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Patients repeatedly removed from GP lists: a mixed methods study of “revolving door” patients in general practice

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Thesis submitted in fulfilment of the requirements for
the Degree of Doctor of Philosophy

University of Glasgow

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October 2011

Abstract

Introduction Patients who have been repeatedly removed from General Practice (GP) lists, so-called “revolving door” patients in general practice have not been examined in the literature. This mixed methods study sought to define and characterise “revolving door” patients in general practice in Scotland. It investigated the impact they had on the NHS and the impact this status may have on “revolving door” patients themselves.

Methods Thirteen semi-structured interviews with Practitioner Services and GP professional key informants and one “ex-revolving door” patient were conducted and analysed using a Charmazian grounded theory approach. Patient removal data from the Community Health Index were used to construct cohorts of “revolving door” patients and link them with routine NHS data on hospital admissions, outpatient attendances and drug misuse treatment episodes. These data were analysed quantitatively and qualitatively and all the data were integrated dialectically.

Results “Revolving door” patients were removed four or more times from GP lists in six years. There was a dramatic decline in the number of “revolving door” patients in Scotland whilst the study was conducted. It appeared this was because the NHS response altered due to changes in approaches to treating problem drug use and pressure to reduce removal activity from professional bodies. The final influence was the positive, ethical, regulatory, and financial climate of the 2004 General Medical Services contract. “Revolving door” patients had three necessary characteristics: unreasonable expectations of what the National Health Service had to offer, inappropriate behaviour and unmet health needs. Problem substance use and psychiatric health problems were important. Professionals who came into contact with “revolving door” patients found it a difficult experience and they generated a lot of work. Being a “revolving door” patient impacted on the quality of care that patients received in general practice in terms of relational, informational

and management continuity of care. “Revolving door” patients were more likely to be admitted to hospital after they have been removed from a GP list and more likely to be referred for addiction care after they were re-registered.

Conclusions It was the status of being repeatedly removed from GP lists that set “revolving door” patients apart from the usual general practice population. I suggest that GPs were able to suspend their core values and remove “revolving door” patients because the legitimate work of general practice was challenged. There were two ways in which this may happen. The first was that “revolving door” patient’s dominant health needs were not viewed as biomedical because they contained aspects of a moral schema of understanding. The second was that their behaviour or expectations threatened the doctor-patient relationship. These were features common to other patients reviewed in the literature on problem doctor-patient relationships. “Revolving door” patients did not understand the unwritten rules of the doctor-patient relationship; so removing them from GP lists did not change their behaviour. Current theories about personality disorder and adult attachment should be integrated into the work of general practice and further researched in this context. This might help GPs and patients to improve problem doctor-patient relationships.

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Acknowledgements

Thank you to Phil Wilson my main supervisor who stayed the course with verve and good nature; he provided the light touch, consistency and wise counsel I needed, and even made treks to Bell St Hostel for supervision. And to Alison Petch, Mick Bloor and Ken Mullen for being successive great co-supervisors, steering me and stopping me at the right moments.

My thanks to lots of individuals in Practitioner Services, Greater Glasgow and Clyde, ATOS Origin, and ISD Scotland who supported this project from the start; especially to Janet Mair and Leanne Hopkins.

Thank you to the professional key informants who gave up their time, and to the Practitioner Services staff and GPs who tried their hardest to recruit patients; it was appreciated. To the ex revolving door patient who allowed himself to be interviewed, thanks; for allowing this study to meet all of its aspirations- just.

My thanks to Paul Johnson, Robertson Centre for Biostatistics for his professionalism and expert support during the statistical analysis, to Roy Robertson, University of Edinburgh for taking the time to comment on a draft of the thesis, and to Jane Williamson, Mani Rasphone and Graeme Bingham for their graphical and editorial support.

My enduring gratitude to all my community of colleagues in General Practice and Primary Care; especially to Jilly Hamilton, Pat Smith, Phil Cotton, Graham Watt and Catriona McPhail. That they allowed me the space to get this thing done, with such belief in my chances- meant that I did. Also to colleagues and patients at Homeless Health Services, Glasgow for a weekly dose of reality and humour that kept me professionally sane.

My loving thanks to Saket, Sanand and Ashwin and my wider family and friends, who stayed, with support, even when they were tired of my absences (literal or virtual).

Author's declaration

I, Andrea E Williamson, confirm that I as the named author conducted the research study detailed in this thesis. I declare that all the material presented in this thesis is my own work unless specifically stated otherwise.

The following posters have been presented based on material contained in this thesis:

- The “revolving door” in general practice: patients who are repeatedly removed from GP lists. Homelessness and Health inaugural conference (RCGP), University of Oxford, 2006
- Defining “revolving door” patients in general practice: data from key informant interviews and the Community Health Index, Scotland. Primary Care strategy day, Glasgow, 2009

The following presentations have been made based on material contained in this thesis:

- Patients who are repeatedly removed from GP lists: the “revolving door” in general practice. ADEG, Scottish Academic General Practice annual meeting, 2007
- Defining “revolving door” patients in general practice: data from key informant interviews and the Community Health Index, Scotland. Society for Academic Primary Care, annual meeting, 2009

Abbreviations

CHI -Community Health Index

DNA -did not attend

GP -general practitioner

GROS -General Register Office for Scotland

ISD- Information Services Division (NHS National Services Scotland)

LMC- Local Medical Committee

nGMS -2004 General Medical Service contract

NHS- National Health Service

PC- post code

PSD -Practitioner Services Division (NHS National Services)

QUAL- qualitative

QUAN- quantitative

SDMD- Scottish Drug Misuse Database

SIMD- Scottish Index of Multiple Deprivation

1. Introduction

1.1 Background

“People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care.”
(Frank, 1995)

A “revolving door” patient has been repeatedly removed from General Practice (GP) lists at the GPs' request. The impetus for interest in researching this area comes from my clinical background as a GP working in homelessness health care. One of the aims of working with homeless patients is to enable patients' eventual re-integration back into mainstream general practice once they are re-settled in a local community. I had found that this proved difficult for some patients to achieve, as they would say that practices would not take them on their list. This sat at odds with the generally accepted viewpoint that registration with a practice is accessible and easy; and sparked my interest. A small exploratory study examining how patients achieve registration with GP practices followed. Practice receptionists and Health Board officials involved in GP registration matters were interviewed and “revolving door” patients were described to me for the first time (Williamson, 2004). I was intrigued to find out who they were and what prompted this situation for some patients; being repeatedly removed from GP lists. What is going on with these patients; effectively shunned from a general practice system that has a claimed reputation for trust, co-ordination, continuity, flexibility, coverage, and leadership (Gillies et al., 2009)? An initial brief review of the literature, surprisingly, found that despite there being a body of work on single patient removal episodes, these repeatedly removed patients were excluded from final analyses (O'Reilly et al., 1998b), or mentioned in passing at the ends of reports (Munro et al., 2002). This gap in the literature prompted me to continue, with what has turned out to be a challenging and rewarding odyssey into understanding who these patients are; what this status means for them; and what it means for the health service. Carrying out research about a group of patients, who do not fit into straightforward clinical or behavioural

categories that the health service demands of patients, has brought its own additional challenges, alongside those of completing a doctoral thesis. Moreover, during the six years that the study was conducted “revolving door” patients effectively disappeared; investigating this development has brought further rewards. I have ended up following theoretical routes I would never have expected to; and learning from fields that have enhanced my other professional roles in teaching and clinical practice.

