Patient de-registration from GP lists: and professional and patient perspectives

Final report to the Department of Health

An independent research study carried out by the Medical Care Research Unit of the University of Sheffield, on behalf of the Department of Health. The views expressed are those of the authors and not necessarily those of the Department of Health.

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1. EXECUTIVE SUMMARY

General practitioners working for the NHS have always had the right to remove patients from their list. For many years this appears to have been an uncontroversial arrangement, but during the 1990s became a matter of public and political concern. In the 1997/98 report of the health service ombudsman, a Wigan GP was criticised for removing three households from his list when only one removal appeared justified. In 1999 this report was considered by the Select Committee on Public Administration of the House of Commons, which expressed concern that little information was readily available on the number of removals occurring, or the reasons for them.

Accordingly, research was commissioned to determine the scale and reasons for doctor-initiated patient de-registration in England, and to describe professional views on issues relating to de-registration.

We report here the results of a study which included the following elements:

- semi-structured interviews with ten representatives of professional and patient organisations;
- a postal survey of a national sample of 1,000 general practitioners;
- a postal survey of 104 health authority IT directors;
- analysis of the routinely available data from six health authorities;
- a postal survey of 207 GPs and 338 patients with recent experience of removal.

We have estimated the incidence of removals in England to be 4.3 per 10,000 patients per year, a figure which is close to that of 4.8 per 10,000 patients per year reported from Northern Ireland.

There is no strong evidence from health authority data that this rate is either rising or falling. However, the routinely available data frequently fail to distinguish between patients removed at the doctor’s request and those removed because they have moved from the practice area. There is evidence that this rate varies between health authorities and between individual practices with health authorities.

According to GP reports, violence, threatening or abusive behaviour is by far the most common factor leading to removal, being a primary factor in 59% of cases and a contributory factor in a further 8%. Much of this behaviour is abuse, rather than violence, and much is directed at practice reception staff. Refusal to accept childhood immunisation or cervical cytology is reported as prompting removal only very rarely, both by doctors and by patients.

In many, and perhaps most, cases the removal follows a period during which the relationship between doctor and patient – or between practice and patient – is under strain, and the removal represents a final step in a sequence of events. Patients are frequently as distressed or angered by the process as by the fact of the removal, and may not know why they were removed, may have difficulty in understanding any reason which has been given, may face
difficulties in re-establishing regular contact with a primary care service, and may experience lingering anxiety or insecurity in their relationships with health professionals.

There is therefore a case for considering whether the process of removal might be improved in ways which avoid such outcomes whenever possible, whether or not removals can themselves be avoided. We suggest a range of possible improvements which might be made, including:

- A good practice guide on removal, published or endorsed by key stakeholders and widely disseminated;
- A review of deduction codes and coding practice in the Exeter system;
- Annual review of the number of patient removals from each practice by the local primary care organisation;
- Locally agreed arrangements for the care of repeatedly removed patients;
- Locally agreed arrangements for the care of violent patients, in accordance with existing guidance;
- A clear written explanation of the removal decision to all patients, unless there is a compelling reason not to do so;
- Routinely provided information on what to do after removal, and access to a local source of information and advice for removed patients;
- Information for new patients on how to use services appropriately;
- Additional support or training for reception staff on handling abusive or threatening patients.
2. INTRODUCTION
National terms of service for general practitioners contracting with the NHS have always included the provision for doctors to remove patients from their lists.¹ This has generally been regarded as an important safety-valve for a service which depends upon a close and trusting relationship between doctor and patient in order to function effectively. The terms of service do not require the doctor to provide a reason for the removal to either the patient or their local health authority.

In the 1997/98 report of the health service ombudsman, a Wigan GP was criticised for removing three households from his list when only one removal appeared justified.² In 1999 this report was considered by the Select Committee on Public Administration of the House of Commons, which expressed concern that little information was readily available on the number of removals occurring, or the reasons for them.³ Although national statistics are available, these do not distinguish between patients removed after moving out of a practice area and those removed for other reasons.⁴ Nor are the available statistics able to supply any reasons for removal beyond identifying, since 1994, those removed immediately because of an “act or threat of violence”.

The committee recommended that the statutory terms of service be amended to restrict such removals and to ensure that “an account be provided to the patient of the reasons for the removal”. In addition, it recommended changes to the terms of service to require that “information be provided to the health authority on the reasons for the removal of any patient not moving out of the area”, that the authority would have to approve the removal, and that patients should have a right of appeal against the decision. These recommendations were opposed by the General Practitioners Committee of the BMA.⁵

In the light of the scarcity of information available on patient removals, the Select Committee also asked the then chief executive of the NHS, Sir Alan Langlands, to commission research on “the scale of and reasons for patient de-registration by GPs in England”. This research was undertaken by the Medical Care Research Unit and we report here the results.

2.1 Policy background
A general practitioner working in the NHS provides care to a defined list of individual patients who have “registered” with that doctor, and has the right to ask for a patient to be removed from their list under paragraph 9 (paragraph 7 in Scotland) of their national terms of service. The health authority must be informed of the request in writing and the removal normally takes effect eight days after the request is received by the health authority.

In 1994, in response to concern over apparently increasing levels of violence towards GPs, the terms of service were amended to allow immediate removal of patients who assault, or threaten to assault, a GP. From 1 April 1994 the new provision (paragraph 9A) allowed a GP to request immediate removal where “the patient has assaulted the GP, or has behaved in such a way that the GP has fears for his or her safety, and the GP has made a complaint to
During the early 1990s the issue of patient removals by GPs became a matter of some public and media concern, in the context of two significant changes in the economic context of general practice: the 1990 contract, and the introduction of fundholding in 1991. The former introduced new obligations, including the requirement to offer annual examinations to patients aged 75 or over and target payment schemes for childhood immunisation and cervical cytology. The latter required fundholding practices to constrain spending on certain services within a fixed budget. These developments introduced a “perverse incentive” to remove certain patients — such as those refusing immunisation or cervical cytology, or incurring high costs to a fund holder’s budget — from a doctor’s list for reasons other than breakdown of the relationship. Although these incentives were widely recognised and debated, there is almost no evidence available on whether they led to changes in GP behaviour.

Nonetheless, media and political speculation that doctors might remove patients from their lists for essentially financial reasons was encouraged by anonymous statements by some doctors that they removed patients they perceived as “high demand”. One MP claimed in Parliamentary debate that “the increase in the number of patients who are being struck off doctors’ lists will continue” as a result of these incentives. The Royal College of General Practitioners responded by issuing guidelines on the removal of patients, which made it clear that “an exacting, or highly dependent patient, condition or disability” never justified removal. It also suggested that doctors should normally provide removed patients with a reason, and this echoed similar guidance to GPs from the General Practitioners Committee of the BMA. Although interest waned thereafter, possibly as a result of the ending of the fundholding policy, the issue resurfaced as a matter of concern during 1999, at the time of the Select Committee’s deliberations, with speculation that patients are removed because they have mental health problems, refuse childhood immunisations or are “uncooperative”.

2.2 Existing research

Given the long-running concern in this area, it is surprising that there has been so little research to identify how many removals occur, the factors underlying such removals and whether the rate of removals is changing. A search of six bibliographic databases identified a small number of studies in this area prior to this project.

2.2.1 Epidemiology of patient removals

Two studies based on routinely collected administrative data on removals have attempted to quantify removal rates over time and by patient characteristics. O’Reilly et al concluded that removals in Northern Ireland were “relatively rare events for both patients and practices”, but had been increasing in recent years, and more so in fundholding than in non-fundholding practices. Munro and Skinner undertook a similar study in Sheffield, covering a shorter period of time, which also found that “removal from a doctor’s list was a rare event”, but that removal rates in Sheffield were not increasing.
Interestingly, the overall removal rate for non-movers in Sheffield (16 removed persons per 10,000 registered patients per year) was considerably higher than that reported from Northern Ireland (4.8 per 10,000). Routinely collected data from Scotland gives an intermediate figure of 11 per 10,000 per year.”

Both studies found marked variation in removal rates for different patient age/sex groups and for different practices. In both studies removal rates were relatively high for children (0-10 years) and for young women (20-29 years) and to a lesser extent young men. While removal rates increased over the age of 70 in Sheffield, this was not seen in Northern Ireland. Both studies found an association between removal rates and population deprivation. Neither study examined changes in age-sex specific removal rates before and after the introduction of the 1990 GP contract.

These findings are also consistent with a small study of removals based on routine data collected in the Lothian health district over an eight month period.”

2.2.2 Reasons for patient removals

Four studies of the reasons GPs give for removing patients have been published, in addition to our own findings from this research. Two of these are studies in which doctors were asked about hypothetical situations or events which would prompt them to remove a patient, and two are studies which ask about recent actual events which did result in a patient removal.

In the former category, Perry wrote to all 97 FHSAs in England and Wales, of whom 35 replied, and found a modest increase in removals during 1990-94, with removal rates per GP higher in urban than rural areas. She also asked GPs in Kent why a doctor might deregister a patient. The commonest reasons given were violent or abusive behaviour, “inappropriate use of services”, loss of trust and persistent non-compliance.

Similarly, Cummings and Young asked GPs in Newcastle and North Tyneside about situations which might prompt removal. They found that 79% of respondents cited violence, rudeness or antisocial behaviour as the main reason for removal, followed by “breakdown of relationship” and “abuse of services”.

In the latter category, McDonald et al conducted a telephone survey of 89 GPs who had removed one or more patients from their list during a three month period. Excluding those removed because they moved away, the commonest reasons for removal were “unreasonable requests for medication” (mostly for addictive drugs), “unreasonable requests for home visits”, and “threatening or rude behaviour to doctors or staff”.

A fourth study, of reasons given by GPs for their most recent removal, was published as this report was being completed and is considered in Chapter 5, below.

2.2.3 Removal process and patient views

We are aware of only one study which has examined the processes of removing patients in any depth. This study also sought the view of patients as well as of GPs, through semi-structured interviews and a postal survey to recently removed patients, and described the
often complex stories leading to patient removal, and the reactions of patients. The detailed findings are considered alongside our results in section 7 below. Overall, the report’s authors concluded that current policy on patient removal was “both anachronistic and unfair to some patients and to general practitioners and other primary health care professionals”.

In addition to the research identified above, an account has also been published of difficulties in carrying out research into the removal of patients with psychiatric illness, which was abandoned following lack of support from local health authorities.11
3. RESEARCH DESIGN

3.1 Research aims and objectives

The aim of the research reported here was to determine the scale and reasons for doctor-initiated patient de-registration in England, and to describe professional views on issues relating to de-registration.

The research focused only on de-registrations initiated by the doctor, rather than the patient, and only on those occurring without the patient moving from the practice area. We have noted above that the routinely available statistics do not make a clear distinction between removals where the patient moves from the practice area, and those where they do not.

The more specific objectives of the research were:

1. to estimate an overall de-registration rate for England;
2. to determine the views of GPs, professional bodies and health service user representatives on issues relating to de-registration;
3. to describe, in a small number of English health authorities, the epidemiology of de-registration, including variation in rates by patient age and sex, urban/rural location and population deprivation;
4. to examine the possibility that removal rates in specific groups have been influenced by incentives such as those introduced by the 1990 GP contract;
5. to identify whether any routinely recorded practice-level or population-level characteristics are associated with de-registration rates;
6. to seek the reasons for de-registration from the GPs of a sample of recently de-registered patients.
7. to obtain an account of the processes of de-registration, from the point of view of both doctor and patient.

The research was designed to achieving these objectives while maintaining the confidentiality of both doctors and patients. Ethical approval for the study was granted by the Trent Multicentre Research Ethics Committee.

The methodological details of each section of the study are reported in the following chapters, along with relevant results.
4. VIEWS OF PROFESSIONAL AND USER ORGANISATIONS

4.1 Introduction
As discussed in the introduction, above, media and research reports on patient removals have raised a range of concerns relating to the frequency, trend, processes of and reasons for removals. While some such reports are anecdotal or hypothetical, others are more soundly based in systematically collected evidence. In designing the research study reported here, we aimed to try to address most or all of the issues previously identified as important.

In order to explore current concerns over patient removals, and ensure that our research could address all important relevant issues, we also interviewed a range of individuals – representing both professional and user organisations – whom we felt would have particular expertise or experience in this area. The objectives of these interviews were

- to identify all relevant issues and concerns, from both professional and user viewpoints;
- to identify any further evidence on patient removals which might be known to interviewees;
- to explore the views of respondents on the causes, processes and effects of patient removals on doctors, practice staff and patients;
- to seek the general support of interviewees for the proposed research.
- to inform the research process, and ensure that the proposed research was comprehensive and addressed the principal questions of relevant organisations.

4.2 Methods
Thirteen organisations representing professional or patient interests in primary care services were asked for their agreement to participate in the research. Of these, one did not reply and two refused to be interviewed. The following ten organisations agreed to participate:

- General Medical Council (GMC)
- General Practitioners Committee of BMA (GPC)
- Royal College of General Practitioners (RCGP)
- Patient Liaison Committee of RCGP (PLC)
- Medical Defence Union (MDU)
- Medical Protection Society (MPS)
- Institute of Healthcare Management (IHM)
- Association of Community Health Councils for England and Wales (ACHCEW)
- Patients Association (PA)
- National Association for Mental Health (MIND)

The Long-term Medical Conditions Alliance and National Association of Patient Participation
Groups did not participate in the research.

We prepared a semi-structured interview schedule, including questions about concerns over deregistration, reasons for deregistration, underlying factors or policy issues, any problems caused by deregistration and any potential solutions (see Appendix 1). Interviewees were asked to respond from their own experience and knowledge, rather than simply state any formal policy of their organisation.

Two interviewers (MP and FS) undertook 5 and 4 interviews respectively during June and July 2000. The interview with the RCGP representative and the PLC representative was conducted as a joint interview. All other interviews took place at the office of the relevant organisation in private rooms with no-one else present.

All interviews were tape recorded and transcribed verbatim. Interview scripts were coded using Winmax 98. Transcripts were read and reread by one of the researchers (FS) to identify the major themes emerging, which were used to structure the summary of the interviews reported below.

4.3 Results

4.3.1 The scale of and trend in deregistration
The interviewees felt that patient removal was a rare event and that the problem of deregistration was "dying down" in general. When asked whether they considered the rate of deregistration to be increasing or decreasing, there was uncertainty: interviewees said they had no actual evidence to show whether the rate had changed.

- It's a problem, but it's a problem more in terms of perception than it is in terms of the numbers and reality of the situation, so my feeling is that it continues to be a very rare occurrence for a GP to remove somebody actively from their list. (BMA)
- I would say it's probably staying about the same or decreasing. I haven't got any figures. (MDU)
- I would say recently, really recently, it seems to have gone down a little. (PA)
- I think it's becoming more common. (RCGP)

Although the problem was acknowledged still to exist, many interviewees felt that removals due to financial incentives had decreased following the media attention and because medical professional bodies had issued guidelines stating that removal for financial reasons was unacceptable.

In contrast to the general perception that removals for financial reasons had fallen, there was a suggestion from the RCGP interviewee that patient removal was becoming more common and was more common in deprived areas, particularly those removals that are due to physical and verbal abuse. The IHM representative also spoke of an increase in violence and aggression within the health service, which may contribute to patient removal.

4.3.2 Main reasons for deregistration
Five of the ten organisations interviewed cited violent or abusive behaviour as a major reason
for removing patients.

I think violence and aggression being number one, there is good evidence of managers, and other members of primary health care team, being particularly abused. (IHM)

I would think the most common reasons are, physical and verbal abuse, probably more verbal than physical…and then probably what was perceived to be excessive demand. (RCGP)

‘Excessive’ demand, or demand for unnecessary treatment or visits was mentioned by three of the professional organisations (MDU, MPS and RCGP) as a common reason for removing patients. The PA representative also considered demand to be the most common reason for removal, but with a change in emphasis from ‘excessive’ demand to justifiable demand.

I think it’s those demanding – quite rightly demanding – treatment. I think demanding is too strong a word, asking for what one should properly expect and it often not being delivered. (Patients Association)

Differences between GPs and their patients over what constitutes ‘reasonable demand’ may be an important cause of stress in the relationship. Patients demanding treatment or appointments they feel they need may be considered by GPs to be abusing the system and making excessive, unreasonable demands.

It happens rarely but it does happen, where a patient abuses the system, doesn’t understand about why a GP can’t drop anything and come out when it’s not an emergency. (IHM)

A breakdown in the doctor-patient relationship for other reasons was also mentioned as a principal reason for removal by four of those interviewed.

The most commonly cited reason I would guess would be the nameless breakdown in the relationship…which covers an impossible multitude of things. (GMC)

In addition, a lack of communication was felt by one interviewee to underpin most removals.

I think that, without a doubt, the most common theme is lack of communication and where the communication does break down. And misunderstanding. Communication and misunderstanding. (PA)

Two organisations mentioned patient complaints against the GP and there was one mention of frequent non-attendance as a principal reason for removal. Neither professional nor user organisations considered financial incentives to be common reasons for removal.

4.3.2.1 Acceptable reasons

All of the interviewees who commented on the acceptability of reasons for removal said that they felt it may be acceptable to remove a patient for violent or abusive behaviour, where the situation could not be resolved.

I think certainly physical and verbal abuse, intimidation of other patients on the premises…harassment, bullying of staff I think is unacceptable. (RCGP)

Other reasons felt to justify removal were deception, stealing or fraud and ‘gross abuse of and persistent abuse of the service after explanations and reasoning’ (GMC).

Again, the breakdown of doctor-patient relationship was mentioned as a potentially
acceptable reason for removing a patient, where communication and trust between the doctor and patient had been lost.

