other avenues that might be open to you... (Agent, male, aged 41)

The current process of decision making can be conceptualised as a system of equivocation. Although economists would assume that the health authority acts as the agent for citizens, making decisions on an objective basis, in practice decisions are the result of a complex set of interactions in which there are a number of obstacles that mean

that initial decisions are not made purely on the basis of citizens' preferences. This is followed by the dilution of decisions by those who are increasingly concerned with, and influenced by, patient preferences (justifiably 'emotional') rather than objective societal preferences. At all levels of the decision making process, agents are keen to allow decisions to be passed onto other levels of decision making, a process which can be explained by the attempt to avoid the distress, or disutility, associated with the denial of care. The inevitable result of this process of decision making is that the choices eventually made on the basis of the GP's 'subliminal' threshold may bear little relationship to societal objectives, or even to the health authority's interpretation of these objectives.

DISCUSSION

The findings of this research suggest that there is no clear citizen-agent relationship in the same way as there is a clear patient-doctor agency relationship. Instead a system of equivocation appears to result, in large part, from attempts to avoid the disutility associated with denial,^{37; 38} in which all collude to minimise any distress arising from the responsibility for denying care. The ultimate impact of decisions taken on an explicitly societal or citizen basis may be relatively small and any 'agency relationship' is produced only by default through interactions across the health care system. Specifically these interactions are those between the health authority, the political system and pressure groups at the time of decision making; the dilutions of the health authority's decisions as they come to be implemented; and the creation of the general practitioners' "subliminal threshold". A variety of mechanisms are used to enable decisions to take place whilst minimising the associated disutility including the "fudging" of decisions, the expectation that resources will be reallocated as decisions get closer to the patient (and particularly reallocated towards life saving treatments), the use of contracts or guidelines set at higher levels to justify decisions once those closer decisions are reached and the implicit alteration of thresholds of need (the latter occurring in a similar manner to that noted by Aaron and Schwarz in the early 1980s^{39; 40}).

Previous work on the citizen-agent model has been extremely limited and has tended to stop at the suggestion that the role of agent for the citizen should be taken either by health policy makers, administrators or politicians.^{7; 10} Here a model has been developed of the current 'citizen-agent' relationship in the context of one UK health authority. Whilst the model is unlikely to be directly generalisable to other situations, given differing financial and organisational contexts, the motivations of health care decision makers in other cultures may be similar. It should also be noted that the empirical work was undertaken at a time of change to the UK health system and, as roles and responsibilities alter, the exact model developed may need revision: in particular, as GPs take a greater role in commissioning, they may become the main societal agents – although this of course poses difficulties for the group in relation to their other role of advocate for the patient. One solution to this issue was suggested on a number of occasions by clinical informants: the use of national frameworks within which clinicians would take decisions.

Perhaps the most important question in relation to modelling the citizen-agency relationship is whether agency is a helpful concept. Here, the concept of agency was

found to be a useful starting point for the research although the system of equivocation developed suggests that, currently at least, there is no obvious single agent for the citizen in health care. Agency may be a useful concept to pursue (it was, for example, alluded to among both citizen and agent informants) but trying to identify a single 'agent' may be futile. This difficulty, however, suggests that complex fee schedules such as those advocated in the mainstream economics literature would be almost impossible to develop.

It is interesting to note that agents concentrated on poor information and lack of objectivity as reasons why citizens should not directly take societal health care decisions. Although these issues were important amongst at least some citizens, it appears that avoiding the distress of denial is of equal or greater importance. This latter fact may be significant in policy terms in relation to maximising citizen preferences. For patients, the informed decision making approach has been advocated as a means of sidestepping the high informational requirements of the agency relationship, in particular by avoiding the need for doctors to have information about individual patients' utility functions.⁹ For citizens, however, if a large part of the desire for an agency relationship results from the wish to avoid responsibility for decisions, such an approach would be unhelpful.

Avoiding the disutility associated with the denial of care also appears to motivate societal agents. The findings of this research suggest that attempts to avoid denial disutility are made by health authority members, trusts and management as well as by doctors. Even if a single citizens' agent was explicitly put in place, this research suggests that the role would be unsuccessful unless it was also possible to avoid the disutility associated with denial.

Although the system of equivocation provides a means by which the rationing dilemma can largely be avoided by decision makers, there must be questions about whether this system is sustainable in the face of increasing constraints and the greater conflict that will inevitably ensue. Given the preferences of both citizens and agents for avoiding denial, however, even if it is not maintained in its current format, it could be predicted that some form of equivocation will continue to form a large part of any future decision making model.

Table 1. Basic socio-demographic information for interviewees

	Citizens (n=13)	Agents (n=11)
Number of females	7	5
Median age (range)*	50 (29-71)	45.5 (30-70)
Informants aged:*		
25-44	4	5
45-64	5	3
65+	4	2
Route by which informants were asked to participate in focus groups:		
Key informants	1	11
Random sampling from electoral roll	7	0
Selection from interest groups	5	0
Occupational status:		
Full time employment	2	6
Part time employment	2	2
Unemployed	1	0
Self employed	0	1
Retired	6	2
Other	2	0
Age of leaving full-time education:£*		
16 or below	6	0
17 or 18	3	2
Over 18	3	8
Health service employment:		
Previous health service employment	1	
Current health service employment	2	
Health service role:		
Treating patients		4
Management		3
Decision making at board level		4
Health service use in previous year:*		
GP visit	11	6
Outpatient visit	4	3
Inpatient stay	0	0

£ Data missing for one citizen informant

* Data missing for one agent informant

Table 2. Socio-demographic details by focus group attended

Type of group	Number in group	Number of females (males)	Median age (range)	Number employed full-time	Number having worked in the NHS	Median age at which left full-time education (range)	Number having seen a GP in last twelve months	Number with out-patient appointment in last twelve months	Number having stayed in hospital in last twelve months
Citizen groups									
Working class random	9	3 (6)	42 (31-73)	2	1	16 (14-21) ^c	7	4	1
Middle class random	8	5 (3)	62 (29-66)	2	3	17.5 (14-23)	8	3	0
Pilot group	9	7 (2)	35 (30-48)	7	9	23 (18-32)	9	1	0
Health interest group	8	6 (2)	50 (39-58)	4	3	18 (16-24)	7	3	1
Non-health interest group	2	1 (1)	(a)	0	0	24 (21-27)	1	1	0
Non-health interest group	9	3 (4)	63 (51-76) ^b	0	2	15 (14-17)	7	4	1
Elected representatives	5	1 (4)	59 (54-67)	1	1	18 (14-22)	4	0	0
Agent groups									
Group 1	7	7 (0)	46 (35-51) ^a	6	7	19.5 (16-21)	6 ^a	0 ^a	0 ^a
Group 2	7	3 (4)	62 (55-67)	0	4	18 (14-24)	6	2	0
Group 3	3	0 (3)	41 (41-43)	1	3	24 (24-24)	0	0	0
Group 4	8	2 (6)	53 (39-70)	4	6	22.5 (15-25)	5	2	1
Group 5	4	0 (4)	45 (40- >50)	4	4	23 (23-26)	1	1	0

a Data missing for one informant

b Data missing for two informants

c Data missing for one informant (teacher)

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