1.1.1 Importance of registration with a GP

All patients have a right to register with the GP of their choosing. However GP practices have a right to refuse a patient and to remove patients from their list (Scottish Executive, 1998; Scottish Government, 2004). Permanent registration with a GP is necessary to have access to most health services in the UK and universal registration (Goddard & Smith, 2001) (that all UK residents are registered with a GP) is falsely assumed in the extensive literature on access to services.

1.1.2 Health as normal function

This study was undertaken with the view that the presence of “revolving door” patients in the context of general practice registration was not desirable. This is underpinned by a widely held aspiration of the National Health Service. This clearly expresses that all patients should have access to health services irrespective of need (Ross, 1952), and corresponds to the philosophical idea that health (as normal function) has a special status in society. Health is required to protect the citizen’s opportunity to participate in the political, social and economic life of society. This is a component of Rawls principle of “equality of opportunity” and articulates a social justice approach to health care (Daniels, 2001).

1.1.3 Assumptions about the problem

My starting point for this thesis was that it was GPs and practices that were somehow at fault by not providing the continuity and holistic care that every patient in the NHS should expect. Also, that these patients may undergo such

frequent interruptions to health care, that this will affect negatively, their access to care. The impact this may have on individual patient's health and on generating health inequalities, I guessed; as being a negative one. I assumed that patients who change practices often, have great difficulty establishing therapeutic relationships with health professionals.

1.1.4 Previous Scottish data on patient removals

Information Services Division (ISD) of NHS Scotland published patient removals in Scotland for the year 1998/1999 (excluding geographical moves); this included the first data on repeat removals published in Scotland. Only twelve out of fifteen Health Boards were at that time able to provide information on patient removal episodes. It was as follows:

Table 1 Patients removed and number of removals in the year ended March 1999¹

	Number of Patients removed	Number of Removal episodes
Total	3 064	3 841
Repeat	406	1 183
Repeat as % of total	13.3%	30.8%
Number of times removed		
2	264	528
3	71	213
4	24	96
5	9	45
6	12	72
7	11	77
8	6	48
9	2	18
10 and over	7	86

(Information Services Division NHS National Services Scotland & Information Services Division NHS National Services Scotland, 1999)

Deciding when the frequency of removal becomes such that a patient can be defined as a “revolving door” patient was part of the focus of this thesis.

¹ Original text of table modified for clarity

1.1.5 Categories of patient removal at the GPs' request

There were three accepted reasons for removal at a GP's request; such as were contained in the administrative notification form used by Scottish practices (Practitioner Services Division, 2004). The first was “moved out of practice area” (General Practice Committee of British Medical Association, 2005; Practitioner Services Division, 2004) since all practices had an agreed geographical boundary. The second, introduced in 1994 was “violence or threatening behaviour” (General Practice Committee of British Medical Association, 2005; Practitioner Services Division, 2004) such that a police incident number has been generated. This triggered immediate removal and special arrangements for care (depending on Health Board). The third category was “breakdown of GP/patient relationship” (Practitioner Services Division, 2004). Since the inception of the most recent GP General Medical Services (nGMS) contract in April 2004; which sets out how general practice functioned and was funded; practices had to give patients a written warning setting out what the problem was. They then must give a written reason to the patient if removal occurs (although the practice could opt out of doing this if it were able to justify the reason for not contacting the patient). A record had to be kept of the removal process for scrutiny by the Health Board (Scottish Government, 2004). In previous GP contracts there had been no such accountability (Parliamentary and Health Service Ombudsman, 1998).

1.2 Early development of the project

The first stage in the development of the study was to identify the key organisations that may have a role with “revolving door” patients. They were general practices themselves; the Primary Care Divisions of NHS Boards (who did so before this function transferred to Community Health Partnerships, when they came into being in 2006), who have a managerial and governance function within GP practices; Practitioner Services (a Division of NHS Scotland) that administered the GP registration system on behalf of the NHS boards; ATOS Origin who managed the Community Health Index (the data system in which registration is managed) on behalf of the NHS, and Information Services

(a Division of NHS Scotland) that collates, processes and publishes national and area data in the NHS.

I met with a practice manager from a general practice to learn more about the process of patient removal; two Primary Care managers from an NHS board who had an interest in registration issues to find out about the role of the NHS boards; and with managers from one of the Practitioner Services Regional Offices. The purpose of these meetings was to understand how the registration process worked and to gain some early impressions of “revolving door” patients from their perspectives. This early meeting with Practitioner Services staff proved invaluable as one key individual became an advocate for the study; offering advice, and support throughout the key stages of it.

With this more in depth knowledge of the system of GP registration and the issues and challenges of studying “revolving door” patients, I undertook the formal literature review that follows in chapter 2.

2. Literature review

2.1 Scope of the literature

The body of literature that this thesis draws on as it proceeds is necessarily broad ranging. It covers a range of fields both in medicine and the social sciences. The rationale for this is that the interaction between an individual and a service has complex influences, can be observed from many perspectives, and can be explained in multiple contexts.

The literature domains can be considered in four groups. The first two are reviewed in this chapter; the first which forms most of this chapter is a systematic review of the literature on patient removals and the “revolving door”. This is fundamental to the thesis as it sets out the general practice research background to the topic of “revolving door” patients and how other fields have conceptualised the “revolving door”. It demonstrates the gaps in the literature on repeatedly removed patients, sets out the epistemological perspectives employed when considering single patient removal episodes, and the problems researchers have found when attempting research in this area. This literature influenced the formulation of the research questions and the methods employed.

The second is the literature areas that have been investigated for possible evidence of “revolving door” patients; these will be reviewed at the end of this chapter.

The third area is covered in chapter 3 which is an overview of the methodologies and chapter 4 the actual conduct of the study. This was the required reading of research methodologies and methods; complicated territory when even at an early stage it seemed a “mixed methods” approach was necessary if the topic were to be satisfactorily explored.

The fourth area is incorporated into the remaining chapters 5-10. These are some theories from sociology, psychology, and research psychiatry in addition to the general practice field of the doctor-patient relationship. They help in the understanding of the results and locate them within existing theories from these fields. Some are used as “sensitising concepts” (Charmaz, 2006).