   *It’s quite acceptable to say: well, there is a breakdown in communication, you can’t go any deeper than that, it’s quite difficult to find out really.* (ACHCEW)

### 4.3.2.2 Unacceptable reasons

Interviewees felt that unacceptable reasons for removing patients were mainly those related to cost issues, such as attempting to reach financial targets, or people requesting home births. Removing patients who made high demands of the service was felt to be unacceptable if this was for reasons of cost.

   *I think there are clear unacceptable reasons – like just removing patients from the list because they are high demand, they have lots of drug treatment and they’re always calling, and they don’t see that as legitimate – but I think those are very, very small.* (MDU)

   *There could be issues of, I suppose, cost and time but I mean that’s not really an acceptable reason, lots of conditions involve that and that’s what they’re there for, to provide the people who need it so you know, getting rid of the people who need it, that’s rather perverse.* (MIND)

The subject of patient complaints was a ‘grey area’ where it may be unacceptable to remove people from the list in some circumstances. Although a patient complaint may put a strain on the doctor-patient relationship to such an extent that the GP might feel they could no longer treat the patient properly, there was a concern that GPs could potentially use the threat of removal to prevent patients from making complaints at all. There was a feeling that there should therefore be no ‘hard and fast’ rule about whether patient complaint warranted removal, but that it depended on the individual case.

   *I don’t believe the patient should be removed from the list just because they have complained, but it may be that that’s part of a wider scenario, lots of different factors in it, which possibly may lead to break down their relationship.* (RCGP)

The GMC also cited any type of discrimination as being an unacceptable factor in a removal decision.

### 4.3.3 Removing family members

There was a mixed reaction to the question of whether it was reasonable to remove other family or household members along with the patient being removed. Many interviewees felt that although, in principle, they would be against the removal of other family or household members, there might be occasions when it was necessary.

   *Yes, I think it is reasonable on occasions. Each individual patient is a patient in their own right and I think the default should be that you don’t deregister other people just because you’ve chosen to deregister one, but reality is that those people talk to each other and meet with each other, and sometimes one is threatening about the other, so I think if there is a perception that the GP or his or her staff will come under threat of violence or abuse, and they will either suffer some harm, or fear their patients may suffer because they are not in a position to act normally, I think that is a reason for that removal.* (BMA)
If you take the example of someone who is removed from the doctor's list, for being verbally abusive to staff and other patients in the waiting room, if that person has children who stay on the doctor's list, then presumably they would return to surgery with the children and the situation. So although as a point of principle it would seem unreasonable...when you think about it, there may well be circumstances where it would probably be illogical to do otherwise. (RCGP)

The handling of the situation was recognised as problematic, and removal of family or household members should be a last resort, as 'it is often seen as a much more vindictive and provocative act than just merely removing one patient' (MDU). However, some patient organisations were more strongly opposed to the idea of removing family members.

Simply because someone has had a row – you know, the doctor has had a row with my mother – then why should I be removed when I am perfectly happy, when I see him we get on perfectly OK...But again, it all comes back to, without giving a reason you don’t know. I mean if they do have a problem with the rest of the family and it’s a legitimate problem, for example they are violent and abusive...and you know that’s quite a legitimate reason, they shouldn’t be putting themselves at risk, faced by violence or attack or something, but if its simply because right that’s it you know, I’m getting rid of you, I’m going to get rid of your family while I’m at it, that sort of attitude then I don’t think...you know they really need to have good reasons for doing that sort of thing. (ACHCEW)

I don’t know. It’s a moral dilemma, because of the fact that should someone’s children suffer because the old man is violent? To be honest, personally, I don’t think they should. (PA)

4.3.4 Policy and financial incentives
The user and professional organisations were asked whether they thought there were any incentives or policy issues that might influence the GP’s decision to deregister a patient. There was a perception that there was an incentive offered by the immunisation and screening targets, but less of an incentive due to drug budgets. Both professional and user organisations had heard of people being removed due to targets, but considered this to be a rare event and becoming even more rare, partly due to GPs negotiating with their health authorities to have people removed from the target group, or removing the patient officially but continuing to treat them.

I think it [removing patients due to not meeting targets] certainly has been muted, where you’ve got a cluster of patients who have refused and my experience of that has been, that those patients when they are part of a target group, that the GPs have negotiated with the health authority, to say that this group is not doing this and actually been taken out of the target group. (IHM)

The potential incentive to remove patients in order to keep within practice drug budgets was not considered to be a major problem. Although some interviewees had heard talk of people being removed due to prescribing budgets, many thought this was a theoretical rather than a real incentive. Some interviewees felt that the abolition of fundholding and the creation of PCG/Ts had removed this incentive.

4.3.5 Problems caused by deregistration
The principal concerns of professional and user organisations were focused on the process of the removal decision, from the GP’s perspective, and on the problems facing a patient who
had been removed.

Interviewees from user organisations, in particular, talked about the practical and psychological problems that patients face following deregistration. Patients may be unable to find another practice in a convenient location (particularly problematic in rural areas where there may not be another GP within several miles) and it may still be necessary to see the local GP for out-of-hours services. Little support may be available to patients to advise them on what to do following the removal and how to register with a new GP.

There were also concerns about the stigma attached to being removed and how much the new GP is told about the removal. Although it was considered important to inform the new GP of any risks involved in taking on a new patient, it was felt that notes made in the patient records may affect the perspective of the new GP, who may not be willing to see someone labelled as a ‘problem patient’.

I think that if someone is thrown off by the health authority, and there is inevitably some sort of stigma attached to that, and particularly if that patient is then allocated to another list, rather than finding a new doctor for themselves, then in a sense they're marked, and also if something is put in the medical records of that patient about, I don't know, being thrown off the list, that too can stigmatise the patient. (MPS)

Coming with the idea that they are a difficult patient – being labelled as, you know, a trouble maker – is a problem. (MDU)

A patient who is unable to find a practice which will accept them onto their list may be ‘allocated’ to a practice by a health authority. Such a patient may be kept on the list for a minimum of three months before being moved on to another allocated practice. Some interviewees were concerned that the continual rotation of a small number of ‘allocated patients’ between different GPs would be detrimental to the care the patients receive.

There was also concern that patients may suffer psychologically from the experience of being removed. Feelings of mistrust towards doctors and a reluctance to deal with health professionals might follow such an event.

I think that once you've been struck off, certainly what we found, is that you become very sensitive about your future relationship with any member of the medical profession. And not just GPs but consultants etc. (PA)

Some people clearly have their trust in their GP’s service completely eroded and don't want to have a GP anymore, which is obviously not in their interests. And people are hurt, their feelings are hurt by it sometimes and that’s a problem. (GMC)

Such problems might be relieved or worsened by the way in which the GP or practice communicates with the patient before, during and after the removal.

The process of removing a patient was also seen as problematic for the GP. The professional groups talked of the pressures GPs are under when removing patients and depicted the process as being a stressful, difficult time for the GP.
It would normally require some hand wringing and angst about ending what’s often a therapeutic relationship that’s been there for some time. It’s not just that somebody walks in that you feel…you don’t want anymore. Often these are patients that you have looked after and seen on a number of occasions, so it’s a measured decision. (BMA)

Although both professional and user organisations mentioned the necessity of allowing GPs to deregister patients where the relationship had totally broken down, the decision of the GP as to when they considered the relationship had reached that point was felt to be difficult. The importance of being able to maintain a good relationship with the patient was again emphasised by the RCGP.

Although I suspect that ‘the doctor-patient relationship’ can also be used as a smoke screen, I also believe that a lot of colleagues do actually believe that’s the most fundamental thing, that the relationship, the therapeutic relationship with the patient is absolutely fundamental and where a doctor has got to the stage where they really severely dislike a patient, that professionally it’s in that patients best interests that they’re no longer looked after by that doctor. (RCGP)

As with the patients, the process of patient deregistration was felt to have a negative effect on GP morale.

It can be difficult for people external to the profession sometimes to realise the strains of the personal connection and where things are going wrong, the problems that that causes, both to the doctors and individual and to the relationship, and more widely to the practice… You know, sometimes you can only take so much and I think that entirely legitimate that we shouldn’t underestimate the importance of this to the morale of individual doctors and professions as a whole. (RCGP)

The BMA interviewee spoke of how they considered the amount of press and parliamentary interest to be disproportionate to the scale of the problem. The public and media portrayal of GPs who deregister patients was perceived to be very negative, particularly combined with the more general media culture of ‘doctor bashing’.

Just as patients can choose to move on from GPs, I think doctors should be able to move on from the patient. The trouble is, it’s always seen as the doctor is being vindictive, and the patient is just making proper consumer choice. (MDU)

Throughout the interviews, concerns were raised as to the management of patients with mental health problems who were often considered highly demanding by doctors, yet might need considerable help and support from health services. Access to other supporting services and good communication between services were highlighted as important factors in the management of patients with mental health problems.

There might be boundary issues with other parts of the service. I mean, if the mental health services as a whole, sort of aren’t organised in a way that GPs feel that they’re in a team or whatever, and being supported, or that there isn’t good communication with the rest of the service. (MIND)

I think some of the frustration about mental health problems is making those links with social services and having access to other services, so that the GP can resolve the problem, I don’t say solve it, but resolve it in a partnership with other services. (IHM)
Interestingly, two representatives of professional organisations felt that deregistration need not always be a negative event. The opportunity to start again with a ‘clean slate’ might be beneficial for patients whose care may have been suffering under their previous doctor due to tensions in the relationship.

4.3.6 Vulnerable groups

We asked interviewees to whether there were particular patient groups who might be at increased risk of being deregistered. The main concern was of anecdotal evidence that patients with mental health problems were at risk of removal, particularly those with ‘personality disorder’ who may be seen as highly demanding.

I think those who are, in inverted commas, a ‘nuisance’ to GPs in some way. So those who have chronic multiple problems who may have some sort of dysfunctional personality and may be extremely demanding and eventually these are the sorts of patients that GPs find they cannot go on looking after, those who demand prescriptions, sick notes, those sort of things. (MDU)

The idea that patients with mental health problems were at increased risk of being removed was opposed by the BMA interviewee, who felt that doctors ‘do not tend to remove mentally ill patients’.

There was also concern by some interviewees over the removal of patients with chronic conditions that require expensive treatments, particularly elderly patients.

Patients who have a chronic illness which requires a lot of attention may be struck off, patients who are deemed to be expensive, I’ve certainly come across that with kidney patients, who are approaching end stage renal failure. (PLG)

From the survey that we did…it was sort of people with mental health problems…Elderly people, probably because there were difficulties in communications and to an extent I think elderly people, I think it was because they felt that at that time particularly GP fundholding was too expensive for the budgets for the practices. So, if they needed a lot of care or they needed a lot of home visits, that type of stuff. (ACHCEW)

Other organisations had heard reports of removals of ‘expensive’ patients in the press, but did not consider it to be a major factor in removal.

I think there will be the odd incident of that [expensive patients] that will no doubt be reported and picked up through the complaints process, but I don’t believe that happens on anything other than a minute scale. (BMA)

No, I mean the cost issue I was never too convinced of. (PA)

Another group of patients suggested as vulnerable to removal were those who did not comply with the treatment or advice of their GP. This group included patients who were highly vociferous, asking questions and demanding certain treatments, and also those who complain a lot about treatment or advice given. Mothers with young children were mentioned as being at particular risk, on the basis that they might disagree with the doctor over home birth, immunisations or other aspects of how to manage their children’s care.
I think the more vociferous the group in terms of perhaps young, female… we tended to get a lot of women from probably about the age of 25 to 40 who were seen to ask questions, quite rightly, and then got the obligatory letter from the health authority saying the doctor doesn’t want to see you any more. (PA)

I think also patients who don’t comply with advice or treatment, again if you can categorise them as a group, but I don’t think necessarily they slot in easily, but I think that again may cause problems with individual doctor/patient relationships. (RCGP)

The RCGP interviewee also suggested that substance abusers are more likely to be removed.

Substance abusers, particularly drug abusers, who – rightly or wrongly – are perceived as being manipulative, devious and untruthful and often criminal in their behaviour. (RCGP)

4.3.7 Reason giving

Interviewees were asked whether they thought GPs should be contractually obliged to give a reason to the patient and/or the health authority. All groups were strongly in favour of the GP giving the patient a reason but there were differences over whether this should be an obligation, and whether there should be exceptions when a reason need not be given.

Three interviewees (from ACHCEW, MIND, PA) felt that the GP should be contractually obliged to give a reason, with no exceptions. There was a feeling that if the GP had reason to remove the patient from the list, they should be able to tell the patient, and that removing patients without giving a reason was unhelpful to the patient.

The key thing to it is that people were fed up because of the fact that they hadn’t been given a reason for being struck off and that’s what really, really pissed people off. (PA)

People with mental health problems get lots of rejections and, you know, getting rejected by your GP, it’s a pretty powerful statement really and you may, if you didn’t know – if you’d gone in and torn up the surgery then you’d have a clue – you may not either know exactly what it’s about or you may be briefed up to what you think it might be about, and more of what you’ve been told about, so I think it’s only fair basically that the reason should be given. It ought to be a fairly substantive reason. (MIND)

Some interviewees felt that being given a reason and an explanation why they had been removed could have educative value for a patient, and allow them to reflect on and alter their behaviour in future.

I think if the reasons are the patient’s behaviour, in one way or another to do with the use of the service or a practice, or the way they conduct themselves, and the way that maybe they don’t perceive that they are doing anything wrong, then it’s very important that an explanation is offered very early on. But not turning up for an appointment, or swearing or spitting in the waiting room or whatever, that they might regard as normal, is not acceptable or is upsetting other patients…and I think we would see it in most circumstances patients either they need to know so they don’t go and do it all over again to somebody else, if they can stop themselves, and that they have at least been given the courtesy of an explanation. One of the things that upsets people is that they sometimes just don’t know what it is what they’ve done. And they’re bewildered by it. (GMC)
The interviewee from MPS also felt a substantive reason should be given, and not just that the ‘relationship has broken down’, as it was important to say where and how trust had been broken. This interviewee felt that giving a reason was almost obligatory already, given the amount of guidance and the complaints procedures.

*Because with the RCGP-type GP guidelines, with the attitudes of the ombudsman, with a terms of service requirement to comply with the NHS complaints procedure, which does not restrict itself to the strict terms of service requirements, I think you would have to say that a doctor who failed to give an explanation, probably has failed to comply with the NHS complaints procedures and was therefore in breech, so I think you might as well make it express and say, you know, where a doctor was removing a patients from a list, an explanation must be given.* (MPS)

Interviewees from the MDU and GMC also argued that a reason should always be given, but were not in favour of making it a contractual obligation, because exceptional circumstances might arise in which provision of a reason might be harmful. The BMA interviewee, although strongly in favour of reason giving, also felt that it should be voluntary rather than contractual.

*No, I don’t think we should need contractual requirements. I think it’s the profession’s policy – the BMA, GPC and the RCGP – that patients are advised of the reason.* (BMA)

There was disagreement over the level of detail which should be provided as explanation for removal. While some interviewees felt that full details should be given, others felt that the level of detail should depend upon the reason, and that just saying the professional relationship had broken down may be appropriate in difficult circumstances. Several groups recognised the need for any explanation to be carefully set out and given in a sensitive manner, often by letter.

*I think there may be degrees of explanation, and I think it would be sufficient for a GP to say that the relationship has broken down to such a point that they didn’t feel confident in treating this patient, rather than go into the detail of specific patient conditions.* (IHM)

There was also disagreement on whether the local health authority should be told the reason. While some interviewees thought this would be appropriate and could be used to monitor or audit removals, others felt it would place patient confidentiality at risk.

4.3.8 Underlying factors

Some interviewees mentioned other factors that they thought might influence removal decisions. Two talked about the stressful environment in which GPs work, suggesting that short consultation times and a lack of time more generally may influence their ability to cope with certain situations.

*I think the most important factor is likely to be stressed overworked staff and GPs – morale is a factor obviously, but I think it’s usually a communication problem and it’s usually because people don’t have the time or the training, or the ability to do what they really in their heart of hearts would like to do, and instead they may knee jerk react, or they may simply act inappropriately, or may be acting wholly appropriately given the stress they’re under.* (BMA)

The importance of good back-up in terms of management staff and staff trained to handle
conflict was stressed. It was suggested that single-handed practices may find it more difficult to cope with removals, as they have less back-up and fewer opportunities to discuss difficult situations with colleagues.

I would be interested to see how things work out with PCGs and PCTs because I think that has, you get a bigger collective, you may well find that these things are discussed more and there is, sort of, more objectivity built into it. I think doctors who are single-handed often find it a little bit more difficult to get things in perspective. So I suspect that you would find that the number of deregistrations from single-handeds is actually greater than from practices with four or more. (MPS)

4.3.9 Potential solutions and future action.
We asked interviewees what, if anything, could be done to avoid deregistrations or to reduce the adverse effects of deregistration. All mentioned some form of early intervention to attempt to avoid the removal, frequently some form of mediation or arbitration process with an independent party who listens to both sides of the story and attempts to resolve the situation, giving both parties a chance to understand the problem.

There should be some sort of appeals system, so you can sort of challenge that, and at least get some kind of, you know, you may well not want to go back to that GP afterwards but at least it could be some kind of setting the record straight, and you’re not dogged by it. (MIND)

Some kind of conciliation process must be brought in… the independent third party that one or either could request to go to. If it comes to comes to the doctor saying, ‘look I’m sorry but I’m not having you on my list anymore’ the patient almost has the right to appeal and say, ‘well, I don’t think you’re right about this, I really feel that you’re acting very wrongly and I think I have my case here that you’re not really listening to me’. (PA)

In addition, the possibility of warning the patient when the doctor begins finding their behaviour troublesome could give the patient a chance to modify their behaviour and avoid being removed.

I think that often doctors are very tolerant with behaviour up to a certain point and then they just decide they’re not going to take it anymore, and the patient has been unaware that whatever they are doing has been aggravating, so I think the doctors need to, you know, start sending some warning signals. And this concept of contracts and so on that we’ve discussed is something which perhaps needs to be sort of expanded a little bit at the moment. I suppose there are people who are on drugs and so on, would be, not routinely, but quite often on contracts of some sort. There are other groups where, you know, people need to be told that their behaviour is actually causing some difficulty. So I think honesty. (MDU)

Similarly, encouraging patients to change doctors if they feel there are problems within the doctor-patient relationship might help to reduce the number of removals.

Patient and, to lesser degree, GP and staff education was also advocated. It was felt that a clearer understanding of how the system works could improve the situation. If patients were made aware of their rights and responsibilities, and ‘ground rules’ for behaviour and expectations were set, the problem might be reduced.
Yes, I think there is a lot to be done on patient education. And it’s not all the patient’s fault, it’s about everybody understanding their rights and responsibilities, right across the primary health care team, and patients, about knowing how to use, accessing the services properly. It’s about understanding the processes people have to go through without making them too laborious, because that’s often what the patient is trying to short-circuit, they just simply don’t know how to get through the system, and I think we can do a great deal more, to explain how to use the system, how better to access it.

(IHM)

I think a more conciliatory attitude sometimes, from some GPs, so that if they felt that there was a problem with patients, that that was something which in itself had to be addressed at an early stage, rather than suffering and then suddenly snapping which is, I think, a bit of a pattern. So that people are told clearly and understand clearly what ground rules are for using the GP service and they understand those rules. And that clearly won’t work for everybody all of the time, but it might help reduce the problem. (GMC)

Similarly, offering support, training and education for GPs and their staff on dealing with potentially violent patients, and improving communication, was felt to be important.

I think there is a huge need for education through medical school, in communicating with patients, and working at listening skills too, which the majority of people are good at, but they are not good actually at sometimes putting their point across and making them understand how best to use the system. (IHM)

There was also a suggestion that it would be helpful for GPs to learn how the health service appears from the point of view of the patient, to improve understanding.

Appointment systems and how they are used, and sort of seeing that from the side of patients. I am sure sometimes, if you have sat in surgery for two hours…things like that can just build up frustration and anger. (ACHCEW)

Organisational and policy changes that might reduce the number of patient removals were also suggested. Three interviewees mentioned the policy of GP payments for reaching targets as detrimental to the situation. Altering the policy to allow patients choice over immunisation or cervical screening without affecting GP payment was seen as a positive move towards improving the doctor-patient relationship.

I think I and the GPC would abolish target payments for immunisation, and I think we’d abolish payments similarly for cervical cytology. Probably substitute some sort of service level agreement for those, in conjunction with other public health initiatives that we could incorporate in the same sort of agreement. Yes, targets appear to have delivered a high level of immunisations and a high level of cytology, although there are pockets that are notoriously low in terms of the smears, usually related to cultural awareness…by both patients and the doctors, and it seems wholly unreasonable that a GP’s pay should be dependent on local cultural variations, people’s beliefs and you can apply that to immunisations as well. (BMA)

Other organisational changes were mentioned that could help deal specifically with the problem of violent patients, such as setting up designated secure areas for patients with a history of violence, or having a specifically designated GP to deal with patients with personality disorders.
Interviewees emphasised the importance of communication in reducing the adverse effects which might follow deregistration. The provision of a reason and explanation was seen as important here too.

*I think [being removed] would be more likely to have an effect if you don’t know why, and if you know why then you can either say ‘that’s not fair, it’s a load of rubbish, I don’t agree with it and I’m just going to find another GP’; but if you’re worrying about why, particularly if you’ve had the GP for a number of years, and suddenly they remove you, you have no idea what you’ve done, you’re feeling guilt or anger, so that may not help things.* (ACHCEW)

Some interviewees felt there was scope for improving arrangements for future care following deregistration. A removed patient may have difficulty registering with another GP and might resort to using inappropriate services, such as A&E, if they remain unregistered.

4.3.10 Further research
After explaining our research plans to interviewees, we asked about any other questions they would like to see answered by research in this area. There was general support for the planned research and recognition of the importance of research to improve understanding of the processes and underlying causes at work in deregistration. Although there were no new areas of work proposed by interviewees as a whole, there were a number of issues that individuals would like to see addressed.

The principal concern, mentioned by three interviewees, was to include the patient’s perspective within the research in order to provide valuable information, particularly around communication problems. Further information was required about the conditions that lead to removals and how to manage the situation better: how communications break down, what conditions lead to violence, who was involved in making the removal decision, what impact training and other preventive strategies may have on reducing removals. There was further interest in research into models of support for primary care, and finding out what strategies could be put in place to prevent problems of removal.

Other research questions asked included information as to the scale of violent behaviour, the epidemiology of patient allocation and whether removals precipitate complaints. While one interviewee wanted to know whether the cost of new, expensive drugs might be a factor, another felt that the number of patient removals related to cost factors was so small that it probably did not warrant further research.

4.4 Discussion
The interviews with members of key organisations confirmed that there was interest in the issue of patient deregistration and that our proposed research would provide findings on major issues of concern. There was general and notable uncertainty about basic information such as the number of removals, trends in removals and the common precipitants, with both professional and user organisations relying principally on anecdotal evidence or routine data. Overall, the research questions we had posed were considered relevant and important and no important gaps in the research were identified.
On some issues the views of those from professional and user organisations were strikingly similar. Neither group considered patient removals to be common, but they nonetheless saw them as problematic events for both patient and doctor. Nobody was certain whether deregistration was an increasing or diminishing problem. Both groups agreed that financial incentives were rarely the reason for removals, but that if this did happen it was inappropriate. Similarly, there was agreement that violent, threatening or abusive behaviour was a factor in many removals and that this was a justifiable reason for removal.

However, the opinions of those from professional and user organisations tended to differ on the question of the justifiability of group removals and on whether there should be a contractual obligation to give patients a reason. While everyone agreed that, in principle, a patient who is to be removed should be given an explanation, there was disagreement over whether this principle should apply in every case, as of right. Those from professional organisations felt that situations might arise in which it could be harmful to the doctor, patient or some other party to give a reason, while those from user organisations supported the idea of a contractual obligation. Similarly, the latter group believed that each patient should be seen only as an individual, and were opposed to removing other family members at the same time. Those from professional organisations emphasised the practical difficulties of delivering care to the families of patients who had been removed, particularly where they may be at risk of violence or abuse.

There were also differences in the emphasis placed on the respective rights and responsibilities of doctors and patients. Those from professional organisations tended to emphasise the responsibility of the patient to behave in a way which would not jeopardise the doctor-patient relationship, and the right of the doctor to remove the patient if they felt they could no longer sustain a therapeutic relationship. By contrast, those from user organisations tended to emphasise the responsibility of the doctor to be understanding with patients who may be seen as difficult, demanding or aggressive, and the right of the patient to be able to access care and to have a clear explanation of how this should happen. However, both groups advocated training and education for patients and professionals in order to clarify mutual roles and responsibilities. Patients need to be warned about their behaviour, informed of ‘ground rules’ and expectations and offered an explanation of the reason when removed in order for them to amend their future behaviour. Doctors could improve their management of removals with better communication skills and appropriate support to cope with demanding or stressful patients.

Neither group offered any radical solutions to reduce the incidence or impact of patient removal. Warning patients about unacceptable behaviour, and offering mediation or appeals procedures were suggested, with considerable emphasis on the need for education of doctors, patients and practice staff. Review of policies associated with financial incentives for removal and the provision of safe arrangements for the management of violent or demanding patients were also suggested as ways to improve the situation.
5. NATIONAL SURVEY OF GPS

5.1 Introduction
The routinely available data do not make a clear distinction between removals in which the patient does, or does not, move out of the practice area, and provide little or no information on the reasons for removal. In view of this, we undertook a national survey to determine the current scale of, and reasons for, patient removal in England and Wales in order to address the central questions raised by the Select Committee on Public Administration.

In addition, we sought the views of GPs on the Committee’s recommendation that they be obliged to supply reasons for removal to the patient and local health authority, on perceived financial incentives for removal, and on GPs’ sources of guidance in relation to patient removal. Because of uncertainty over how best to achieve a high and unbiased response in a postal survey of GPs, we also used this opportunity to conduct a methodological sub-study on writing to the GP versus writing to the practice manager.

5.2 Methods
In April 2000 we sent a four page postal questionnaire to 1000 general practitioner principals in England and Wales, randomly selected from a general practitioner survey carried out by the Department of Health in October 1999. One week in advance of the questionnaire a brief letter outlining and supporting the study was sent from the General Practitioners Committee of the British Medical Association, in order to boost the response rate. Up to two reminders were sent to non-respondents at fortnightly intervals.

The questionnaire asked about the number of patients removed from the practice list in the previous 6 months (for reasons other than living outside the practice area), the reasons contributing to the most recent removal and whether the removed patient was given a reason. In view of the fact that any one doctor’s experience of deregistration is likely to be limited, we felt that a formal qualitative development phase would be of limited value. Instead, a list of suggested reasons for removal was compiled in the light of published opinions and discussions with local general practitioners. Respondents were asked to indicate which of these was the “primary” reason, and which others were “contributory”.

In addition, the questionnaire sought general practitioners’ views on whether a range of reasons for removal were definitely or possibly appropriate, or definitely not appropriate, on whether they felt particular financial incentives for removing patients existed and on whether general practitioners should be contractually obliged to inform either their patients or local health authority of removal reasons. We also asked what guidance on de-registration GPs had received, whether they felt further guidance would be useful and from whom they would like such further guidance. The survey is reproduced at Appendix 2.

The questionnaire was piloted with a small number of local general practitioners before use. We entered data into a Microsoft Access database and undertook descriptive analyses using SPSS 9.0 for Windows.
The sample size was calculated according to the main objective, which was to estimate a national de-registration rate to compare with that derived from routine health authority data. Assuming a national rate of about 10 removals per 10 000 patients per year and a survey response rate of about 65%, a survey of 1000 GPs can estimate this rate to within ± 3.5 per 10 000 per year. This sample size was also sufficient to estimate the proportion of GPs agreeing with a given statement to within ± 4%, assuming that about half of GPs agree.

5.2.1 Sub-study on mailing to GPs
There is a common perception that postal surveys of GPs are likely to achieve low response rates (i.e. below 60%), although we know from experience that this is not inevitably the case. For example, a recent postal survey of GPs in Sheffield on an issue of local importance, and with a financial incentive to respond, achieved a response rate of over 90%.24 Although a range of techniques is available to improve response rate, such as pre-notification and sending reminders (both used in this study), one practical question is whether it is better to send the survey to a named GP in the practice, or to the practice manager with a request to pass it on to one of the GPs. The latter approach might be thought to increase response rate (thus limiting possible non-response bias) yet might also be expected to lead to the selection of particular kinds of GP by practice managers, such as those seen as helpful or friendly (thus introducing a different response bias).

In order to test these two methods, we divided our sample of GPs randomly into two groups. In the first group, the postal survey was sent to each named GP, and in the second, to the practice manager. In the latter case, an additional covering letter was enclosed asking the practice manager to pass the survey to one of the GPs in the practice.

5.3 Results
Of the 1000 doctors surveyed, 14 replied saying they were not working in general practice. Of the remaining 986, 748 (76%) responded, and their characteristics are shown in Table 5-1.

<table>
<thead>
<tr>
<th>Table 5-1: Characteristics of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctors</strong></td>
</tr>
<tr>
<td>Age: mean</td>
</tr>
<tr>
<td>Sex: male n (%)</td>
</tr>
<tr>
<td>Years as principal: mean</td>
</tr>
<tr>
<td><strong>Practices</strong></td>
</tr>
<tr>
<td>Number of principals</td>
</tr>
<tr>
<td>One: n (%)</td>
</tr>
<tr>
<td>Two or three: n (%)</td>
</tr>
<tr>
<td>Four or five: n (%)</td>
</tr>
<tr>
<td>Six or more: n (%)</td>
</tr>
<tr>
<td>List size: median</td>
</tr>
<tr>
<td>Doctors' lists are shared*: n (%)</td>
</tr>
</tbody>
</table>

* excludes single handed practices
5.3.1 **Overall removal rate**

In the previous six months, 40% (300/745) of doctors had removed one or more patients from their lists. Excluding 21 respondents whose list size was not given, 988 patients had been removed in all during this period from a registered population of 4.6 million, giving a mean population removal rate of 4.3 per 10,000 patients per year (95% CI: 4.1, 4.6).

5.3.2 **Reasons for most recent removal**

The primary and contributory reasons given for the most recent removal by each of these 300 doctors are shown in Figure 5:1. Violence, threatening or abusive behaviour was given as the primary reason in 59% (176/300) of removals, and as a contributory reason in a further 8% (24/300). Patient complaint was the primary reason in 1.7% (5/300) of cases, and non-compliance with childhood immunisation or cervical cytology in 1.3% (4/300) and 0.7% (2/300) cases respectively.

![Figure 5:1: Primary and contributory reasons for most recent removal](image)

Although violence was frequently cited along with other reasons for a removal, in 20% (60/300) of cases it was the sole reason given. Non-compliance with appointments was given as a sole reason in 4.3% (13/300) and deception in 3.6% (11/300). By contrast, drug/substance misuse, inappropriate demand out of hours, patient complaint, and refusal of childhood immunisation or of cervical cytology were never cited alone, but only in conjunction with other reasons for the removal.

In 83% (238/288) of most recent removals, the practice gave the patient a reason for the removal, either in writing (55%, 157/288) or in person (28%, 81/288). Among practices with at least two partners, the decision to remove the patient was made by an individual doctor in 22% (54/242) of cases and by the practice as a whole in 74% (179/242) of cases.
Table 5-2: Primary and contributory reasons for most recent removal

<table>
<thead>
<tr>
<th>Reason</th>
<th>Primary %</th>
<th>Contributory %</th>
<th>Ever a factor %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Violence, threats or abuse</td>
<td>58.7</td>
<td>8.0</td>
<td>66.7</td>
</tr>
<tr>
<td>Drug or substance misuse</td>
<td>12.0</td>
<td>17.0</td>
<td>29.0</td>
</tr>
<tr>
<td>Inappropriate demand: in hours</td>
<td>12.7</td>
<td>15.7</td>
<td>28.3</td>
</tr>
<tr>
<td>Inappropriate demand for medication</td>
<td>10.3</td>
<td>18.0</td>
<td>28.3</td>
</tr>
<tr>
<td>Non compliance with appointments</td>
<td>12.7</td>
<td>13.0</td>
<td>25.7</td>
</tr>
<tr>
<td>Deception or crime</td>
<td>14.7</td>
<td>8.7</td>
<td>23.3</td>
</tr>
<tr>
<td>Non compliance with treatment</td>
<td>8.3</td>
<td>14.7</td>
<td>23.0</td>
</tr>
<tr>
<td>Inappropriate demand: out of hours</td>
<td>8.0</td>
<td>10.3</td>
<td>18.3</td>
</tr>
<tr>
<td>Patient complaint or litigation</td>
<td>1.7</td>
<td>4.7</td>
<td>6.3</td>
</tr>
<tr>
<td>Other</td>
<td>3.7</td>
<td>1.0</td>
<td>4.7</td>
</tr>
<tr>
<td>Inappropriate sexual behaviour</td>
<td>2.3</td>
<td>2.0</td>
<td>4.3</td>
</tr>
<tr>
<td>Non compliance with childhood immunisation</td>
<td>1.3</td>
<td>1.7</td>
<td>3.0</td>
</tr>
<tr>
<td>Patient request for unconventional treatment</td>
<td>1.0</td>
<td>2.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Non compliance with cervical cytology</td>
<td>0.7</td>
<td>1.7</td>
<td>2.3</td>
</tr>
<tr>
<td>Cultural differences</td>
<td>1.0</td>
<td>1.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Patient request for particular kind of GP</td>
<td>0.7</td>
<td>1.3</td>
<td>2.0</td>
</tr>
</tbody>
</table>

5.3.3 Views of general practitioners

5.3.3.1 On appropriate reasons for removal

Figure 5:2 shows respondents’ views on the appropriateness of various reasons for patient removal. A large majority of general practitioners regarded removal following violent, abusive or threatening behaviour as definitely appropriate, and similarly large proportions felt that patient requests for a particular kind of GP or for unconventional treatment, refusal of cervical cytology or childhood immunisation, or cultural differences between doctor and patient were definitely not appropriate reasons for removal.

There was a significant association between views and recent experience, with those who had removed one or more patients in the previous six months more likely than others to judge reasons as definitely appropriate ($\chi^2=267$, 30df, P<0.001).
5.3.3.2 On being obliged to give a reason

On whether giving a patient a reason for their removal should become a contractual obligation on doctors, 31% (231/736) believed that it should and 57% (420/736) that it should not. The remaining 12% (85/736) supported a level of obligation, with some exceptions allowed. There was less opposition to requiring doctors to give their local health authority reasons for patient removals: 44% (318/728) believed this should be obligatory, 50% (361/728) that it should not,
and 7% (49/728) that it should be obligatory with some exceptions.

Those respondents who felt that giving a reason should not be obligatory offered a range of justifications. The most common, in about half of all cases where a comment was offered, were responses along the lines of “patients do not have to give a reason for ending the relationship, so why should we?”, or justification in terms of the rights or freedoms of the GP. About one in five of those who offered a comment raised concerns about violence or recrimination if a reason were given.

5.3.3.3 On financial incentives

General practitioners’ views of the existence of financial incentives to remove certain groups of patients are shown in Table 5-4. About half of general practitioners believed that the target payment systems for childhood immunisation targets and cervical cytology had created such incentives. Smaller, but still substantial, proportions of respondents considered that financial arrangements for practice drug budgets and out-of-hours care also created incentives to remove patients. One doctor mentioned that targets to prescribe generically might also introduce such an incentive, since some patients would refuse generic (unbranded) drugs and therefore inhibit the ability of the GP to attain the target.