2.2 Patient removals

2.2.1 Search strategy

Search terms	general practice registration	patient removals	struck off	refusal to treat	general practice lists	revolving door patients
Databases used	1.OVID medline(R) 2.CINAHL 3.EMBASE, 4. Psychinfo From 1966 (or subsequently when the database commenced) to Jan 2011					
Filter 1	The databases were searched for Human and English language citations. Duplicates across databases were removed.					
No. of References	13	11	129	19	46	261
Filter 2	On the basis of the title and abstract, references were retained if they related directly to general practice registration in the United Kingdom. References were also retained if they were a letter or comment on a research paper.					
No. of References	0	4 papers 2 letters	1 paper 3 letters	2 papers	0	0
Filter 3	The complete articles were obtained and the citations from these articles mined to retrieve further articles relating to patient removal episodes in general practice registration.					
No. of Refs	8 papers 2 commentaries 2 letters					
Total Refs	15 papers 2 commentaries 7 letters					

Figure 1 Search strategy for peer reviewed literature

Of the total references obtained by the search strategy papers were subsequently not included in the review if they were of poor quality. This is either because the methods in the studies described did not adequately answer the research question(s) or they were anecdotal accounts.

Relevant policy documents and reports contained in the grey literature were also obtained from searching the citations in the peer reviewed literature. A “Google” search was also performed using the keywords described and I also utilised my knowledge of documents from my clinical role in general practice. Potentially relevant documents were also requested from stakeholders involved in GP registration from Primary Care Division, Practitioner Services, Scottish Executive Health Department and a manager of a General Practice.

2.2.2 Introduction

Research examining general practitioners removing patients from their lists began to be published in the late 1990’s in the UK. There was media and patient group concerns that GP fund holding had financially motivated GPs to increase patient removals. However these concerns seemed to go away from 2003. However the Health Care Commission in England focussed on how GPs manage their patient lists when they instigated a broad review of NHS Complaints in 2007 (Commission for Healthcare Audit and Inspection, 2007).

2.2.3 Patient removals from GP lists: quantitative data

Patient removal decisions

The first body of work from Northern Ireland examined data from a register that recorded all patients removed at the GPs request from 1987 until 1996 (O’Reilly et al., 1998a; O’Reilly, Steele, Merriman, Gilliland, & Brown, 1998b). The unit of measurement was “removal decisions” rather than patient removals as families being removed together along with an index family member would increase the frequency of removals. The researchers

felt “subsequent removals may distort decisions to remove a patient from a list” so only first time removals were considered. This constituted 89% of the total data set. An overall removal rate of 2.43 per 10 000 person years was calculated using practice list size as the denominator (O'Reilly, Steele, Merriman, Gilliland, & Brown, 1998b). However, this rate obscured the variation in practice. One practice removed 91 patients (88 women aged between 25 and 64 years) over 14 days was excluded from the analysis as a deviant case and not examined separately. Thirty-three practices did not remove a patient for the first time during the interval of the study yet one practice had 82 removal decisions from a list size of 12,000. The research concluded that removals were “relatively rare events” although increasing (O'Reilly, Steele, Merriman, Gilliland, & Brown, 1998b).

Reasons for variation in removal rates

There was no relationship between practice size and removal rates and interestingly “practices with some of the highest and lowest removal rates were based within the same town” (O'Reilly, Steele, Merriman, Gilliland, & Brown, 1998b). There was no speculation as to why this might be the case.

Existence of “revolving door” patients

Although those patients who had had more than one removal decision were excluded from the final analysis some detail was provided on those patients. One patient was removed and assigned 26 times during the study period (11 times in 1996) and 53 patients (0.8% of the sample) were removed and assigned 5 or more times (O'Reilly, Steele, Merriman, Gilliland, & Brown, 1998b). No further exploration or explanation was made regarding why subsequent removal may be “distorting” decisions and if the characteristics of those patients who did undergo repeat removal were similar to the first episode removals ones. This reporting of this group of patients may be considered the first researched evidence for the existence of “revolving door” patients. The study succeeded as a first quantitative foray into examining the data on patient removals but a much fuller understanding of

the issues would have been extracted from further examination of deviant cases and the outliers in the data set and further exploratory qualitative work.

A study of routine health authority data in Sheffield examined all patients removed from GP lists between 1991 and 1996. They noted three reasons for removal “moved out of area, violence (recorded from 1994) and other”. They calculated removal rates by electoral ward giving a rate of 2.4 per 1000 Sheffield residents per year. After the figures were adjusted for geographical move this became 1.6 per 1000 Sheffield residents per year. The study concluded that removal rates were not increasing. They noted that 9% of patients were removed more than once (excluding geographical move as the reason) but did not examine this further. There was wide variation in removal rates per practice with the removal rate being under 1 per 1000 for 61% of practices and the top practice having a removal rate of 16 per 1000 patients per year. The top seven removers remained so for five out of the seven years of the study interval.

Given the age and gender distribution of the data the researchers hypothesised that financial disincentives to maintain patients who refused screening interventions and those who generated higher workloads may be factors in patients being more readily removed. Again there was inadequate explanation of the range of removal activity (Munro & Skinner, 1998).

Questionnaire bias

Two papers attempted to find out why GPs removed patients from their lists using postal questionnaire surveys of GPs, one in Northern Ireland (O'Reilly et al., 2001) and one in England (Pickin et al., 2001). 40% had removed one or more patient in the past six months in the English study (Pickin, Sampson, Munro, & Nicholl, 2001) and 46% of GPs stated they had removed a patient in the past two years in the Northern Irish study (O'Reilly, Gilliland, Steele, & Kelly, 2001). There are problems in using questionnaires to ask GPs about an aspect of their practice that they may feel uncomfortable about. For

example recall bias is inevitable; GPs may only recall those removals that are memorable, those who were particularly fraught or those that the GP felt overtly justifiable in carrying out. Those that may have been for less professionally acceptable reasons or were more difficult to explain may be forgotten. As Stokes and McKinley pointed out in a response letter to this paper, investigating the topic in such a way may give an “oversimplified view of what is a complex and stressful process” (Stokes & McKinley, 2001).

The English questionnaire survey was part of a larger Department of Health commissioned study that included interviews with professional and patient organisations concerned with GP patient registration, examination of routinely held Health Authority data on patient removals, and an attempt to cross link accounts of GPs and patients recently involved in a removal episode. This generated a further paper on the topic (Sampson et al., 2004). The findings of the commissioned study largely replicated the different study findings already described. The analysis failed to move beyond description of what was said by whom, and unfortunately therefore to make significant progress on understanding the issues further. However, the report does provide a detailed, informative account of the practical issues surrounding obtaining both a robust data set from the various Health Authorities -despite a national software and coding system being in place- and the discrepancies contained in the accounts of the linked GP and patients accounts of removal. Despite there being no mention of “revolving door” patients in the analysis, a recommendation was made that there should be “locally agreed arrangements for the care of repeatedly removed patients”(Munro, Sampson, Pickin, & Nicholl, 2002).