In some cases respondents believed that they knew of practices which had responded to the incentives listed in the table.

Table 5-4: General practitioners’ views on financial incentives for removal

<table>
<thead>
<tr>
<th>Do you consider any of the following to create financial incentives for practices to deregister patients?</th>
<th>Yes n (%)</th>
<th>No n (%)</th>
<th>Don’t know n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targets for childhood immunisation</td>
<td>370 (51)</td>
<td>298 (41)</td>
<td>64 (9)</td>
</tr>
<tr>
<td>Targets for cervical cytology</td>
<td>360 (49)</td>
<td>303 (41)</td>
<td>69 (9)</td>
</tr>
<tr>
<td>Practice drug budgets</td>
<td>295 (41)</td>
<td>354 (49)</td>
<td>79 (11)</td>
</tr>
<tr>
<td>Cost to practice of out of hours consultations</td>
<td>321 (44)</td>
<td>320 (44)</td>
<td>92 (13)</td>
</tr>
</tbody>
</table>

5.3.3.4 On professional guidance

Within the past 5 years, the Royal College of General Practitioners, the British Medical Association and the General Medical Council have offered some guidance on removing patients from doctors’ lists, including advice on when removal is not appropriate and on the desirability of giving a reason. Of respondents to this survey, 58% (429/744) remembered having received guidance from at least one of these sources, or from elsewhere (Table 5-5). Conversely, 42% (315/744) of respondents could recall receiving no guidance on removal from any source.

About a half of respondents (55%, 309/694) felt that no further guidance for doctors was needed.
### Table 5-5: Sources of advice on patient removal

<table>
<thead>
<tr>
<th>Sources mentioned</th>
<th>RCGP n (%)</th>
<th>BMA n (%)</th>
<th>GMC n (%)</th>
<th>Others n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had received guidance from</td>
<td>87 (12)</td>
<td>276 (37)</td>
<td>221 (30)</td>
<td>81 (11)</td>
</tr>
<tr>
<td>Would like further guidance from</td>
<td>74 (10)</td>
<td>186 (25)</td>
<td>191 (26)</td>
<td>62 (8)</td>
</tr>
<tr>
<td>Sources mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colleagues, local medical committee, health authority, medical defence organisation, CHC, magazine/journal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local medical committee, health authority, medical defence organisation, PCG/T</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 5.3.4 Methodological sub-study

The methodological sub-study compared the results of sending postal surveys to a named GP or to the practice manager to pass on to a suitable GP. The purpose was to assess the effect on response rates and on the possibility of response bias.

In fact, the response rate proved to be the same for each method, as Table 5-6 shows.

### Table 5-6: Response rates, by mode of contact

<table>
<thead>
<tr>
<th></th>
<th>Addressed to named GP</th>
<th>Addressed to practice manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveys mailed</td>
<td>500</td>
<td>500</td>
</tr>
<tr>
<td>Surveys returned as gone away or addressee not a GP</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Completed responses</td>
<td>370</td>
<td>378</td>
</tr>
<tr>
<td>Crude response rate</td>
<td>74%</td>
<td>76%</td>
</tr>
<tr>
<td>Effective response rate</td>
<td>75%</td>
<td>76%</td>
</tr>
</tbody>
</table>

Table 5-7, below, compares the characteristics of GPs responding in each group, and also suggests no important difference between the groups. However, Table 5-8 shows that the number of practices reporting a removal tended to be higher in the group contacted via the practice manager than in the group contacted through a named GP. This raises the possibility that the practice manager is passing the survey to a GP who is known to have an interest in, or perhaps recent experience of, a removal and whose recall of events may be more complete.
Table 5-7: Characteristics of respondents, by mode of contact

<table>
<thead>
<tr>
<th></th>
<th>N Addressed to named GP</th>
<th>Addressed to practice manager</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age: mean</td>
<td>717</td>
<td>47.7</td>
<td>47.3</td>
</tr>
<tr>
<td>Age: median</td>
<td>717</td>
<td>48</td>
<td>47</td>
</tr>
<tr>
<td>Sex: male n (%)</td>
<td>730</td>
<td>274 (76.1)</td>
<td>272 (73.5)</td>
</tr>
<tr>
<td>Years as principal: mean</td>
<td>711</td>
<td>15.9</td>
<td>15.8</td>
</tr>
<tr>
<td>Years as principal: median</td>
<td>711</td>
<td>15.0</td>
<td>15.0</td>
</tr>
<tr>
<td><strong>Practices</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of principals</td>
<td>746</td>
<td>82 (22)</td>
<td>79 (21)</td>
</tr>
<tr>
<td>One: n (%)</td>
<td></td>
<td>135 (37)</td>
<td>137 (36)</td>
</tr>
<tr>
<td>Two or three: n (%)</td>
<td></td>
<td>96 (26)</td>
<td>97 (26)</td>
</tr>
<tr>
<td>Four or five: n (%)</td>
<td></td>
<td>56 (15)</td>
<td>64 (17)</td>
</tr>
<tr>
<td>List size: mean</td>
<td>727</td>
<td>6121</td>
<td>6470</td>
</tr>
<tr>
<td>List size: median</td>
<td>727</td>
<td>5200</td>
<td>5670</td>
</tr>
<tr>
<td>Shared list: n (%)</td>
<td>585*</td>
<td>237 (83)</td>
<td>244 (82)</td>
</tr>
</tbody>
</table>
* excludes single handed practices

Table 5-8: Removal experience, by mode of contact

<table>
<thead>
<tr>
<th></th>
<th>N Addressed to named GP</th>
<th>Addressed to practice manager</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Removal numbers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any removals in past 6 months: n (%)</td>
<td>745</td>
<td>134 (36)</td>
<td>166 (44)</td>
</tr>
<tr>
<td>Practice removal rate: mean</td>
<td>727</td>
<td>10.2</td>
<td>11.1</td>
</tr>
<tr>
<td>Practice removal rate: median</td>
<td>727</td>
<td>5.6</td>
<td>5.7</td>
</tr>
<tr>
<td>Of respondents who have removed at least one patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number removed</td>
<td>300</td>
<td>446</td>
<td>565</td>
</tr>
<tr>
<td>Of respondents who have removed at least one patient, and excluding respondents with missing list size</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number removed</td>
<td>438</td>
<td>550</td>
<td></td>
</tr>
<tr>
<td>Mean removals per respondent</td>
<td>3.33</td>
<td>3.40</td>
<td></td>
</tr>
<tr>
<td>Median removals per respondent</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Most recent removal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Of respondents who have removed at least one patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice decision: n (%)</td>
<td>242*</td>
<td>81 (75)</td>
<td>98 (73)</td>
</tr>
<tr>
<td>Patient given a reason: n (%)</td>
<td>288</td>
<td>107 (83)</td>
<td>131 (82)</td>
</tr>
</tbody>
</table>
* excludes single handed practices

5.4 Discussion

This large national postal survey of general practitioners suggests that patient removal occurs rarely. When it does occur, doctors report that it is frequently in response to the violent,
threatening or abusive behaviour of a patient, and that patients are given a reason for their removal in more than four-fifths of cases. Our findings indicate an overall patient removal rate of about 4.3 per 10,000 patients per year in England and Wales, close to the rate of 4.8 per 10,000 patients per year reported in an analysis of routine data in Northern Ireland, and about a quarter of that found in Sheffield.

Violent, threatening or abusive behaviour dominated the list of reasons doctors gave for removal, being cited in two-thirds of cases in this survey and in 58% of cases in the smaller Lothian survey. This result is also consistent with a recent report of a GP survey in Northern Ireland, in which GPs reported that “violent or threatening behaviour” had been the reason for removing a patient in 49.9% of cases. This is in marked contrast to the impression given by national statistics, which record fewer than 2% of removals as due to “an act or threat of violence.” For a removal to be counted in this category in the statistics, under changes to the terms of service introduced in April 1994, a practitioner must have informed the police of the patient’s behaviour. Since only a small proportion of the aggression directed towards general practitioners involves serious incidents which might result in police involvement, it is not surprising that the official statistics seriously under-report the contribution of violent and abusive behaviour to patient removal. It remains to be seen whether recent policy initiatives to tackle violence in primary care settings will improve this situation.

In contrast to the high prevalence of violence as a reason for removal, patient complaint or non-compliance with childhood immunisation or cervical cytology were only occasionally given as reasons, and then never alone but always along with other reasons. In the Northern Ireland survey, no GP was reported as having given these reasons.

In this survey 83% of doctors said they had given a reason for the removal to the patient, slightly higher than the 69% reported in the Lothian survey. The views of general practitioners on the appropriateness of various reasons for removal are broadly in line with guidance issued by the Royal College of General Practitioners and the General Practitioners Committee of the British Medical Association.

The survey suggests that the Select Committee’s recommendation that doctors be obliged to provide both patient and health authority with a removal reason would encounter considerable resistance, a finding also confirmed by the Northern Ireland survey. Despite the finding that the majority of general practitioners already provide reasons to their patients, the proposed changes to the terms of service would meet opposition from at least half of the profession. Since, on the face of it, the practice of giving a reason appears widely accepted while the principle is resisted, some further exploration of doctors’ views seems to be required. In particular, there may be occasions when a doctor feels that withholding a reason would be in the best interests of a removed patient, or justifiable in terms of, for example, the safety of practice staff.

A substantial proportion of our respondents felt that financial incentives to remove patients do exist, most notably the target payment schemes for childhood immunisation and cervical
cytology. However, the fact that no respondent admitted to removing a patient for either of these reasons alone may indicate that these incentives are not strong, or that responding to them is not regarded as acceptable or admissible. Nonetheless, the widespread recognition by doctors of such incentives will do little to alleviate the concerns of the public and policymakers. In the case of the target schemes, at least, an administrative change allowing patients to formally “opt out” of the scheme and be removed from their doctor’s target denominator, but not from their list, would be a simple way to remove this incentive.

We believe that this survey provides more reliable and valid evidence than previous research on doctors’ reasons for removing patients from their lists, because we asked, not about which reasons might prompt removals, but which reasons did prompt them in the most recent case. In addition, the large national sample and high response rate improve on previous work in this area. Nonetheless, the validity of our findings clearly depends on the degree to which doctors were able and willing to identify and report both the number of, and reasons for, removals. If our respondents were unaware of all removals from the practice, or were not truthful about their reasons for removing patients, our findings will misrepresent the true picture.

Our results present the situation solely from the doctor’s point of view and patients may have quite different perceptions of the events leading to removal, which we explore further in section 7.5, below. This study has identified more clearly than before the “final straws” which cause doctors to remove patients. The need now is to develop a much better understanding of the processes which precede relationship breakdown, so that the considerable emotional and practical difficulties associated with removals, for both patients and doctors, might be better avoided, or at least minimised.
6. ROUTINE DATA AND IT SURVEY

6.1 Introduction
At the start of this study there was marked uncertainty over the availability and meaning of routine statistical data on patient removals. While operational data on registrations with general practitioners is held in the Exeter system maintained by health authorities or primary care agencies, we are aware of no study of deregistration which has used this data source directly. For example, the previous study in Sheffield used data held by the health authority in a separate dedicated removals database,16 and in Northern Ireland researchers compiled their own database from the available paper records.14 In addition, the results presented in the previous chapter demonstrate how uncritical use of the published routine statistics can be misleading when compared with the reports of GPs themselves, especially in regard to the importance of violent and threatening behaviour.

In view of this uncertainty we undertook a survey of health authorities in England to determine the availability, format, detail and time period of available data, with two purposes in mind: first, to establish a national picture of the data available, and second, to identify six health authorities in which we might undertake a more detailed analysis of the data over a long period. Using the routine data, we aimed to examine the possibility that trends in deregistration rates may have been related to the introduction of the new GP contract in 1990 or GP fundholding in 1991, and to describe the epidemiology of deregistration for six health authorities. We intended to examine the role of age, sex, urban/rural location and population deprivation as factors in deregistration rates.

6.2 Survey of deregistration data held by health authorities

6.2.1 Methods
We undertook a short postal survey of IT directors of all health authorities in England and Wales in order to identify which would be able to provide data for the current study. We mailed 104 surveys in February 2000, with reminders sent to non-respondents after two and four weeks. The questionnaire asked whether the health authority maintained a record of GP requests to de-register patients, the period for which data was available and whether de-registrations where the patient had not changed address could be identified separately from those where they had. We also asked about how the data was kept and how easy it would be to extract, and about the details which were available about each instance of de-registration, including identity of GP/practice, reasons for removal and patient details. Finally, we asked whether the health authority held information about practice and practice populations, to allow further analysis of rates by population attributes to be calculated. The questionnaire is reproduced at Appendix 3.

The responses of all health authorities who claimed they could identify movers from non-movers were reviewed by the researchers and a shortlist of health authorities was drawn up, taking into account the number of years of data available, whether the data was easily
extractable and the level of detail held. Six health authorities were selected to include both rural and urban areas. We estimated, from the national removal rate, that six authorities would experience sufficient removals to allow a total of 500 instances in the past three months to be identified for the specific instances survey (see next chapter).

6.2.2 Results
Of the 104 health authorities surveyed, 97 responded after 2 reminders. Of these, 95% (92/97) maintained a record of GP requests to de-register patients, and 77% (75/97) believed they could identify separately those removals in which the patient had not changed address. However, only a third of health authorities (33/97) thought that they had data available in computerised form. Of these, nine said they had data available from before 1990.

Only 20 health authorities believed they held all of the details of deregistration that we requested (date of de-registration, identity of GP, identity of practice, length of time patient been on GPs list, number of people removed in same instance, reason) and all of the patient details (postcode, age/date of birth, sex). Six of these could also provide the information about the local practices that we required (number of GPs in practice, fundholding (including wave), list size, population age structure, Townsend deprivation index, Jarman deprivation index).

About one-third (37%, 26/70) of respondents felt it would be reasonably straightforward to extract data from their system, a third (31%, 22/70) felt it would not, and a further third (31%, 22/70) were unsure. Some authorities did not provide information as to how their data was collected or held, or stated that records were only available manually. However, 47 authorities did provide details of their computer system, and of these 34 mentioned the Exeter system.

6.2.3 Discussion
There was wide variability in the reported availability, completeness and accessibility of data held by health authorities. Almost a fifth of respondents believed that they could not identify whether the patient had changed address. Of those who claimed they could identify whether the patient had changed address 63% had computerised records, mainly using the Exeter system. However, only a third of health authorities claimed to have easily extractable information. Very few authorities had data available from pre-1990, and most believed that that data would not be straightforward to extract for our research.

However, in reading through the responses to the survey, we came to the conclusion that while all authorities in England and Wales used the Exeter system, only some of these indicated that data was complete and extractable. In principle then, since the Exeter system is a single system with nationally standardised operational procedures, one might imagine that in fact all authorities are collecting the same data in the same format, and all have the same deregistration data available, whether they realise this or not. The reported variation between authorities may therefore relate more closely to the knowledge, skill or motivation of the respondent than to the data actually held or its extractability. This observation informed the
methods of the study of routine data reported below.

6.3 Epidemiology of deregistration in selected health authorities

6.3.1 Methods

In view of the results of the survey of health authorities, we sought further advice on how doctor-initiated deregistrations were recorded in the Exeter system. In essence, patients “deducted” from doctors’ lists at the request of the doctor are coded as DDR (“deducted at doctor’s request”), while those removed because they are outside the practice area are coded as OPA (“practice advise outside their area”). In regard to this latter code, it should be noted that the code may include either a patient who has changed address and now lives outside the practice area, as well as patients who have not changed address but find themselves outside the practice area if it is redrawn by the practice. In discussions with system specialists at the NHS Information Authority and local patient registration managers operating the system, both indicated that the DDR code covered exactly the doctor-initiated patient de-registrations we were interested in, and only these deregistrations. Patients moving out of the area would be covered by the OPA code.

6.3.1.1 Selection of health authorities

Therefore, in order to standardise data collection as far as possible across authorities and limit the workload impact on authorities themselves, we asked Exeter system support staff at the NHSIA to write a single data extraction routine which could be deployed at multiple authorities. This proved to be practical only for authorities which ran the “M-Connect 2” query tool on their systems. This is an optional software tool which not all authorities have bought. In the light of this, we aimed to select from our survey of authorities those which believed they had extractable data covering the longest period and with the greatest amount of detail, and who ran M-Connect 2. No health authority fitted all our selected criteria perfectly, but we identified a shortlist of six authorities which looked promising and which also represented a mix of urban and rural areas, in both the north and south of England. These were:

- Durham and Darlington
- St Helen’s & Knowsley
- Doncaster
- Kingston and Richmond
- East Surrey
- West Surrey

For each authority, we wrote to the director of public health to gain permission for the NHSIA to extract data from their system. An additional data request was made directly to each authority for additional information on the characteristics of local practices and their populations.

The data extracted by NHSIA would be anonymised before being provided to the research team. Ethical approval for the study was granted by each of the 11 local research ethics committees covering the six authorities selected.
6.3.1.2 Extraction and analysis of deregistration data

System specialists at NHSIA wrote a programme to extract deregistration data using a standard technique which would apply in each health authority using M-Connect 2. This was used to extract a uniform dataset from each of the selected health authorities during October and November 2000. Data was collated by the NHSIA and sent to the research team in November 2000.

Each authority generated two databases: one ‘live’, with patients who still resided within the health authority boundary, and one ‘deducted’, which included patients who had either died or had moved outside the health authority boundary. We cleaned the data of duplicates, defining a duplicate as any instance where the transfer date, patient identification and GP identification were identical. Because patients are often removed as a household group, we also assigned each removal to a group. We defined a removal group as all removals which shared the same postcode and GP code and which were removed within the same 7-day period.

In addition to the tables of removal instances, each health authority provided details of the practice code for each GP, including the start and end date of working at the practice. This was intended for use in linking the removal data to the practice characteristics data provided by the health authorities. All datasets were linked together and analysed in Microsoft Access.

6.3.2 Results

Patient removal data was provided for each authority for the period mid-1993 to October 2000 (see Table 6-1). Data for East Surrey and West Surrey health authorities were provided in a single table and were analysed together as ‘Surrey’. On the face of it, the table suggests a marked (4 to 5-fold) variation between the removal rates for the different authorities.

<table>
<thead>
<tr>
<th>Health authority</th>
<th>Population</th>
<th>Period of data supplied</th>
<th>Removed individuals*</th>
<th>Removed groups*</th>
<th>Individual removal rate per 10,000 per year*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doncaster</td>
<td>222,000</td>
<td>08/93 – 10/00</td>
<td>681</td>
<td>505</td>
<td>30.7</td>
</tr>
<tr>
<td>Durham &amp; Darlington</td>
<td>382,000</td>
<td>07/93 – 10/00</td>
<td>305</td>
<td>260</td>
<td>8.0</td>
</tr>
<tr>
<td>Kingston &amp; Richmond</td>
<td>303,000</td>
<td>02/94 – 10/00</td>
<td>681</td>
<td>506</td>
<td>22.5</td>
</tr>
<tr>
<td>St Helens</td>
<td>336,000</td>
<td>09/93 – 11/00</td>
<td>325</td>
<td>256</td>
<td>9.7</td>
</tr>
<tr>
<td>Surrey</td>
<td>1,038,000</td>
<td>06/93 – 10/00</td>
<td>708</td>
<td>170</td>
<td>6.8</td>
</tr>
</tbody>
</table>

* during 12 months 1 October 1999 to 30 September 2000

The charts below show, for each health authority and year, the number of individual and group removals, and the individual removal rate per 10,000 population per year.
Figure 6:1: Annual removal numbers by health authority

Figure 6:2: Annual group removal numbers by health authority
A number of observations may be made about the charts above. First, it seems likely that some of the figures are spuriously high, as a result of specific one-off activities by authorities or practices, such as list cleaning or redrawing of practice boundaries. The figure for Durham and Darlington in 1995 is an obvious case in point.

Second, Figure 6:1 shows that the number of removals recorded as DDR by each authority is of a similar order of magnitude, being about 500 per year. Of course, because these authorities serve populations of different sizes, the crude removal rates are markedly different, as Figure 6:3 makes clear.

Third, there is little suggestion from the data that the number of removals is rising, and if anything it may be falling slightly.

In the following chapter we report on the results of sending a postal survey to the GPs and patients involved in recent instances of removal represented in this data. One finding of this survey relevant here was that many of the instances of removal included in this dataset were, in fact, cases where the patient lived or had moved out of the practice area. Although the Exeter system documentation suggests that these should be coded as OPA, it is clear from our survey findings that in many cases these are being coded as DDR. Table 6-2 below shows the proportion of respondents to our surveys who gave “out of practice area” as the reason for the removal. This suggests that in some health authorities about a half of all removals coded as DDR should in fact be more appropriately recorded as OPA, indicating that the patient is outside the practice area.

In the case of Kingston and Richmond, this issue was recognised before the postal survey
was sent out, and staff in the primary care agency manually removed records where they believed the correct code should have been OPA. Thus, from a sample of 70 GPs and 142 patients in DDR-coded records, they identified 7 GPs and 11 patients who were not removed due to moving out of the practice area (i.e. were true DDRs).

Table 6-2: Proportion of recent removals reported as out of area

<table>
<thead>
<tr>
<th>Area</th>
<th>Respondents to GP survey reporting removal reason as “out of area”</th>
<th>Respondents to patient survey reporting removal reason as “out of area”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Doncaster</td>
<td>Durham &amp; Darlington</td>
</tr>
<tr>
<td>Respondents to GP survey</td>
<td>55.1%</td>
<td>47.9%</td>
</tr>
<tr>
<td>Respondents to patient</td>
<td>52.0%</td>
<td>45.5%</td>
</tr>
</tbody>
</table>

Therefore, to give a more realistic estimate of the number of true doctor-initiated deregistrations in each of these authorities, we have deflated the crude figures by a factor (one minus the mean of the GP and patient-reported out of area proportions) which takes account of the degree of miscoding in each area. In Kingston and Richmond, we have deflated by the “true DDR proportion” which is 11/142. The adjusted removal rates are shown in the chart below, and suggest rates below 10 per 10,000 population per year. This is a similar order of magnitude to the rate estimated in the national GP survey and in the Northern Ireland study of routine data.\textsuperscript{14} The rates in St Helens and Knowsley are higher than this – approximately 15 per 10,000 per year – which is close to the rate of 16 per 10,000 per year previously reported from Sheffield.\textsuperscript{16} Of course, given the method of adjustment these rates are subject to a large degree of uncertainty.

Figure 6:4: Adjusted removal rates by health authority
Given the apparent lack of a clear distinction between the use of DDR and OPA codes to record deductions in the Exeter system, we asked staff at each health authority how doctor-initiated removals were coded locally. As expected, this revealed that there were indeed wide variations in local practice, and indeed in some authorities the OPA code did not appear to be used at all.

In view of the evidence pointing to extensive miscoding, which may of course vary unpredictably over time and in different authorities, we felt that any further and more detailed analysis of removal rates by time, place or person would be unwise and probably misleading. Nonetheless, we have included below charts of removals by age and sex of the patient removed, which a pattern which is broadly similar in each area, and indeed similar to that published in previous work.15 16

**Figure 6:5: Age and sex of removed patients, by health authority**
6.4 Conclusions

Taken together, the findings of the survey of IT directors, the analysis of routine data and the results of the postal survey based on recently recorded removals lead us to a number of conclusions.

There is a nationally standardised software system – the Exeter system – in use for managing the operational aspects of patient registration. In principle, one might expect this system to be recording the same events in the same way in each health authority, and to have the same ability to generate removal data or produce statistical reports in each area. However, the results of the health authority IT survey suggests widespread uncertainty over the nature, quality and availability of the data held by the system. This may in part be a result of the complexity of the Exeter system. It is not clear whether those authorities reporting that they do not have removal data in fact have any less data than those who believe that they do have data. It seems more likely that the difference between authorities reflect differences in awareness and understanding of the system rather than real differences in the data collected and stored by the system.

Nonetheless it is also clear that, at least in regard to the coding of doctor-initiated removals, there are substantial differences in coding practice between authorities. The registration reference manual sets out a range of codes which may be used for “patient deductions”. The DDR code is intended to be used only for doctor-initiated deregistration, and excludes removals where the “practices advises outside their area”, which is to be coded as OPA. However, not all authorities in our sample made this distinction in practice.

There is a further distinction which may be important, but is not made in the codes available to the Exeter system. A patient may be outside the practice area either because they have changed address and moved out of the area, or because the practice has redrawn the area in a way which excludes the patient’s address.

Given the uncertainty over the specificity of the available data for the doctor-initiated removals which are the focus of the this report, only a very limited analysis was undertaken. The observed differences in removal rates between authorities may be real or a result of differential coding practices, but substantial differences remained even after an attempt to adjust the rates for miscoding was made.
7. SURVEYS OF RECENT INSTANCES OF REMOVAL

7.1 Introduction
In order to gain a more detailed picture of the events leading to removal, the processes of the removal itself and the experience from the point of view of both doctor and patient, we undertook a postal survey of doctors and patients with recent experience of a removal. The recent instances of removal about which we sought information were identified from the routine data discussed in the previous chapter.

The survey of GPs aimed to collect further detail on the more common reasons for removal and about the process and consequences of removing patients. The survey of patients aimed to find out about the patient’s perspective on and understanding of the removal, their view of why they were removed, how the removal was managed and how the removal affected them and their use of the health services.

We also identified a small number of matched pairs of patients and GPs in order to compare their perspectives on the same events and provide a greater insight into events leading to deregistration.

7.2 Methods

7.2.1 Sample selection
The extraction of routine data on removals from six health authorities has been described in the previous chapter. Using this data, we identified all instances of removal in the most recent four months (July to October 2000) listed as “live deductions” (i.e. instances in which the patient is still living within the health authority area), with the aim of generating a sample of approximately 100 removals per health authority. The resultant sample size of 600, with a response rate of 70%, would be sufficient to give 95% confidence intervals around a proportion of 10% within ± 3% and a proportion of 50% within ± 5%.

As described previously, the removals were classified into groups to represent removals of whole households. Groups were defined as those removals with the same postcode, GP code and a removal date within the same seven day period.

For the patient survey, we selected one patient from each group: if a group had more than one adult (aged 18 or over), an adult was selected at random. If there was no adult in the group, a patient under 18 was selected at random. If the selected individual had been removed more than once, we asked only about the most recent instance.

For the GP survey, we selected all the GPs of patients represented in the patient survey. Some GPs had removed more than one patient during this period, and to minimise the impact on GPs and maximise the response rate, we asked the GP to focus on a single instance of removal which we selected at random, in advance.

7.2.2 Survey design
The questionnaires were designed using the results from the national survey of GPs to obtain
further details on issues arising from the survey and with a view to enabling the GP and patient results to be compared.

The questionnaire to the GP asked why the patient was removed and requested further details about the removal where the reason was violent, threatening or abusive behaviour, deception or crime or inappropriate demand for consultations. The categories of violent, threatening or abusive behaviour were based on those used within a survey of aggression and violent behaviour in general practice. The list of potential reasons for removal was drawn up using the results of the national survey.

Respondents were asked how the practice communicated with the patient before the removal and whether the patient or health authority were informed about the reason for removal. They were asked about how the removal was undertaken, what advice or support they received and whether other people were removed in the same instance. In addition, the questionnaire sought general practitioners’ views on whether the removal could have been handled better. We also asked for the patient age and sex, how long the patient had been registered with the practice and whether the patient had a mental illness, a chronic medical condition or drug or substance abuse.

The patient questionnaire asked for a brief explanation of why the doctor removed them from the list and what events led up to the removal. In order to gain a fuller picture as to which contributory factors may have affected the removal decision, we also asked the patient to answer a series of questions designed to reflect, in a non-judgmental way, the list of reasons for removal given by GPs in the national survey. We asked patients to say whether they thought any of the listed factors could apply to them, but not whether they thought the factor may have contributed to the GP’s decision to remove them.

Patients were also asked how the doctor or practice communicated with them before the removal and how they were told about the removal and reason for the removal, how long they had been registered with the practice and whether they had any mental health problems or a long-term medical condition.

The surveys are reproduced at Appendices 4 and 5.

7.2.3 Survey mailing
One week in advance of mailing the survey to GPs, a brief letter from the General Practitioners Committee of the British Medical Association outlining and supporting the study was sent, in order to boost the response rate. Up to two reminders were sent to non-respondents at fortnightly intervals for both the patient and the GP survey. Neither GP nor patient were told that the other was being surveyed.

In order to comply with the ethics committee requirement for confidentiality, both GP and patient surveys, including reminders, were sent out by the local health authority on our behalf. Responses, identified only by a study number, were returned directly to the researchers. Thus, the researchers remained unaware of the identity of any respondent, and the health
authority had no access to the completed survey. This safeguard for the confidentiality of responses was made clear to potential respondents in the covering letter.

7.2.4 Data analysis
We entered the data into Microsoft Access 2000. Data were analysed in Access and SPSS version 10. Results were calculated for respondents who had not moved out of the area and who gave a usable response. For the cases where both GP and patient had a usable response to a structured question, agreement between GP and patient for comparable questions was calculated using the kappa statistic.\(^{31}\)

We also performed content analysis on the free text responses to open-ended questions. A coding framework was developed to describe the thematic content of responses, and individual responses were coded using this.\(^{32}\) An assessment of the agreement between GP and patient accounts was made by one researcher (FS).

7.3 Results
7.3.1 Sample sizes
In total, 606 instances of removal in the most recent four months were identified from the routine data, comprising 471 distinct removal groups (or events). Thus, study identifiers for 471 patients and 282 GPs (since many GPs were involved in more than one event) were supplied to health authorities undertaking the mailing.

Local health authority staff then reduced the samples further by removing patients or doctors from the samples where they felt the survey would be inappropriate. Almost all of those removed were in Kingston & Richmond, where staff manually filtered out a large number of instances in which the removal had been due to the patient moving out of the area, but which had still been coded as ‘DDR’.

The final sample sizes are shown in Figure 7:1. In all, surveys were mailed to 338 patients and 207 GPs.
7.3.2 Response rates

Of 207 surveys mailed to GPs, 3 were returned by the Royal Mail and 158 were returned completed, giving an effective response rate of 77.5% (158/204). Of 338 surveys mailed to patients, 19 were returned by the Royal Mail and 120 returned completed, giving an effective response rate of 37.6% (120/319). This low response rate by removed patients was not unexpected, and is consistent with experience from elsewhere: in Lothian a postal survey of removed patients achieved a response rate of 26%, and a similar rate was achieved in Northern Ireland (O’Reilly, personal communication). However, a response rate as low as this clearly raises the strong possibility that response bias will influence our quantitative findings.

We were reliant on local health authority staff to mail the survey and up to two reminders. In some authorities staff did not have time to send all the reminders required. Unsurprisingly, therefore, response rates were highest for Durham & Darlington, St Helens and East Surrey, where we know that GPs and patients both received two reminders. The patient response rates achieved in these areas are encouraging and suggest that it may be possible to achieve higher rates if surveys are well planned and perhaps relate to more recent events.

Response rates by health authority are shown in Table 7-1, below.
### Table 7-1: GP and patient survey response rates by health authority

<table>
<thead>
<tr>
<th>GP survey</th>
<th>Durham &amp; Darlington</th>
<th>Doncaster</th>
<th>St Helens</th>
<th>East Surrey</th>
<th>West Surrey</th>
<th>Kingston &amp; Richmond</th>
<th>Other (no ID)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveys mailed</td>
<td>53</td>
<td>70</td>
<td>54</td>
<td>6</td>
<td>17</td>
<td>7</td>
<td>0</td>
<td>207</td>
</tr>
<tr>
<td>Returned by Royal Mail</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Responses</td>
<td>48</td>
<td>49</td>
<td>44</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>158</td>
</tr>
<tr>
<td>Response rate (%)</td>
<td>92.3</td>
<td>71</td>
<td>83</td>
<td>83.3</td>
<td>29.4</td>
<td>71.4</td>
<td>77.5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient survey</th>
<th>Surveys mailed</th>
<th>64</th>
<th>152</th>
<th>85</th>
<th>8</th>
<th>17</th>
<th>11</th>
<th>0</th>
<th>338</th>
</tr>
</thead>
<tbody>
<tr>
<td>Returned by Royal Mail</td>
<td>9</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Responses</td>
<td>22</td>
<td>50</td>
<td>36</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>120</td>
<td></td>
</tr>
<tr>
<td>Response rate (%)</td>
<td>40</td>
<td>33.8</td>
<td>45</td>
<td>42.9</td>
<td>23.5</td>
<td>36.4</td>
<td>37.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

An initial assessment of the reason given for the patient removal revealed that many GPs and patients said the removal was because the patient had moved outside the practice area. Of the responses from GPs, 38% had "moved out of the area" as the reason for the removal. Similarly, of patient responses, 33% gave this as the reason for removal. We had hoped that in selecting only instances coded as DDR we might have avoided such removals in our sample, since they are not of interest in the current study. The inclusion of such removals suggested that in many cases removals were being miscoded in the Exeter system. We discuss this issue in greater detail in the previous chapter.

We removed such cases from the dataset prior to analysis, as well as a small number of responses which were unusable. In all, 89 responses from GPs and 77 from patients remained. The figures are shown by health authority in Table 7-2 below.
Table 7-2: Usable and unusable responses by health authority

<table>
<thead>
<tr>
<th>GP responses</th>
<th>Durham &amp; Darlington</th>
<th>Doncaster</th>
<th>St Helens</th>
<th>East Surrey</th>
<th>West Surrey</th>
<th>Kingston &amp; Richmond</th>
<th>Other (no ID)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out of area (n)</td>
<td>23</td>
<td>27</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>60</td>
</tr>
<tr>
<td>Out of area (%)</td>
<td>47.9</td>
<td>55.1</td>
<td>18.2</td>
<td>20</td>
<td>20</td>
<td>0</td>
<td>0</td>
<td>38</td>
</tr>
<tr>
<td>Unusable</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Usable responses</td>
<td>23</td>
<td>18</td>
<td>33</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>89</td>
</tr>
</tbody>
</table>

Patient responses

| Out of area (n) | 10 | 26 | 2 | 1 | 0 | 0 | 0 | 39 |
| Out of area (%) | 45.5 | 52 | 5.6 | 33 | 0 | 0 | 0 | 32.5 |
| Unusable | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 4 |
| Usable responses | 11 | 23 | 33 | 2 | 4 | 3 | 1 | 77 |

7.4 Results from the GP survey

7.4.1 Characteristics of respondents
The characteristics of the 89 GP respondents are summarised in Table 7-3, below. The age and sex of respondents to this survey were similar to respondents to the national survey (45.9 years, 74% male v 47.5 years, 75% male). However, respondents to this survey tended to work in larger practices than respondents to the national survey, with the majority working in practices of 4 or more principals and a median list size of 6482, compared with a median of 5400 for the national survey.

Table 7-3: Characteristics of GP respondents

<table>
<thead>
<tr>
<th>N</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age: mean</td>
<td>83</td>
</tr>
<tr>
<td>Sex: male</td>
<td>87</td>
</tr>
<tr>
<td>Number of principals</td>
<td>88</td>
</tr>
<tr>
<td>One</td>
<td>18 (20%)</td>
</tr>
<tr>
<td>Two or three</td>
<td>24 (27%)</td>
</tr>
<tr>
<td>Four or five</td>
<td>31 (35%)</td>
</tr>
<tr>
<td>Six or more</td>
<td>15 (17%)</td>
</tr>
<tr>
<td>List size: median</td>
<td>86</td>
</tr>
</tbody>
</table>

7.4.2 Characteristics of removed patients
We asked GPs about the characteristics of the patient they had removed, and responses are shown in Table 7-4. Removed patients had been registered with the practice for a mean of over five years.