Geographical move masking motivation for removal

Further work by O'Reilly and Steele concentrated on examining the coding distinction between patients removed from the GP practice list at the GPs request and for those removed because they move outside the GP practice boundary. Some evidence from a small, unpublished study in Lothian that

was cited in this paper² suggested that the distinction is blurred. Using data linked to geographical distance and a proxy for deprivation (that is also linked to GP workload), the study seemed to add weight to the hypothesis that GPs are selective in which patients they choose to remove on the basis of geography, sometimes using geographical distance as a less stigmatising method of removing problem patients whilst choosing to retain other patients who live further away (O'Reilly & Steele, 2005).

2.2.4 Patient removals from GP lists: qualitative data

Qualitative research on the topic of patient removals has examined the perspective of patients (Stokes et al., 2003) and general practitioners (Stokes, Dixon-Woods, & McKinley, 2003).

Patient perspectives

The perspective of the patients was that they viewed themselves as:

““good” patients who complied with the rules that they understood to govern the doctor-patient relationship: they tried to cope with their illness and follow medical advice, used general practice services “appropriately”, were uncomplaining, and were polite with doctors”

They felt the removal to be deeply shocking and stigmatising. They viewed the doctor as having broken the rules of the relationship and these “bad” general practitioners were rude, impersonal, uncaring, and clinically incompetent and lied to patients. The patients feared that their removal might lead to future problems with their identity as “good” patients with indeed some being repeatedly removed:

“Some participants found themselves being repeatedly removed and reallocated, often only staying on GP’s lists for a few months at a time”.

² I was unable to obtain a copy despite contacting the authors directly

This was attributed to “enacted stigma” but no further elaboration was provided.

Recruitment difficulties

The researchers found this a challenging area to research; there were difficulties in recruiting patients as they had to be recruited anonymously through the Health Authority who administered GP registration. They also felt that the characteristics of the patient group “often socially disadvantaged and difficult to reach” made this process difficult. Patients who had been removed for reasons of violence were excluded from the study for safety reasons, and non-responders were not followed up for ethical reasons. It was therefore not possible to consider the study sample entirely representative of the population sample.

The researchers hypothesised that there are a set of rules governing the doctor-patient relationship and that patients are not always clear that they may have broken them. They argued that an articulation of these rules may facilitate improved relationships between doctors and their patients and that a formal smoothing of the pathway to finding a new GP when previous relationships have disintegrated may aid stigmatised patients (Stokes, Dixon-Woods, Windridge, & McKinley, 2003).

GP perspectives

The same research team also looked at GP perspectives on patient removals.

As in the previous quantitative work, GPs articulated patient removals as “a rare and unusual event, “last resort”. They described two distinct types of patients who were removed. The first was “bad” patients who were viewed as having broken the rules of the doctor-patient relationship. This was constructed around three areas: “respect”, “trust” and “appropriateness of use of service”. “Respect” centred around issues of violent or threatening

behaviour and “trigger episodes” were mentioned frequently. “Trust” related to patients making complaints or attempting to manipulate doctors. Removal was seen as a method of sanctioning bad behaviour and “educating” patients into behaving better with their next GP.

The second type were “difficult” patients where the “doctor-patient relationship is so strained they can no longer care for them” The GPs articulated this as a qualitative difference in the relationship such as patients they strongly disliked (eg those who were racist or were neurotic) and those they “lost affective neutrality with” (examples described were patients with somatising conditions, personality disorders and drug misusers). Removal in these cases was seen as “divorce” where the conditions for a therapeutic relationship were no longer met and terminating it would have benefits for both parties.

The researchers acknowledged the account given by GPs may be a partial one. It is unlikely they would present a picture that could be viewed in any other way than one of impeccable professionalism. They also make the point that it is difficult to overcome this partiality (Stokes, Dixon-Woods, & McKinley, 2003).

Patient and GP perspectives

In two follow up papers Stokes et al (2004, 2006) used these studies, to review the doctor-patient relationship.

In the first paper they proposed a model for ending the doctor-patient relationship in general practice. They reviewed the central place that the doctor-patient relationship had in general practice. To do this they used a theory of social relationships and a paper by the sociologist Hayes-Bautista on Mexican patients terminating doctor-patient relationships. They described the “boundary rules” that determined the doctor-patient relationship and how when they were broken it was the alienated party’s intent to redefine the relationship. They also drew a distinction between

breakdown (disorder) and “termination” (dissolution). Breakdown happened when there was a “major breach of the rules” or a series of “minor breaches” over time but did not necessarily result in an end of the relationship. “Termination” described the range of ways that doctors and patients used to end the doctor-patient relationship which included patients moving doctor, patients seeing a different doctor in the practice as well as patient removal from the GP list; “lock out” so described. An important conclusion from this study was that Stokes et al suggested that the doctor-patient relationship for a patient should be seen as a “career” as it has many aspects and influences as described in the paper. They also call for more research to examine the “rules and rituals governing entry into and maintenance of the doctor-patient relationship in general practice” and for mediation strategies that might help (Stokes, Dixon-Woods, & McKinley, 2004).

In the second paper, Stokes et al used a subset in the studies; the “paired” accounts of the patient’s and GP’s involved in the same removal episode, to focus again on patient removal as the end to the doctor-patient relationship. Patients and GPs described each other as bad or good depending on whether they had broken the unwritten rules of the relationship. Social interactionist theory is used to explain these accounts, invoking “substantive rules” (“formal rules of the civic-legal order”) and “ceremonial rules” (“the rules of etiquette”). This continues the analysis of the “ceremonial order of the clinic,” in the tradition of Goffman, Stimson and Webb, and Strong. Following Strong and his focus on the central importance of power relations to the relationship, Stokes et al incorporated Bourdieu’s “theory of practice,” to help explain that within their own “habitus.” This is “people as agents who understand their world and behave accordingly.” Both the patient and the doctor felt they were justified in their responses to what they each saw as a rule breach. The rules were described as “the obligation to render appropriate medical assistance and seek help appropriately”; “the obligation to treat people politely and with respect”; and “the obligation to provide high quality medical care.”

Importantly it was the GP in the relationship who had the “capital”; able in the final outcome to remove the patient and end the relationship. This was viewed as an important use of the exercise of power and another example from the sociology literature of the central and unequal part that power has to play in the doctor-patient relationship (Stokes, Dixon-Woods, & Williams, 2006).

2.2.5 Discussion

Here is a summary of patient and practice characteristics from the studies on patient removals:

Table 2 Summary from the literature of factors associated with single patient removal episodes

Patients			GP practices		Source
AGE	FAMILY MEMBERS	CHARACTERISTICS	DEMOGRAPHICS	GP	
Aged 1-4 Aged 20-45	Children as part of families	Nursing home residence Family poverty	Increased urban setting Increased population mobility Increased population density		O'Reilly, Steele, et al. 1998
Under 10 Aged 20-29 Over 75	Women >men Some children independently of parents	High users of services	Increased deprivation		Munro & Skinner 1998
	Children as part of families	Violence/aggression Screening non-compliance Patient makes complaint Inapprop. demands consultations			Pickin, Sampson, et al. 2001
		Violence/aggression Appointment non compliance Deception or crime Inapprop. demand medication Substance misuse			Munro, Sampson, et al. 2002
	Children as part of families	Violence/aggression Alcohol and drugs Unrealistic/unreasonable demands Treatment differences	Increased urban setting Increased with smaller practice list		O'Reilly, Gilliland, et al. 2001
				Uncaring Impolite Untruthful Clinically incompetent Not valuing personal care	Stokes, Dixon-Woods, et al. 2003
		Bad patients; violate doctor-patient rules Difficult patients; strain doctor-patient relationship			Stokes, Dixon-Woods, et al. 2003

This summary table helps to guide the patient and practice considerations that may be required later in the study.

Importantly the review of the quantitative studies on single episode patient removals draws attention to the weaknesses of using a quantitative approach in this type of research. They did however important background information for the qualitative studies that followed.

The qualitative papers on single episode patient removals and the theories they draw on offered some useful insights into the nature of the doctor-patient relationship and the unwritten rules that might govern them.

One extended the work already conducted on the “ceremonial order of the clinic” (Stokes, Dixon-Woods, & Williams, 2006). The central role that power has in the work of general practice and more particularly in the unwritten rules of the doctor-patient relationship and when that relationship is terminated; is going to be accepted as an intrinsic part of the social world I am about to explore. This means that I acknowledge it is fundamental but I am not going to consider it further as a theoretical focus. This is because, having reviewed additional substantive work on this topic focussed on general practice (Elston et al., 2002; Maseide, 1991; Strong, 1980) I have concluded that using this theoretical perspective does not add to my understanding of the topic or add anything new to the literature.

There were three assumptions underpinning these studies that are potentially challenged by considering the case of “revolving door” patients in general practice. The first was that the doctor-patient relationship was an established one between the doctor and the patient (Stokes, Dixon-Woods, & Williams, 2006; Stokes, Dixon-Woods, & McKinley, 2004), the second was that all patients understand that there are unwritten rules in the doctor-patient relationship and the third was that the removal of “bad” patients was an educative process that means the patient will be a “good” patient with their next GP. These assumptions will be explored later in the thesis.

2.3 The “revolving door”

The term “revolving door” has been invoked by many professions and applied to many people outside of primary care research. A review of the broad range of contexts and how it is applied may help to decipher what the phrase may mean for research about “revolving door” patients in general practice.

In the field of health, its use has been mostly confined to labelling patients according to the interaction they have with secondary care health services.

2.3.1 *Psychiatry*

Attempts to characterise psychiatric hospital in-patients who revolved in and out of hospital has constituted the bulk of “revolving door” patient research along with some work on patients repeatedly presenting for emergency assessment (Ledoux & Minner, 2006). Studies in the USA, UK, Denmark, New Zealand, Israel and Germany defined “revolving door” in-patients and attempted to describe them (Haywood et al., 1995; Hofmann et al., 1992; Kastrup, 1987; Langdon et al., 2001; Lewis & Joyce, 1990; Rabinowitz et al., 1995). Their definitions ranged from patients admitted at least three times to hospital over their lifespan (Langdon, Yaguez, Brown, & Hope, 2001), or four or more admissions in less than 2 years (Hofmann, Gougleris, Panzer, Tigiser, Warken, & Zimmer, 1992), or four or more in less than 2.5 years (Rabinowitz, Mark, Popper, & Slyuzberg, 1995), or four or more in a five year follow up period, (Lewis & Joyce, 1990) or four or more in a ten year follow up (Kastrup, 1987). Early definitions were derived intuitively and subsequently informed by the existing literature.

The UK study was a small cohort study that compared a group of “revolving door” patients to a group who had been admitted less frequently. Routinely available population data was examined in the Danish, New Zealand, Israeli and German studies. The studies found a range of patient characteristics related to their “revolving door” status and it is difficult to conclude

whether this range related to the initial definition of “revolving door”, the study design or to patient population differences between countries.

One paper by Shaw (2004) stood out in the psychiatry “revolving door” literature. Not only did it make a link between “revolving door” patients in psychiatry with those in general practice, it also considered some sociology perspectives that have been influential when considering important theoretical areas for this thesis. The paper reports on a portion of a wider study on psychiatric “revolving door” patients (the definition being admitted to psychiatric hospital on six or more occasions in the previous three years) that sought to also interview a sample of those patients’ GPs. These patients were typified as having:

“sub threshold mental disorders; conditions that are identified not through specific diagnostic symptoms but simply based on a level of distress above a certain subjective threshold as decided by the GP...very demanding of their time and emotions”

A subset of these patients was described as being repeatedly removed from a succession of GP practices too, and early work by Stokes (cited in section 2.2.4) was discussed. Shaw considers there to be three reasons why GPs repeatedly removed these patients; the hope that someone else would sort them out, that they would be taught a lesson and turn into good patients, and the idea of “deviancy amplification”; the latter which I took to mean enacted stigma. The paper introduced some core theories that are intended to explain psychiatric “revolving door” patients. “Dirty work designations” and “good and bad patients” (Kelly & May, 1982; May & Kelly, 1982) which is linked with “legitimacy” and Strong’s evaluation of Goffman’s ceremonial order of the clinic (Strong, 1980) are introduced. Using these the analysis adds excellent insights into the issues. However, despite wrestling with the authentic difficulties of who should be providing care for the patients they describe, the tone of the paper adds the research team’s own challenge of legitimacy and moral censure to the burden they describe these patients as coping with. This is particularly stark when they discuss “medicalising distress”(Shaw, 2004). A more reflexive discussion is missing, one of the

pitfalls of conducting research in territory at the edges of the medical discourse.

More recent psychiatry papers have revisited policy and practice ways in which to reduce recidivism in this setting (Dale, 2010; Fresan et al., 2007; Lichtenberg et al., 2008).

One unique paper compared historical data from the records of an American state hospital in the 1880s, 1930s and 1980s. It examined patient characteristics and hospital utilisation records for those time periods and used the evidence produced, to refute the idea that in the past patients were not discharged from hospital; they were; and therefore “revolving door” patients did not exist. It concludes the main reason for the modern phenomenon of “revolving door” patients in psychiatric hospitals relates to the current pattern of care offered, rather than an alteration in patient characteristics (Geller, 1992). This helps contextualise the patient characteristic centred interpretations that are the dominant psychiatric perspective on the issue.