Respondents reported that 44% (39/89) of the patients had a drug or substance misuse problem; 25% reported that this had been a factor in the removal. This figure is difficult to interpret in the absence of any data from a matched control sample, but it is clear that a drug misuse prevalence of 44% is high, suggesting that this may be an important risk factor for removal.
Given reported concerns over patients with mental illness being at increased risk of removal,\textsuperscript{11,12} we asked GPs whether the removed patient suffered from any mental illness. Again, the figures are difficult to interpret in the absence of control data, but the proportion of patients with any mental illness (18%, 16/89) does not suggest as strong a risk as that of drug or substance abuse.

<table>
<thead>
<tr>
<th>Table 7-4: Characteristics of removed patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Age: mean</td>
</tr>
<tr>
<td>Sex: male</td>
</tr>
<tr>
<td>Years registered with practice: mean</td>
</tr>
<tr>
<td>Conditions:</td>
</tr>
<tr>
<td>Drug or substance misuse</td>
</tr>
<tr>
<td>Chronic medical condition</td>
</tr>
<tr>
<td>Acute mental illness</td>
</tr>
<tr>
<td>Chronic mental illness</td>
</tr>
</tbody>
</table>

7.4.3 Reasons for removal

Respondents were asked to indicate the primary and any contributory reasons for the removal, given the same list of reasons used in the national GP survey (section 5). Results are shown in Figure 7:2 and in Table 7-5, below.

As in the national survey, violence, threatening or abusive behaviour was much the most common reason given, being cited as a factor in 64% of cases and as the primary reason in 54%. The results of this survey of recent instances were broadly consistent with those of the national survey with regard to the prevalence of reasons for removal. Non-compliance with appointments was reported slightly more often in this survey (in 30%), with drug or substance misuse being slightly less frequent (25.8%). However, because of the smaller number of respondents in the current survey, these differences may be due to chance. The only result that differed significantly from national survey findings was that on "inappropriate demand for consultations", both within and out of hours. Only 10.1% and 11.2% of GPs respectively felt these were factors in the removal decision, compared with 28.3% and 18.3% in the national survey.

Financial incentives were not reported as a primary reason for removal by any respondent, although there were two instances where non-compliance with cervical cytology and one instance where non-compliance with childhood immunisation were contributory factors.
Figure 7.2: Primary and contributory reasons for removal, from GP survey

Table 7.5: Primary and contributory reasons for removal, from GP survey

<table>
<thead>
<tr>
<th>Reason</th>
<th>Primary n (%)</th>
<th>Contributory n (%)</th>
<th>Ever a factor n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Violence, threatening, abusive behaviour</td>
<td>48 (53.9%)</td>
<td>9 (10.1%)</td>
<td>57 (64.0%)</td>
</tr>
<tr>
<td>Non compliance with appointments</td>
<td>16 (18.0%)</td>
<td>11 (12.4%)</td>
<td>27 (30.3%)</td>
</tr>
<tr>
<td>Deception or crime</td>
<td>14 (15.7%)</td>
<td>12 (13.5%)</td>
<td>26 (29.2%)</td>
</tr>
<tr>
<td>Inappropriate demand for medication</td>
<td>9 (10.1%)</td>
<td>17 (19.1%)</td>
<td>26 (29.2%)</td>
</tr>
<tr>
<td>Drug or substance misuse</td>
<td>10 (11.2%)</td>
<td>13 (14.6%)</td>
<td>23 (25.8%)</td>
</tr>
<tr>
<td>Non compliance with treatment</td>
<td>8 (9.0%)</td>
<td>13 (14.6%)</td>
<td>21 (23.6%)</td>
</tr>
<tr>
<td>Inappropriate demand: out of hours</td>
<td>3 (3.4%)</td>
<td>7 (7.9%)</td>
<td>10 (11.2%)</td>
</tr>
<tr>
<td>Inappropriate demand: in hours</td>
<td>7 (7.9%)</td>
<td>2 (2.2%)</td>
<td>9 (10.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (5.6%)</td>
<td>3 (3.4%)</td>
<td>8 (9.0%)</td>
</tr>
<tr>
<td>Patient complaints</td>
<td>3 (3.4%)</td>
<td>1 (1.1%)</td>
<td>4 (4.5%)</td>
</tr>
<tr>
<td>Unconventional treatment</td>
<td>1 (1.1%)</td>
<td>3 (3.4%)</td>
<td>4 (4.5%)</td>
</tr>
<tr>
<td>Particular kind of GP</td>
<td>0 (0.0%)</td>
<td>3 (3.4%)</td>
<td>3 (3.4%)</td>
</tr>
<tr>
<td>Inappropriate sexual behaviour</td>
<td>0 (0.0%)</td>
<td>2 (2.2%)</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>Non compliance with cervical cytology</td>
<td>0 (0.0%)</td>
<td>2 (2.2%)</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>Non compliance with childhood immunisation</td>
<td>0 (0.0%)</td>
<td>1 (1.1%)</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td>Cultural differences</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
</tr>
</tbody>
</table>

7.4.3.1 Violent, threatening or abusive behaviour

Respondents were asked to give further details of any violent, threatening or abusive behaviour which had prompted the removal, and responses are shown in Table 7-6. Of the 57 cases in which this type of behaviour was a factor in removal, verbal abuse was by far the most common category reported, (91%, 52/57) followed by specific verbal threats or physical
action against property (42%, 24/57). No serious incidents, such as producing a weapon, were reported.

Reception staff were the most common recipients of verbal abuse, who were involved in 81% (42/52) of such incidents – almost half of all the removal instances under study (47%, 42/89). GPs were also frequently recipients of verbal abuse, being involved in 52% (27/52) of such incidents. Specific verbal threats, physical action against property and physical action without injury were also directed principally against GPs (71%, 17/24), although again reception staff were frequent targets (42%, 10/24). There were 9 cases in which other patients were abused, of which two involved verbal threats and two incidents where other patients were subjected to physical action without injury.

<table>
<thead>
<tr>
<th>Nature of behaviour</th>
<th>All instances</th>
<th>Behaviour directed towards</th>
<th>Reception staff</th>
<th>Other patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal abuse</td>
<td>52</td>
<td>27</td>
<td>4</td>
<td>42</td>
</tr>
<tr>
<td>Specific verbal threats, or physical action against property (eg banging table)</td>
<td>24</td>
<td>17</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Physical action without injury (eg pushing or obstructing)</td>
<td>10</td>
<td>5</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Serious incidents: producing a weapon or actual injury to a person</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>All forms of behaviour</td>
<td>57</td>
<td>33</td>
<td>5</td>
<td>44</td>
</tr>
</tbody>
</table>

In many instances respondents reported behaviour of more than one sort directed against more than one subject.

In four of the 57 (7%) cases in which violent, threatening or abusive behaviour was given as a reason for removal, the patient was reported to have caused damage to the surgery or practice property.

In a quarter of cases (14/57), the patient’s behaviour was formally reported to the police and in 10 cases (17.5%) the patient was removed immediately, under paragraph 9a of the terms of service. In 9% of cases (5/57) the doctor felt that the patient’s behaviour was motivated by racism.

7.4.3.2 Deception or crime
In 26 cases deception or crime was cited as a factor leading to removal. In 20 of these cases, doctors gave further details. Most (16/20, 80%) were reported as being related to prescription fraud or theft. In 4 cases, patients were reported as registering at more than one practice, and in 2 cases as stealing from the surgery. There was one case of sick note fraud.

7.4.3.3 Inappropriate demand for consultations
In 33 cases inappropriate demand was a factor in the removal. In 24 of these, doctors gave further details in an open text section of the questionnaire. The most common reasons involved patients coming to the surgery or requesting home visits immediately for problems
the GP regarded as non-urgent, and often being rude and abusive. Three GPs described patients who insisted on making urgent appointments but failed to attend.

*Immediate home visits for child. Not willing to attend surgery.*

*Walking into surgery and demanding to see doctor immediately while he was in consultation.*

*Frequent non-surgery appointment attendance but yet frequent out of hours home visits by rota.*

There were also descriptions of patients demanding urgent unnecessary appointments for repeat prescriptions or requesting referrals.

*Asking for medication and referral does not need.*

7.4.4 Communication with the patient before the removal

Before deciding to remove a patient from their list, three-quarters (73%, 58/79) of doctors reported taking actions which might avoid the removal (Table 7-7).

In 51/75 (68%) cases the patient was warned that they were at risk of removal, mostly in person, and occasionally in writing. Of the 17 patients given written warnings, 11 were removed due to failure to keep appointments.

In 56% (38/68) of cases doctors advised patients how they should act to avoid being removed, and in 25% (16/65) cases they were encouraged to find another practice, to avoid being removed. These actions were usually taken in person.

**Table 7-7: Communication with the patient before removal**

<table>
<thead>
<tr>
<th></th>
<th>Yes…</th>
<th>51</th>
<th>38</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>… in person</td>
<td>37</td>
<td>30</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>… by phone</td>
<td>7</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>… in writing</td>
<td>17</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>30</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>14</td>
<td>21</td>
<td>24</td>
<td></td>
</tr>
</tbody>
</table>

7.4.5 Communication with the patient after the removal

Table 7-8 shows the actions taken by practices to communicate with patients after the removal decision had been made.

In 49/76 (64.5%) of cases the practice told the patient they had been removed, and in 44/75 (58.7%) the patient was given a reason for their removal. This figure is considerably lower than that found in the national survey (see section 5 above), in which 83% (238/288) of GPs reported that had given the patient a reason for the most recent removal. The majority of those informed of their removal and given a reason were given this information in writing.

The health authority was given a reason for the removal in 44/79 (55.6%) of cases. In 18/81 (22.2%) of cases there was further communication between the practice and the patient after the removal had occurred.
Table 7-8: Communication with the patient after the removal

<table>
<thead>
<tr>
<th></th>
<th>Practice told patient they had been removed</th>
<th>Patient was given a reason for the removal</th>
<th>Health authority was given a reason for the removal</th>
<th>Further communication between practice and patient after removal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes…</td>
<td>49</td>
<td>44</td>
<td>44</td>
<td>18</td>
</tr>
<tr>
<td>… in person</td>
<td>11</td>
<td>11</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>… by phone</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>… in writing</td>
<td>38</td>
<td>30</td>
<td>38</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>31</td>
<td>35</td>
<td>63</td>
</tr>
<tr>
<td>Missing</td>
<td>13</td>
<td>14</td>
<td>10</td>
<td>8</td>
</tr>
</tbody>
</table>

7.4.6 The process of removal

In practices which were not single-handed, the decision to remove the patient was undertaken by the partners together in 76% (52/68) of cases, and by an individual doctor in the remaining 24% (16/68). When asked how they knew what to do to remove the patient, the majority of GPs (78%, 69/88) said the practice had previous experience of removal. 23% said they sought advice from the health authority and 14% followed published guidance from various sources. Two GPs said the practice manager had attended a course on managing patients. Most GPs (73/85, 86%) did not feel any additional advice or support would have helped them with the removal.

Other relatives or household members were removed in a fifth of cases (21%, 19/89). This is slightly higher than the proportion of group removals we estimated from the routine data (15%). In 12 of these cases, children under 16 were removed with GPs saying they did not feel they could continue to treat the children without contact with the parents.

7.4.7 Lessons from the experience

GPs felt the removal could have been avoided in 23/84 (27%) of cases. In the majority of these cases the GP considered the patient to be the one who could have acted differently to avoid the removal.

Only if the patient had modified his behaviour and apologised.

If patient had behaved and listened to medical advice.

If patient had cancelled appointments.

One GP felt the removal could have been avoided if better services for patients with substance misuse problems were available and one GP requested prior notification of patient’s violent behaviour in order to allow precautionary measures to take place. Only 4/84 (5%) GPs said they felt they could have done anything differently to improve the way they handled the removal.

Refused to provide treatment earlier on and suggested a ‘cooling off’ period for the patient to think about making a commitment to the programme. I always felt very pressurised by him.

Only a minority of GPs (7/84, 8%) felt the practice had suffered any adverse effect as a result of the removal. These adverse effects included stress to the practice staff, wasted
appointments, a complaint against the staff and the reputation at the Primary Care Agency; one GP said they felt a failure.

7.5 Patient survey results

7.5.1 Characteristics of respondents
Of the 77 patients responding to the survey, 53% (40/76) were male. The mean age of respondents was 39.7 years, and their mean length of registration with the removing practice was 14 years.

7.5.2 Reasons for the removal
We provided space in the questionnaire for the patient to give a brief explanation of what happened. We also asked them to consider a list of statements and tick any that they felt might apply to them. The statements were intended to provide a non-judgemental counterpart to the list of potential reasons for removal we had provided in the GP questionnaire (Table 7-9)

The reason for the removal was often harder to identify in patients’ accounts than in doctors’ accounts. Comparison of the patient and GP view is difficult: the GP can give an account of their motivation in removing a patient, while the patient can only give an account of events, and what they believe the motivation of the GP may have been.

Table 7-9: List of factors that patients felt may apply to them

<table>
<thead>
<tr>
<th>Do you feel that any of the following might apply to you?</th>
<th>n</th>
<th>% (N= 76)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to visit a doctor often</td>
<td>30</td>
<td>39.5%</td>
</tr>
<tr>
<td>Let doctor know you disagreed with treatment or advice</td>
<td>28</td>
<td>36.8%</td>
</tr>
<tr>
<td>Miss appointments on more than one or two occasions</td>
<td>24</td>
<td>31.6%</td>
</tr>
<tr>
<td>Ask for treatment the doctor did not wish to prescribe</td>
<td>24</td>
<td>31.6%</td>
</tr>
<tr>
<td>Drug or alcohol problems</td>
<td>22</td>
<td>28.9%</td>
</tr>
<tr>
<td>Threaten or shout at the doctor, practice staff or other patients</td>
<td>14</td>
<td>18.4%</td>
</tr>
<tr>
<td>Need a home visit often</td>
<td>11</td>
<td>14.5%</td>
</tr>
<tr>
<td>Complain about or threaten to sue the doctor or practice</td>
<td>11</td>
<td>14.5%</td>
</tr>
<tr>
<td>Ever not tell truth in order to get prescriptions</td>
<td>4</td>
<td>5.3%</td>
</tr>
<tr>
<td>Attack or push the doctor, practice staff or other patients</td>
<td>2</td>
<td>2.6%</td>
</tr>
<tr>
<td>Refuse a cervical smear</td>
<td>1</td>
<td>1.3%</td>
</tr>
<tr>
<td>Refuse any immunisations recommended by the doctor</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Do any damage to practice property or surgery</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Ever try to steal anything from the doctor’s room or practice premises</td>
<td>0</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

The most commonly reported factor was the need to visit a doctor often (30/76, 39.5%), and 14.5% (11/76) of patients considering they often needed a home visit from the doctor. These patients may be those considered by GPs to be ‘high demand’. Over a third of patients reported having let the doctor know they disagreed with their treatment or advice.

Perhaps surprisingly, a fifth (15/76, 19.7%) of patients admitted threatening, shouting at,
attacking or pushing the doctor, practice or other patients. As suggested by the GP survey, the majority of these were threats or shouts, with only 2 cases where the patient made a physical attack.

Only one patient reported having refused a cervical smear and none reported refusing any immunisations recommended by the doctor for themselves or their children. This is consistent with results from both GP surveys and suggests that financial targets are not a significant factor in removal decisions.

Where possible, we paired the list of factors in the patient survey with the corresponding reason in the GP survey to compare the prevalence of reports from each (Figure 7:3). In some categories of reason, such as missed appointments or demand for medication against the GPs advice, there was a surprising degree of concordance between results. A similar proportion of patients claimed to have drug or alcohol problems (29%) as the proportion of GPs who felt this to be a factor in the removal decision (26%). However, GP and patient reports differed considerably on other issues, particularly on deception or crime and violent, threatening or abusive behaviour, where the high prevalence reported in the GP was not reflected in the patient survey.

The issue of demand was difficult to compare: we asked doctor whether inappropiate demand was a factor, whereas we asked the patient simply whether they felt they needed to visit a doctor often or needed a home visit often. Although a large proportion of patients reported needing to see a doctor often, inappropriate demand in-hours was not reported by the GPs to be a major factor in the removal decision.

Figure 7:3: Comparison of GP and patient reported factors affecting removal
7.5.3 Patient accounts of events leading to the removal

We asked patients why their doctor removed them from the list and to explain briefly what happened. Respondents often gave long and detailed explanations within the available space, occasionally using further sheets of paper to give more details. The length and style of writing (use of capital letters, underlining) indicated that many respondents felt very strongly about the removal decision. The accounts were often unclear and it was not always possible to gain a clear picture of the events that led to the removal. Of the 77 responses, there were 39 in which the patient gave some idea of what happened to cause the removal.

The doctors did not give a reason for removing me from their list, but I had missed several appointments without notifying the surgery, and thought this must be the reason.

A further 21 patients attempted to give an explanation, or described a situation which they appeared to link with the removal decision, but the reason was still not clear.

I was sat in my chair in the doctors room, I asked for a repeat prescription and the doctor quickly removed himself out of his chair and started waving his arms telling me to leave the surgery (angrily). So I respected his wishes and left the surgery.

The remaining 17 patients claimed not to know the reason.

I was given no explanation.

Informed by local health department.

The majority of the 39 respondents who gave an explanation of the events leading to the removal described events which fell within the scope of the list of possible reasons we had originally drawn up. There were 13 patients who mentioned some sort of incident involving the doctor or practice staff. However, while the GPs described abusive or threatening behaviour, the patients reported little more than raised voices.