Forensic psychiatry services have attempted to find solutions to patients “revolving” from the community repeatedly through the court system and state mental hospitals in the USA by introducing an “outpatient commitment system”. This change in the provision of services, has succeeded in improving treatment compliance, and hence helped to prevent relapse and re-admission (Hiday & Scheid-Cook, 1991).

2.3.2 General medicine

Despite the use in common parlance in the UK of “revolving door” patients to describe elderly patients with complex medical co-morbidity who have frequent emergency admissions to hospitals, the research literature avoids the phrase and prefers (multiple) “hospital readmissions” (Walter, 1998). Only one paper in this field used the phrase “revolving door” and this is in a commentary on an evaluation of a nursing intervention to reduce

readmissions (Bixby, Konick-McMahon, & McKenna, 2000). Is perhaps the phrasing in the literature different from the day-to-day words used, an attempt to provide a more precise “medicalised” definition?

The consideration of “revolving door” patients as requiring a repeated need for a medical intervention rather than in some aspect of their interaction with a service; has been applied only to patients requiring physiotherapy for the treatment of chronic limb lymph oedema; a condition for which there are few effective therapies (Foldi, 1999).

2.3.3 Health related fields

The psycho-analytical literature has used the phrase when considering sabotaging behaviour in the contexts of triggering long term unemployment and repeated homelessness, (Smith, 1997) and the psychological literature when recognising the life stressor effect on women, of children “revolving” back through the home after they have already permanently moved out (Dennerstein, Dudley, & Guthrie, 2002; Khandwala, 1998).

The term “revolving door” has been used in the context of street drug misusers accruing repeated criminal convictions and hence “revolving” in and out of prison, and this was largely instrumental in the successful introduction of drug treatment courts as a solution (Harrison, 2001; Hora, 2002). It has been hypothesized too that a mismatch between prisoners’ mental health morbidity and treatment availability has resulted in mentally ill people “revolving” through prison in the UK; (Birmingham, 1999) again adding to the view that it is the service response to an issue that determines “revolving” status.

2.3.4 Other fields

“Revolving door” is a familiar phrase in economics. It is used to describe the employment and reward patterns of practice that occurs when ex-regulators are employed as experts in the area they used to regulate (Heyes, 2003) and to describe the relationship between “capital flight and external debt in

developing countries” (Chipalkatti & Rishi, 2001). In the field of migration it is used to describe the circular migratory pattern of people moving out and in, that increasingly occurs between two countries (Duany, 2000).

2.4 Evidence from related research areas

As the topic of “revolving door” patients in general practice is so little researched I felt it prudent to consider whether repeatedly removed patients were evident in other health research areas that may be relevant. A search in the literature on access to general practice for distinct patient groups revealed that for homeless patients achieving registration was more problematic than for the general population and attendance rates were poor (Crane & Warnes, 2001; Riley et al., 2003). One English Department of Health funded study found that gypsy travellers have difficulty registering with GPs (Parry et al., 2004), and, similarly a review of primary care services for asylum seekers and refugees found the same (Feldman, 2006). Despite there being a modest literature on treatment of alcohol and drug use in primary care no paper could be found that considered GP registration issues. No literature could be found on the role of violence and aggression in GP registration and attendance. Patients who may be repeatedly removed from GP lists did not explicitly feature in any of these literature areas.

2.5 Conclusions

“Revolving door” patients were not examined in the single episode patient removal research conducted in the late 1990s and mid 2000s. Scrutiny of the research reveals evidence of the existence of repeatedly removed patients in the form of deviant cases that have been excluded from the statistical analysis (O'Reilly, Steele, Merriman, Gilliland, & Brown, 1998b). In a recommendation in a research report to the UK government it was advised that their management be considered (Munro, Sampson, Pickin, & Nicholl, 2002); and there was a description of repeatedly removed patients in a qualitative study of patient perspectives on removal from GP lists (Stokes,

Dixon-Woods, Windridge, & McKinley, 2003). Furthermore the findings and the range of methods employed in the studies described, provided useful insights into the benefits and drawbacks of different methods and the possible research settings that might be used for this study.

The theoretical conclusions drawn from the body of qualitative research with GPs and patients in this area form an important context too. One of those; the central role that power has in the work of general practice I am not going to consider further as a theoretical focus because this does not add to my understanding of the topic or add anything new to the literature. I will return to three of the assumptions made about the doctor-patient relationship when patients are removed from lists in these papers. These are that there is an established relationship that all patients understand the unwritten rules governing the doctor-patient relationship and that removal changes the patient's behaviour.

A door that neither closes nor opens but moves round and round is an apt metaphor for the contexts described in the "revolving door" literature across many fields. There is an implicit sense that its use is intentionally pejorative; being about undesired states that are not successfully resolved. Two studies from the psychiatry literature are important for this thesis; the first highlighting some sociological theories that will be revisited later (Shaw, 2004) and the second providing a temper to the patient characteristic focus of much of the other studies in psychiatry (Geller, 1992). Its long historical view of the phenomenon of "revolving door" patients in psychiatry concludes that it is a feature of the provision of services rather than intrinsic characteristics of the patients that lead to the production of "revolving door" patients.

A review of the literature on access to primary care services for marginalised patient groups revealed no specific consideration of removal from GP lists.

The next chapter describes the focus of the study and consideration of the methodologies used.

3. Focus of the study and methodology

3.1 Aim

The systematic review of the literature on single episode patient removals in general practice confirmed that the focus of this thesis - repeatedly removed patients- is a new research area. The aim of the thesis is therefore:

To analyse the phenomenon of “revolving door” patients in the context of GP registration.

The definition of who might be considered to be a “revolving door” patient in general practice has not yet been investigated; and this was the natural starting point. To then follow curiosity would be to ask questions like; who are these patients? Why do they end up being repeatedly removed? What effect does it have on them, their health and their health care? What effect does their existence have on those who work with them and provide their health care? Four discrete research questions were subsequently developed based on these.

3.2 Research questions

1. What is the definition of a “revolving door” patient in the context of GP registration in Scotland?
2. What are the characteristics of “revolving door” patients in the context of GP registration in Scotland?
3. What is the meaning of the existence of “revolving door” patients from a health service perspective?