I used bad language.

Had an argument with the receptionist.

I started shouting a bit.

There were three accounts in which the patient spoke of losing their temper, but gave few details as to what actually happened.

I have a temper problem and showed this bad side of me.

The other commonly reported reasons were missed appointments (7 cases) and disagreement over treatment or advice (6 cases).

I missed 3 appointments with a doctor.

For missing an appointment at DRI (his version). Really because I was not in agreement with him for reducing my medication.

The only reason I can think of is because I have had three children under him and in all cases I didn't want to have my post-natal examination.

The reason I was given was that I required a cure for an infection that I was against as I had not long before been on some. I was told that I was not willing to help myself get well by taking his instruction.
A small number of other reasons emerged from the free text answers that we had not asked patients about elsewhere. In one instance the patient requested a particular GP and there were also two instances where the removal appeared to be due to cultural differences between the patient and GP.

I asked for Dr X and they sent a lady doctor. I just told her I wanted the doctor that I asked for, that’s all.

...was taken off the list because I changed my doctors because they were religious and had beliefs and did not agree with a decision I made to have a termination. I could no longer see that doctor so therefore I moved practices and my daughters were removed from the list.

I am a reformed alcoholic in my case the doctor threw me off the list as he is Pakistani and does not believe in drinking he had no time for me when I needed help the most.

There were three instances that we included within this analysis where the reason given by the GP was that the patient had moved out of the practice area, but the patient felt there were other factors involved as well.

After seeking help for a detox from authorities I got very little help so I decided to go private … I went to see Dr X and he was very blunt and rude and told me I would be removed from the surgery because I was living out of the … area. I know the real reason was because of the nature of the visit.

No patient mentioned refusing immunisation or cervical screening, or needing expensive treatments as a factor in the removal; thus, the low incidence of removal for financial reasons reported by GPs are corroborated by patients.

7.5.4 Communication with the GP before the removal

Patients reported little communication from the practice prior to the removal. Although some patients (13/75, 17.3%) said they were warned of the risk of removal, very few (3/68, 4%) were told how to act in future to avoid being removed or were encouraged to find another practice (4/69, 6%), as Table 7-10 shows. This contrasts with results from the GP survey which suggested that GPs warned patients in 68% of cases that they were at risk of removal and told patients in 55% of cases how to act in future to avoid being removed.

<table>
<thead>
<tr>
<th>Did the doctor or practice…</th>
<th>... warn you that you were at risk of removal?</th>
<th>... tell you how to act in future, to avoid being removed?</th>
<th>... encourage you to find another practice, to avoid being removed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>... in person</td>
<td>7</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>... by phone</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>... in writing</td>
<td>6</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>62</td>
<td>65</td>
<td>65</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>

7.5.5 Communication with the GP after the removal

Similarly, there was also a difference – though less marked – between patient and GP perceptions of communication after the removal (Table 7-11). Only 36% of patients said they
had been given a reason for the removal, compared with 59% of GPs who reported giving the patient a reason. Of the patients who were given a reason, 71% (17/24) did not agree with the reason the GP had provided. Fifteen of these provided brief explanations.

*It was a convenient excuse to use me missing an appointment Drs don't like addicts on lists.*

*I was very ill and hysterical.*

*I never missed 3 appointments.*

A small number of patients (13/70, 19%) said they had made an official complaint about the removal. Of these, seven were addressed to the health authority or primary care agency and three to a member of the practice (doctor, practice manager or receptionist).

About a fifth of patients said they had been removed from a doctor’s list before (16/75, 21%). Ten of these had been removed more than twice before, and one reported having been removed ‘dozens’ of times and said they were being moved every 12 weeks. Other household members or relatives were removed at the same time in almost a third of instances (23/74, 31%). Of these removals, over half (11/21) involved removing children under 16.

### Table 7-11: Communication with the GP following the removal

<table>
<thead>
<tr>
<th>Did the doctor or practice...</th>
<th>...tell you that you had been removed?</th>
<th>...give you a reason for the removal?</th>
<th>...have further communication with you after the removal?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>40</td>
<td>26</td>
<td>14</td>
</tr>
<tr>
<td>... in person</td>
<td>5</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>... by phone</td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>... in writing</td>
<td>35</td>
<td>17</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>34</td>
<td>46</td>
<td>59</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

### 7.5.6 Coping with the removal

Responses to the patient survey suggested that patients suffered some difficulties following their removal. The majority (59/76, 78%) reported there being a period of time during which they were not registered with any doctor, though about a half of patients had found a new doctor within a month (24/50, 48%). Half of respondents reported having difficulties in finding another doctor, with the most common problem being that surgeries in the area were not taking on new patients.

When finding a new doctor, almost half of the patients (37/76, 49%) found another doctor by themselves, and 16 patients (21%) received a letter telling them which doctor they should go to. Eleven patients (14%) had not yet found another doctor. Nineteen patients reported having received advice or support in trying to find another doctor, mainly from the local health authority, primary care agencies or local nurse or health visitors.

About two-thirds (52/76, 68%) of patients said that being removed from the doctor’s list had caused them problems. When asked to give details as what problems they encountered, the most common problem was related to not being able to receive treatment or medication they
felt they required. A few patients also mentioned psychological effects, such as being anxious, stressed or suffering from depression.

Anxiety and depression and needing psychiatric help for paranoia. Distress and upset within my home at my family seeing me in these states of trauma.
Could not get treatment for back problem and asthma.
Stress and trauma, upset.
Worry, anxiety, shame, embarrassment and still does.

The experience of being removed also affected the relationships with other doctors, nurses or health professionals for 39% of patients (29/75). The most common problems were a lack of trust in doctors, and a feeling of insecurity or anxiety about doing something that may lead to their being removed again.

7.5.7 Improving the situation
The majority of patients (62%, 44/71) said that additional advice or support would have helped them cope better with the removal. Many patients spoke of wanting more communication with the GP before the removal.

Person to visit me to explain the full situation and to show a bit of sympathy after what happened.
More time and he could have given me a reason for his actions which wrecked about 6 months adjusting to another doctor.
Telling me what I should do.

87% (61/70) of patients felt the doctor or practice should have done something to avoid removing them from the list. Patients felt the practice should have communicated better before the removal and given them more warning beforehand. Some patients also said they would have wanted more information about why they were removed.

Talk to me and warn me of the dangers of what I was doing.
Contacted me to explain the full situation and to see if I was fine and to sort differences out.
To have used his professional compassion and understanding and his practice staff should not have judged me or talked to their friends about myself and my problems.
Recognized my frustration with my illness.

In contrast, only 40% (29/73) thought that they could have done anything themselves to avoid the removal. Although this figure may be surprisingly high, many of the written comments suggested that the patient may not in fact have accepted any responsibility for the removal.

I could have avoided the alcohol with more help which I never got. The doctor could have given me more support.
Notified surgery of non-attendance.
Tell lies about my addiction.
Not to have suffered from brain haemorrhages. Please excuse my sarcasm.
7.6 Matched cases

In 31 instances of removal, we received a response from both the patient and the GP involved. Although this is only a small number of cases, it does provide an opportunity to compare directly the patient and GP perspective of the events leading up to the removal itself.

We asked both doctors and patients to give a brief explanation of the events which led to the removal, and also provided space for further comments at the end of the questionnaire. Of the 31 matched cases, 30 GPs and all 31 patients provided a written account of events. Reading the comments offered by the GP and patient in each case allowed a greater degree of insight than was possible from the other parts of our study.

7.6.1 Level of agreement between patients and GPs

Six structured “tick box” questions related to communication between the GP and patient both before and after the removal, and were asked of both. For these, we compared GP and patient responses in the matched pairs. For each question the $\kappa$ statistic was calculated as a measure of agreement. Interpretation of $\kappa$ is generally taken as: $\kappa > 0.75$ implies excellent agreement, $\kappa$ between 0.4 and 0.75 good agreement, and $\kappa$ below 0.4 poor agreement.\textsuperscript{31}

Of the six questions, agreement was very poor in four (warned, encourage to find another practice, told had been removed, given reason), not calculable for one (told how to act in future) and good in only one (further communication).

Table 7-12: Measure of agreement between GP and patient for selected questions

<table>
<thead>
<tr>
<th>Question</th>
<th>$\kappa$</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the patient warned that they were at risk of removal?</td>
<td>0.14</td>
<td>Poor</td>
</tr>
<tr>
<td>Was the patient told how to act in future to avoid being removed?</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Was the patient encouraged to find another practice to avoid being removed?</td>
<td>0.23</td>
<td>Poor</td>
</tr>
<tr>
<td>Did the doctor or practice tell the patient that they had been removed?</td>
<td>0.31</td>
<td>Poor</td>
</tr>
<tr>
<td>Did the doctor or practice give the patient a reason for the removal?</td>
<td>-0.11</td>
<td>Indicates less agreement than expected by chance alone</td>
</tr>
<tr>
<td>Was there further communication between the practice and the patient?</td>
<td>0.60</td>
<td>Fair to good</td>
</tr>
</tbody>
</table>

7.6.2 Comparison of GP and patient stories

The stories related by the GPs and patients differed greatly, both in the actual events recounted and in the way in which the stories were told. The GP stories were generally short and provided only information about the removal decision itself. In contrast, patient stories were often lengthy and difficult to understand. Frequently, the patient account did not give any particular reason or explanation for the removal, but described a chain of events or a situation, without actually saying what they felt had led to them being removed.

*My doctor removed me from his list as he no longer wanted to treat me. He told me no other doctor in his practice would treat me and told me to find another practice in town. He also refused to amend any medication which had been authorised by my consultant and told me to leave his place of practice. (Patient 10)*
Basically I was very ill, more mentally than anything else and the doctors, especially Dr X, had no experience in caring. I have now been given a chance by myself, no thanks to the above. I know I had a lot of problems at the time, however I now have one of the best doctors, who understands, listens and cares. (Patient 11)

When comparing the account of events, there were different degrees of agreement. In one third of cases, there was a reasonable level of agreement as to the events that caused the removal, although the emphasis and degree of severity of events differed.

Case 20
Persistent failure to keep appointments, in spite of verbal discussion and warning letter. (GP)
I was removed from my doctor as I missed a few appointments. (Patient)

Case 31
Rudeness, unreasonable demands. Removed all family. Son (2 years) had several UTIs and although parents were rightly concerned they were very rude and demanding and we could do not nothing right. (GP)

The doctor we saw reported an unusual viral infection in our 2 year old son’s urine. When they went to recheck the urine again they repeatedly lost the urine sample 3 times to be exact. Our son has been known to have a low immune system along with other health problems. With all this in mind and the report of a specific bug in his urine which alarmed the doctors and them losing the urine sample 3 times, we ran out of patience and there seemed to be no sense of urgency. As we were extremely concerned for the health of the child we threatened to report the doctor concerned and said we would take it legal if they continued to be incompetent. (Patient)

In a further third of instances, the stories were quite different but had some common elements suggesting that they were referring to the same events.

Case 5
Patient was very abusive, shouting for his prescription. He was told his prescription has been sent to the chemist for collection. Patient didn’t want to go to the chemist which is approx 100 yards form surgery. He wanted his prescription now, not prepared to go to the chemist – was shouting, threatening to sue me and was very abusive in front of 10 people waiting in the surgery. (GP)
I was prescribed methadone for my heroin addiction and I stopped taking it whilst still receiving prescriptions. (Patient)

Case 14
Verbal abuse from patient. Swearing at staff over the phone on 2 previous occasions. On this occasion she told me to f*** off and slammed the phone down. She did not contact the surgery and when the health visitor went to her house the following day she was given verbal abuse and not let over the threshold. I decided she and her sons could not re-establish a therapeutic relationship with us. (GP)
I had a 2 ½ inch laceration to my left foot I went to hospital whom told me to see the Doctor. I couldn’t walk so I asked her to come out to see me she refused told me to go back to the hospital. I received a letter 2 days later to say me and my two sons have been removed from the Doctor’s surgery. (Patient)
In the final third of cases, the stories did not appear to relate to the same event at all.

**Case 24**

Aggressive behaviour to GP and staff. Unrealistic demands on GP. (GP)

The doctor removed me from his list because he didn’t like where I lived. (Patient)

**Case 19**

1. Aggressive and abusive. 2. Alcohol abuse. 3. Demanding immediate attention. (GP)

When I mentioned to each doctor about my past they seemed ‘to me’ that they did not want to know! I’ve had several, in as many years. Why do they not listen? (Patient)

Despite the lack of agreement and consistency between the two sets of views, a number of themes emerged that helped to explain the differences.

7.6.3 Events leading to removal

The description of events leading up to the removal suggested that the removal decision was rarely based on a single incident that triggered the removal, but was the result of a series of events or problems that contributed to progressive strain on the doctor/patient relationship. In all but one of the instances, the GP described an incident, or series of events where the patient was aggressive or unco-operative with the practice. Over a third of cases referred to repeated patterns of behaviour that caused the removal.

There had been repeated episodes of the patient coming into the waiting room and shouting abuse at the receptionists and doctors. There had been numerous abusive phone calls. (GP 12)

Swearing at staff over the phone on 2 previous occasions. (GP 14)

Persistent failure to keep appointments. (GP 16), (GP 20)

Similarly, the removal decision frequently seemed to result from a combination of events or factors. The events were often complex and combined several reasons.

Aggressive behaviour to GP and staff. Unrealistic demands on GP. (GP 24)

Patient did not attend for appointments given within the surgery hours. Too many out of hours visits which were not emergencies. (GP 6)

Where the patient described the event, they often spoke of disagreements with the doctor or practice staff, either over treatment or over the way an episode had been handled. By contrast with GP accounts, patients often referred to a single incident only, with no mention of previous conflicts.

I used bad language to ask a Doctor to leave my house. I’d been having fits and didn’t think my treatment right. (Patient 9)

I was using too much inhaler. And my husband is asthmatic too and the Doctor said that he was using too much inhaler. What do you do when you can’t get your breath? (Patient 18)

The circumstances leading to the removal decision were unique for each removal but often seemed due to a lack of communication and understanding of the rights and duties of both parties. Many problems arose due to difficulties in the individual doctor-patient relationship, with the patient’s trust in the doctor lacking or the doctor feeling the patient was
uncooperative.

Epileptic patient with personality disorder who refused the offer of help I considered appropriate, ultimately leading to detention by the police. (GP 9)

He was requesting inhalers in spite of appropriate advice from GPs, nurses and chemists. (GP 18)

Patient did not trust any doctors and requested me to check on others advice and reassure her that she should comply with specialists advice. I felt I had made her too dependent on me. (GP 28)

Doctors often reported the relationship being broken by the behaviour of the patient (abusive, uncooperative), while patients reported situations in which they considered the GP or practice to have been unsuccessful in meeting their needs or expectations.

7.6.4 Perceptions of responsibility

There were marked differences in perceptions of responsibility for the removal shown by GP and patient. Patients tended to consider their GP to be at fault – not being caring, or being unresponsive to their needs – and did not mention their own behaviour as contributing to the removal, often not mentioning significant events reported by the GP. Where the patient described the reason, or the events that led to the removal, the story was often worded to make it clear that they did not feel responsible or felt that they were acting in an appropriate way.

Because I called her out repeatedly, although I was ill. (Patient 28)

He removed me because he misdiagnosed my twin sister, who later died of her condition so I told him what I thought of him. (Patient 1)

This may be a form of defensiveness, but could also be because the patients did not believe that they were ‘at fault’ in any way.

Case 2

Social worker was threatened, eventually had to be sectioned. (GP 2)

I had recently lost my partner, my job and consequently very nearly my home therefore I got very depressed and eventually turned to drink – I needed a lot of understanding, help and moral support. (Patient 2)

In some cases there were clear differences between patient and GP in their understanding about how services should be used, particularly around the appointments or home visits, and attending for appointments which had been made.

Case 17

We removed the patient as she failed to attend appointments on 6 occasions. (GP 17)

I was removed from the doctors list as I was supposed to have missed 3 appointments. But I only missed 2 as I never made the 3rd appointment so I was wrongly removed from the practice. (Patient 17)

In addition, the question of ‘appropriate’ demand was highlighted in a number of instances, with doctor and patient opinions differing as to when home visits or urgent appointments were required.
Patients within the matched case sample reported higher levels of mental illness than did the
doctors (mental health problems were reported by 15 patients but only seven of their GPs),
perhaps suggesting that they see themselves as having a greater need for medical care than
do their GPs.

Although there was some evidence of GP tolerating a certain level of what they saw as rude
or unacceptable behaviour from patients, they also appeared to be conscious of their
responsibility to protect their staff and other patients from abuse.

The last straw came when she came in drunk, lay on the waiting room floor and screamed abuse at
the doctors and staff. There were other patients in the waiting room who were frightened of this. (GP
12)

Verbal abuse towards the practice by the son. Some reflecting itself badly on a hard working
dedicated staff. Upsetting other patients. (GP 22)

7.6.5 Perceptions of abuse

The perspectives of patients and doctors in instances where the GP reported some level of
abuse were markedly different. In line with previously reported reasons for removal, 20 GPs
(66% of this sample) talked of the patient being abusive as a factor in the removal. Again, the
majority of the abuse was verbal (rudeness, swearing, aggression, etc.) but there were five
incidents in which the patient was felt to be threatening and two incidents in which they were
physically threatening.

Again, in line with other findings from this survey, the prevalence and severity of threatening
or abusive behaviour reported was considerably less in the patients’ accounts than in those of
the GPs. No patient mentioned threatening behaviour or physical abuse. There were five
instances where verbal altercations were mentioned but the level of severity described
differed from the account of the GP.

Case 1

The person removed from the list had phoned myself and threatened me physical harm if she came
across me. I felt that in view of this I would be unhappy either visiting the patient at home or seeing
the patient in the surgery. (GP 1)

So I told him what I thought of him … Dr X removed me because of a single comment I made to him,
on the phone. (Patient 1)

Case 7

Adult patient and two friends surrounded practice manager and threatened her verbally. When they
were asked to control children in the surgery and then pushed manager… (GP 7)

Person A, I and Person B went in and on the way out were told the children were noisy. So Person
A, who is a single parent of two, was upset so I went back in and asked politely for her to apologise
to Person A because I felt it was not fair, kids are noisy. (Patient 7)

Sometimes patients did not appear to recognise the abuse as a reason for removal, often not
mentioning the abuse at all. In some cases, where the GP felt the abuse was a sufficient
reason for removal, the patient appeared to feel the abuse was justified in the situation. While
the doctor simply reported the abuse itself, the patient reported the events that led to them being abusive – presumably as a way of explaining and justifying their behaviour.

_He removed me because he misdiagnosed my twin sister, who later died of the condition so I told him what I thought of him._ (Patient 1)

_On the Tuesday I phoned to speak to the doctor (I had a navel infection), by the Thursday I was still waiting for the doctor to call. So I phoned up the surgery to speak to doctor. I asked what had happened on the Tuesday and asked why he didn't call. I was told there was nothing wrote down … The receptionist advised me she would ask him to call me after surgery about 5 o'clock. My daughter had to go out. I had to drop her off, I left the house 5.20pm, the doctor phoned me 5.30pm so I missed him. I phoned on the Friday the receptionist answered who answered on Tuesday. I told her what I thought of her. She was a waste of space with a few swear words._ (Patient 13)

The abuse in such instances appeared to be a result of the patients’ frustration with what they saw as incompetence on the part of the doctor or the practice, or related to their anxiety or distress about the condition about which they were consulting the doctor. This frustration or anxiety appeared to be heightened by differences between doctor and patient over how services should be used and what medical care could realistically achieve.

_Doctors staff member phoned (my wife who has bowel cancer and was waiting for results from blood tests), your results are here and doctor wants to see you, do you want an appointment now? Wife I will phone later. Try and imagine what you would feel if someone rang you who knows you have cancer of the bowel and drops this on you. On the face of it they have done nothing wrong, what they don't realise is that you the patient have been waiting for this call day after day hoping its all clear, no one says don't worry, all's well, but the doctor would like to see you just the same. Instead you sit in your kitchen in tears fearing the worst. So I phone to speak to doctor I am told he starts at 16.30 hours but it is unlikely I could speak to him because he is so busy, to which I reply he will speak to me w---y, 30 seconds later w---y phoned me back and asked why are you talking like that, I reply w---y I don't have time for this right now. I decide to go to doctor's surgery and see him. I arrive at 16.35 hours there are no patients waiting in the waiting room (so much for busy). I see w---y and say I would like to see doctor. Doctor comes out of his office what's the problem j---. I say to him is there any cause for my wife to worry about these results none he says. I say then why could your staff not say that when they phoned instead of leaving my wife in tears fearing the worst, I hope your staff never have to go through what she has, God help them if that ever happens. Doctor replies I have to look after my staff. What about the patients I reply or do they come second to your staff I leave before I get too involved (Patient 25).

In some instances in which the GP reported abusive behaviour, the patient did not mention the abuse or their part in the removal decision but talked of how they perceived the GP to be uncaring.

_People like myself are very lucky to be alive and have to live with my personal, emotional and physical disorders. My doctor was about as ‘compassionate as a full bucket of piss’ … What happened to care and understanding and listening._ (Patient 10)

_Basically I was ill, more mentally than anything else and the Doctors, especially Dr X, have no experience in caring._ (Patient 11)
7.6.6 Moving on
There was evidence in the accounts of a lack of resolution following the removal decision. Some patients reported not knowing the reason for the removal, or not fully understanding why they had been removed. Only one of the patients in our sample appeared to accept to some extent why they had been removed.

Although I agree that my missing several appointments without notice would not be acceptable, I think the surgery should have given me prior notice and a chance to explain the reason. (Patient 16)

Many of the patients wrote detailed explanations as to what happened, suggesting a level of frustration remaining weeks or months after the removal event. There were some instances in which the patient reported not knowing what had happened, and the GP reported not giving a reason.

I had no idea I had been removed until I received a letter from X health authority telling me I had been removed from my doctor's books with no explanation. (Patient 6)

I gave the doctor no reason to remove me from his books. I suspect the conduct of my social worker due to the mix up in my medication from the doctor has something to do with it, for peace of mind I need to know, I suffer from paranoia and it is not made any easier not knowing the truth. (Patient 15)

Patients appeared confused or angry about their removal, whether or not they had been given a reason. Few accounts suggested that patients accepted any reason given for their removal or felt they had taken anything positive from the experience: there were two instances where the patient commented about their new doctor being more responsive to their needs.

However I now have one of the best Doctors, who understands 'listen!' (and cares) (Patient 11).

We have recently registered with a new practice and found the staff and doctors to be more in control, friendly and organised. (Patient 31)

7.7 Discussion
This survey of patients and GPs with recent experience of de-registration provides important information about the process and consequences of this event. The findings of the GP survey reflect those of the national GP survey, reporting violent, threatening and abusive behaviour as by far the most common reason for removing a patient from their list. The majority of these incidents involved verbal abuse, often directed at other member of practice staff. Doctors were the most frequent target of more severe forms of abuse (notably threats). Verbal abuse and specific verbal threats constituted the majority of cases, with physical abuse occurring in just over a tenth of removals. The proportion of incidents of each type of abuse, with verbal abuse being the most common, reflected those found by in a recent study of aggression and violent behaviour in general practice.26

Patients and doctors reported missed appointments and disagreement with medical advice or treatment as frequently as one another, but reported quite different levels of deception or crime and abuse. Patients reported principally verbal abuse, and often explained their behaviour as responding to problems with the GP or practice staff. They did not refer to their behaviour as being unacceptable, and it may have been a result of the frustrations and
anxiety surrounding their illnesses or conditions.

Concerns about removal due to financial reasons appeared unfounded as neither GPs nor patients reported these as a primary cause of removal. Due to an absence of control data, it is difficult to assess whether patients with mental health conditions or drug and substance abuse are at higher risk of removal than other patients. However, the high proportion of patients reported to suffer from drug or substance abuse suggests that this may be a significant risk factor for removal.

A large proportion of patients reported not knowing why they had been removed and the majority said they were not given a reason. Although this contrasts with the GP account, over 40% of GPs also reported not providing the patient with a reason, suggesting that there may be some patients who genuinely do not know why they were removed, and certainly a large number who do not fully understand the removal decision.

While GPs report a high level of communication with the patient, removed patients do not feel they are being listened to and given a chance to communicate. Prior to the removal, GPs report warning patients of the risk of removal, yet many patients did not feel they were warned and felt they would have benefited from better communication with the GP.

The differences between patient and GP accounts of the events leading up to the removal suggested a lack of knowledge of acceptable behaviour or recognition of the impact of their actions on the part of the patient. The patients' explanations of the removal indicated a lack of understanding of the right of the GP to remove them, or of their own responsibilities within the relationship.

The GP surveys suggested that GPs see themselves as only removing patients after a series of events or problems that increasingly strain the relationship. In contrast, the actual process of removal is relatively unproblematic for doctors, and they suffer few, if any, problems as a result of the removal. By contrast, patients reported a low level of support following the removal and many adverse effects. In addition to the practical problem of finding a new GP, some patients reported feeling anxious about being removed again in the future. These feelings may be exacerbated by not knowing exactly why they were removed in the first place.

The accounts of both GPs and patients demonstrate the necessity for GPs to be allowed to deregister patients in certain circumstances. The evident frustration and disagreement of GP and patient over the events leading to the removal suggest that it would often be difficult or impossible for a therapeutic relationship to be re-established. However, some of the problems surrounding deregistration could be ameliorated by improved communication on the part of practices, with patients offered a full explanation of the reason and preferably an opportunity to discuss this, where possible.

7.7.1 Limitations of this study

As with all postal surveys, the issue of response bias poses a threat to the validity of our findings. While the GP survey response rate was satisfactory (77.5%), the response rate for
the patient survey was worryingly low (37.6%), although higher than that achieved in similar surveys elsewhere. This clearly raises a strong possibility of response bias in the quantitative findings from this survey, which should therefore be treated with some caution.

The fact that others have experienced even lower response rate in this patient group suggests that there may be characteristics of this population – such as frequently moving address, or being disinclined to respond to surveys – which lead to a low response rate. However, we also experienced frustrating logistical problems in effectively managing a postal survey which, for ethical reasons, had to be mailed locally by health authority staff. In some of the authorities we found it was difficult to ensure that the first and follow-up mailings were carried out in a timely manner, and we know that in some areas some reminders were not sent because staff were busy with other matters. Clearly, this may have adversely affected the response rate. We would argue that, in terms of methodological quality and therefore the validity of eventual findings, having surveys sent out from health authorities is definitely second best to having the process under the direct control of the research team.

However, it is increasingly the view of ethics committees and indeed health authorities themselves that in order to remain both ethical and legal initial contacts with patients must be made by the NHS rather than by independent researchers. If this view prevails, then we would argue that in order for research to be effectively carried out health authorities will have to commit a defined resource to support the research which the NHS commissions from independent researchers.
8. CONCLUSIONS

8.1 Summary of findings
The primary aim of the research we have described here was to determine the scale and reasons for doctor-initiated de-registration in England. In addition, we sought to deepen understanding of the events leading to removals and the processes involved in removal, from the perspective of both doctors and patients.

8.1.1 Scale of patient removals
We have estimated the incidence of removals in England to be 4.3 per 10,000 patients per year, a figure which is close to that of 4.8 per 10,000 patients per year reported from Northern Ireland, but much lower than the figure of 16 per 10,000 per year previously reported from Sheffield.

We regard this figure as sufficiently low as to justify describing patient removal as a rare event. Assuming an average list size of 2,000 patients per whole-time equivalent GP principal, an “average” full-time GP might be expected to remove one patient from their own list every 14 months. Since patients are often removed in groups, the frequency of removal events will in fact be lower than this.

However, it is clear that considerable variation in removal rates exists both between health authorities and between practices: for example, in Sheffield almost two-thirds of practices recorded rates of below one removal per 1,000 patients per year, while one practice was found with a rate of 16 removals per 1,000 per year. In the present study, we have noted four- or five-fold variation in rates between health authorities, though the variation in coding practice noted above will account for some of this. Previous work has suggested that population removal rates increase with deprivation, practice size, and in urban populations, but are unrelated to the age or sex of the GP. While at one time fundholding may have been a factor influencing removal rates, this is obviously no longer the case. The implication of such variation is that there are many practices which have very rarely, or never, removed patients, while there are a small number of practices which frequently do so.

In addition, there are particular patient attributes associated with an increased risk of removal, such as age, and possibly drug misuse.

We had hoped, in this study, to advance our understanding of practice and population factors associated with removal rates though a detailed analysis of the data held in the Exeter system. Unfortunately, it soon became clear that different coding practices were followed in different health authorities, so that any detailed analysis would have been likely to produce spurious results. In principle, though, data routinely collected in the Exeter system in the course of managing patient registrations and deductions provides the ideal means of monitoring, auditing and researching doctor-initiated deregistration. For this to happen, clear and unambiguous categories of removal are needed (which is very nearly the case at present), and standard coding practices must be adopted by all coders in all authorities.
8.1.2 Reasons for patient removal

The national GP survey, together with surveys of GPs and patients involved in recent instances of removal, have provided detailed information on the importance of various reasons for patient removal. Of course, there is the risk that self-report by GPs may not provide an unbiased account of removal reasons, so it is reassuring – and perhaps rather surprising – to find that for some reasons, the prevalence of reasons reported by GPs accords quite closely with the prevalence of factors offered by patients.

By far the most common reason reported by doctors is violent, threatening or abusive behaviour, which is much less often reported by patients. Much of this is abusive rather than violent behaviour, and much is directed at reception staff. Doctors also report deception or fraud more often than do patients. Violent, threatening or abusive behaviour was cited by doctors as a factor in two-thirds of removals, consistent with reports from Scotland and Northern Ireland.21 25

Less common, but still frequent, factors involved in removal are disagreements between doctor and patient over advice or treatment, missed appointments, frequent (and, from the GP viewpoint, inappropriate) consultations, and drug or substance misuse. These factors are reported by both doctors and patients.

Finally, refusal of cervical cytology screening or of childhood immunisations are very rarely, if ever, reported – either by doctors or by patients – as factors in the removal. Thus, although there is widespread recognition by GPs of a financial incentive to remove patients for such reasons, this appears to be acted upon only very rarely. In contrast, the media and perhaps public perception is that the target payment schemes are implicated as factors in a significant proportion of removals, which is understandable given the incentives which are clearly recognised by GPs. Given this gap between perception and reality, there is a case for considering whether modifications to these schemes might be made which could attenuate the perverse incentive to remove patients who refuse cervical cytology or childhood immunisation, without compromising their effectiveness in achieving important public health goals.

The detailed written accounts of doctors and patients reveal that in many, and perhaps most, cases the removal follows a period during which the relationship between doctor and patient – or between practice and patient – is under strain, and the removal is simply the final step in a sequence of events. In the accounts we examined, there was often a sense that doctors felt they had tolerated a pattern of troublesome behaviour in a patient for long enough, and could do so no longer; while from the patient’s perspective, there was often a sense of gradually losing faith in the doctor or practice, or of being in a state of heightened anxiety or fear about their own or a family member’s medical condition, or of feeling they needed more care than was being offered. Thus, the threatening or abusive behaviour that so often precipitated removal usually had a context which rendered the behaviour, to the patient at least, understandable and justifiable.
8.1.3 **The processes of removal**
The surveys of recent removals suggested that patients are frequently as distressed or angered by the *processes* of removal as by the fact of the removal itself. In particular, patients may not know why they were removed, may have difficulty in understanding any reason which has been given, may face difficulties in re-establishing regular contact with a primary care service, and may experience lingering anxiety or insecurity in their relationships with health professionals.

Whether or not anything can be done to reduce the incidence of patient removal, these findings suggest that there is a strong case for considering whether the process of removal might be improved in ways which avoid such outcomes whenever possible.

8.2 **Implications for policy and practice**
From what has been said above, it would be reasonable to draw the conclusion that, given the context of strained or difficult relationships which precede them, few patient removals are preventable by any simple or general measure. Nonetheless, there are a number of measures which might be taken at national, local and practice levels to improve matters and to provide more reliable information for audit and research in future.

8.2.1 **National level**
A *contractual obligation* to provide the patient with a reason for removal would be likely to be opposed by a majority of GPs and therefore is unlikely to provide more useful or accurate information for either patients or primary care commissioners than is already provided voluntarily.

However, a *good practice guide* published or endorsed by the Royal College of General Practitioners, the General Practitioners Committee of the BMA, the General Medical Council, medical defence organisations and patient organisations might be helpful. Although guidance has already been published by some of these organisations, awareness among GPs is low. Revised guidance supported by key stakeholders, developed in conjunction with practices and which includes clearly set out practical procedures (for example, checklists, flowcharts or similar materials) and is widely disseminated might have greater impact than existing guidance.

*Available deduction codes, and coding practice, for the Exeter system* should be reviewed to ensure that doctor-initiated removals of non-moving patients are being consistently recorded in all areas. In addition, a standard report of such removals by practice could be generated on a quarterly or annual basis and provided to primary care trust clinical governance leads for local review.

8.2.2 **Primary care trusts and groups**
As part of *local clinical governance* arrangements, primary care organisations should encourage practices to be aware of and follow guidance on good practice in this area, and in particular encourage practices to provide a written explanation to removed patients.
Additionally, primary care organisations should review at least annually the number of patient removals from each practice, using routinely produced figures, in order to identify those with high removal rates. Reasons for the high rates could be discussed with practices concerned to identify any underlying remediable factors.

Local arrangements for the care of repeatedly removed patients may need to be reviewed and if necessary developed further by primary care trusts and groups. In addition, local arrangements for the care of violent patients may need to be developed, in accordance with principles previously set out by the NHS Executive. Models of such services are beginning to be reported.

In addition, primary care trusts and groups should consider offering a formal in-person meeting to removed patients, with the aim of providing a clear explanation for the removal, an opportunity to discuss their experience, information on how to avoid removals in future, how to find a new doctor, and options for care (such as NHS Direct, walk-in centre, minor injury unit) during any period they are without a doctor.

8.2.3 Practices
Practices must be encouraged to provide a clear written explanation of the removal decision to all patients. Although this should not be obligatory, there are likely to be only very few occasions on which it will be unhelpful or harmful.

In the course of writing to the removed patient, an information pack for removed patients could routinely be included on how to find a new doctor, and on NHS expectations of how patients should make use of primary care services. This could also include information on any primary care trust advice service provided locally for removed patients.

Practice leaflets should make clear to patients the expectations the practice has for how services should be used: for example, on use of out-of-hours services or on keeping appointments made in advance.

Reception staff are frequently the subject of the verbal abuse which precipitates removal, and practices should consider how best to train and support their staff in this context.

8.3 Implications for further research
The study reported here has confirmed and enlarged upon findings from elsewhere, and has provided a range of new findings, particularly in identifying the shortcomings of the existing routine data and in providing patient and GP accounts of recent removals. However, there is a need for more detailed qualitative studies to deepen our understanding of the changes in the doctor-patient relationship which precede many or all patient removals.

In addition, a carefully designed case-control approach would be an informative and practical approach to examining patient-specific factors – such as drug use or mental illness – which increase the risk of removal. Further analysis of routine data would be warranted once coding issues have been resolved.
The issue of patient removal is very closely related to that of managing violent, threatening or abusive behaviour in primary care, and more detailed investigation in this area – particularly of the effectiveness of different approaches – would also be helpful.
9. REFERENCES


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