4. What is the impact of being a “revolving door” patient from the patients’ perspective?

3.3 Overview of research methodology

The design of the study sought to consider approaches that best fitted these research questions (Brannen, 1992) rather than being constrained by my favoured methods or my professional background. There were further context specific considerations to take into account too. There was the knowledge of issues gained from reviewing the methods used to investigate single patient removal episodes, and also that the research was being partly undertaken in order to gain technical skills and experience of conducting health service research under supervision. The methods chosen therefore reflected the opportunities and constraints this afforded. It is also important to note that research that is both a higher degree thesis and that hopes to impact on policy or service delivery, as this does, should be framed in such a way that the results will be understandable and meaningful for the target audiences; general practice academics and the UK National Health Service. For all these reasons a mixed methods approach using both qualitative and quantitative tools was chosen.

An overview of this approach is described in this chapter and the specific methods used to generate each data set are described in detail in the next chapter, chapter 4.

3.3.1 Knowledge claims

Choosing particular methods without first attempting to understand the meaning of the knowledge it claims to harness runs the risk of undermining the quality and rigour of the research process (Ritchie & Lewis, 2003). Furthermore, it was important in the process of developing the research project and deciding on the methodological perspective and methods to use, for me to consider my own ontological and epistemological stance. This enabled me to reflect on the philosophical issues the different kinds of

knowledge generated by the different methods might bring. My conclusions were guided by the work of Ritchie and Lewis (2003) in their review of qualitative research practice in applied social policy. To approach the study overall I took the ontological position (what can be known about the social world) of a “subtle realist” attributed to Hammersley (1992):

“Accepting that the social world does exist independently of individual subjective understanding; but that it is only accessible to us via the respondent’s interpretations (which may be then further interpreted by the researcher). We emphasise the critical importance of respondents own interpretations of the relevant research issues and accept that their different vantage points will yield different types of understanding. But we do not feel that diverse perspectives negate the existence of an external reality that can be captured”(Ritchie & Lewis, 2003).

My overall epistemological position or “how is it possible to find out about the world” (Ritchie & Lewis, 2003) has emerged from a professional background that has included medical training (with its emphasis on biomedical positivism) and more recently social science and research methods training (with its emphasis on interpretivism). I take for my own stance, the view that the relationship between the researcher and the researched is interactive, and the process of undertaking and participating in research impacts on the results and all involved in the process (Ritchie & Lewis, 2003). This means I must remain reflexive throughout the whole research process and carefully consider the impact of the study on the phenomenon under examination. As regards the nature of what constitutes truth I most readily accept the “intersubjective or coherence” theory, an interpretivist perspective that states:

“independent reality can only be gauged in a consensual rather than an absolute way. If several reports confirm a statement then it can be considered true as a representation of a socially constructed reality” (Ritchie & Lewis, 2003).

3.3.2 Using mixed methods

In the early stages when I was at the point of exploring different methods for use in the study I found myself trapped by the schism that had

developed between quantitative and qualitative approaches to research in the health sciences. This I saw as a manifestation of the struggle and identity crisis that primary health care research has had in recent decades to establish itself as a legitimate research field. This was in marked contrast to the sociology literature on mixed methods which for some time now has been able to articulate that both quantitative and qualitative research can have similar epistemological stances and that if properly examined have both inductive and deductive elements to them (Brannen, 1992).

The decision was made to use the best available and achievable methods possible to encompass the scope of the research study and to stick with the methodological underpinnings of each. A checklist by Brannen of possible reasons for using a mixed methods approach was reviewed early in the development of the study and the following were considered relevant (in the order of importance for this research rather than the order listed by Brannen):

- "Qualitative research facilitates quantitative research: ...to help provide background information on context and subjects..."
- "Quantitative research facilitates qualitative research:...quantitative research helping with the choice of subjects for a qualitative investigation"
- "Structure and process: quantitative research is especially good at getting to the "structural" features of social life whereas qualitative studies are usually stronger in terms of "processual" aspects...(Brannen, 1992)

Early on I viewed this as a rather linear process in that I would carry out qualitative research to help me work out how to interpret the quantitative data I would receive. I would then use this synthesis of the qualitative and

quantitative data to devise a definition of a “revolving door” patient and then recruit patients for further qualitative work based on that definition.

However as the study got underway, as a series of complex decisions had to be taken and as I attempted to stay true to the methodological underpinnings of the work I found this model of mixing methods did not fit with my experience. As I read more about mixed methods research in the social sciences literature I developed a refined conceptual framework that allowed me to map out the process of the research which is set out at the end of this chapter (Morse, 2010). It enabled me to think through decisions on how to proceed with and integrate the analysis of the qualitative and quantitative results in a rigorous manner.

3.3.3 Analysis considerations

The analytical approaches to the different qualitative and quantitative aspects of the study will be considered in the next chapter on the specifics of conducting the research but some attention needs to be paid to how the results of these analyses will be integrated. A dialectical approach was adopted. It is defined as:

“A dialectic stance actively welcomes more than one paradigmatic tradition and mental model along with more than one methodology and type of method, into the same inquiry space and engages them in respectful dialogue one with the other throughout the inquiry. A dialectic stance “seeks not so much convergence as insight”....the generation of important understandings and discernments through the juxtaposition of different lens, perspectives and stances”

“the dialectic inquirer is especially attentive to the importance of surprises and paradoxes across the different data sets, valuing and even seeking dissonance as a means to deeper insight” (Greene & Hall, 2010).

When attempting to integrate the data “analytical generalisations” from the results were made (Onwuegbuzie & Combs, 2010). I aimed to compare what I discovered, with theories from a number of fields in health and social research. I investigated where they might fit or indeed even add further

weight to these theories taking into account the strengths and weaknesses of each portion.

3.4 The CHI and further development of the study

One of the practical starting points for answering the first research question (what is the definition of a “revolving door” patient in the context of GP registration in Scotland?) was important; as the decisions made about this quantitative portion of the study influenced the direction and focus of the subsequent research. Professionals (doctors, nurses, Practitioner Services staff, Health Board managers) apply the label “revolving door” to a patient after a complex set of activities has occurred. At the administrative level, this is represented by a patient being “on” a GP list, then “off” a list then “re-instated” on another GP list. Patient removal episodes in Scotland are logged and administered along with all other aspects of patient registration by Health Board specific teams of the Practitioner Services Division (PSD) of NHS Scotland. This is co-ordinated by three regional offices in Glasgow, Edinburgh and Aberdeen. This forms part of the national primary care data held as the Community Health Index (CHI). The CHI is the electronic record for each patient who is, or has been registered with a general practice in Scotland and each patient has a unique identifying number. The CHI holds demographic data on each patient, GP registration information, and a number of health screening and immunisation functions (Womersley, 1996). An external organisation (ATOS Origin) administers the CHI on behalf of the NHS. Could this routinely collected health service data be made use of, to construct a definition of a “revolving door” patient? This will be explored in the next section.

3.4.1 Accessing patient registration data

In order to find out whether it would be possible to gain access to this data, permission was sought from the CHI Caldicott Guardian who is the chair of the CHI advisory group, part of NHS National Services Scotland. The principle of “acceptable anonymisation” was an important point of

departure to take into account. This is the principle by which the Scottish NHS considers all data requests that researchers make. It reviews whether express consent for its use is required from each patient the data relates to. If the data are sufficiently anonymised then they can be released without individual consent, but the data must still be fit for the purpose of the research (Confidentiality and Security Advisory Group for Scotland, 2002). Particular scrutiny was paid to my request for data access, as it was the first such data request following the re-configuration of the CHI advisory group. It was considered to be a novel use of the CHI data. After some discussion the level of anonymisation was considered acceptable and fit for the purpose of the research. Caldicott guardianship approval was obtained in October 2005.

3.4.2 Professional key informant perspectives

An attempt to make sense of these “structural” (Brannen, 1992) data on patient registration episodes would be limited without further interpretation both of the processes involved in generating the data, and in what the data meant located in the social world of GP registration and general practice. Qualitative methods which can be used to generate “contextual”, “explanatory”, “evaluative” and “generative” information on a topic (Ritchie & Lewis, 2003) were therefore considered important when defining “revolving door” patients. It was felt that the use of qualitative methods would help to consider ways in which the accounts of professionals, and how they conceptualise this patient group, might be captured in order to help construct the definition.

Attention was paid first of all to who these professionals might be. It was apparent during the early exploratory discussions with Practitioner Services staff that they had a strong interest in “revolving door” patients for a number of reasons (Mair, 2005b). As the administrators of the GP registration system, they may also have a unique insight into the GP registration data generated from the CHI, and an overview of the generation of “revolving door” patients. It was thought that individual GPs may have

limited or no experience of “revolving door” patients. Targeted recruitment from practices in areas that tend to generate “revolving door” patients may have been possible; based on the removal data and informed by the literature on single patient episode removals; however, it was considered unlikely that GPs would readily agree to participate in a research study that sought to explore aspects of their professional working (removing patients from their lists) they may not wish to dwell on. Issues regarding the gathering of reliable data and the offering of partial accounts by professionals, were raised during the discussion on the single episode removal literature and experienced during my previous research experience on patient registration (Williamson, 2004). However I felt that it would be important to try and capture the perspectives of clinicians who had regular contact with “revolving door” patients, but who themselves were not directly involved in removing patients. This might provide a different perspective from the accounts given by Practitioner Services staff. Consideration had to be paid however as to whether their accounts may be biased in a similar way to GPs who may participate in generating “revolving door” patients.

As the study progressed, it became apparent that the phenomenon of “revolving door” patients was in decline and this approach changed. It became possible; because patients seemed to be staying longer on lists and no longer “revolving”, that GPs would be willing to talk about their experiences (and behaviours). They may be able to help analyse what had changed and why.

3.5 Using a grounded theory approach

Particularly because this study was conducted by a solo researcher and examined a previously unexplored aspect of health service practice, careful consideration of the underpinning methodological approach to the study was required at each stage of the study design. This helped to ensure validity and reliability of the research findings. An initial purposive sample of key

informants (set out above) was justified based on my understanding of the topic and it was anticipated this would evolve to include some theoretical sampling as the study progressed. A purposive sample of participants is defined as:

"chosen because they have particular features or characteristics which will enable detailed exploration and understanding of the central themes and puzzles which the researcher wishes to study" (Ritchie & Lewis, 2003).

A theoretical sample is defined as further sampling of participants that occurs once the researcher has evolved some initial themes from the data that will help support and extend the understanding of these themes.

Considering these research methods expressed an early alignment with the grounded theory approach developed by Strauss and Corbin. They advocate for a:

"theory that was derived from the data, systematically gathered and analysed through the research process. In this method data collection, analysis, and eventual theory stand in close relationship with one another" (Strauss & Corbin, 1998).

A cornerstone of grounded theory is the relationship between data collection and data analysis. Each data collection episode is analysed and shapes subsequent data collection episodes. It may influence the content of the means of collecting the data or further theoretical sampling of potential key informants. Data collection must be continued until saturation of themes occurs defined as "reaching a point in the research where collecting additional data seems counterproductive; the "new" that is uncovered does not add that much more to the explanation at the time" (Strauss & Corbin, 1998).

I opted to use the grounded theory perspective used by Kathy Charmaz (2006) for the purpose of this study. This was because she writes engagingly and clearly about her approach to grounded theory. She covers the history and the important epistemological considerations, but most importantly she

guides the reader through the stages of a grounded theory study; from choosing methods, writing memos, to constructing theoretical frameworks and writing. These were all illustrated by examples from Charmaz's own work on living with chronic illness. This is much more than a "how to do" text; she highlighted areas of disagreement in the literature and did not try to render the complex skills required as simply conducted, and linear. Moreover she gives her readers permission to develop their own writing voice in the academic context and this was important for me (Charmaz, 2006).

An early decision was made to carry out analysis with the support of ATLAS Ti software as a means of managing the data and providing an audit trail of the analysis and emerging conceptual framework in qualitative research.

3.5.1 Semi-structured interviews

Based on the early discussions with Practitioner Services that had touched on their day to day interaction with "revolving door" patients, it was understood that the nature of the data collected could be sensitive. Staff were distributed geographically between three centres in Scotland, and although they considered "revolving door" patients to be an important part of their day to day work, interaction with them did not form the bulk of their workload. I was aware of the possibility that a hierarchical administrative structure may influence what Practitioner Services staff may discuss in a group setting; and also had to balance up the time available for data collection. The GPs with a particular experience of "revolving door" patients were also geographically distant from each other. Taking all of these factors into account; semi structured interviews with individual participants were chosen as the data collection method with the professional key informants, as they may generate in-depth personal accounts set in that individual's own context, and allow exploration of complex processes and issues (Ritchie & Lewis, 2003). Focus groups were not used mostly due to concerns about the effect the groups may have on discussing sensitive data and the effects of hierarchy. Participant

observation was discarded too; due to the relative infrequency of interaction and my time constraints.

3.6 Beyond the definition of “revolving door” patients

The next stage was to move beyond the definition of a “revolving door” patient and consider the remaining research questions and how they might be answered. What are the characteristics of a “revolving door” patient and what is the meaning of their existence for the health service?

Many of the methodological and practical issues that were reviewed when designing the methods for use in defining “revolving door” patients were considered relevant and current when thinking about seeking to answer these questions. It was decided therefore to approach these in a similar manner, using a mixed methods approach, synthesising what was to be used to answer these two questions and adding relevant portions as required.

3.6.1 Professional key informant perspectives revisited

During the initial discussions about the research with Practitioner Services staff, I was surprised to hear the depth of knowledge that Practitioner Services staff had about “revolving door” patients. Surprise because conventional understanding would be that a part of the health service that fulfils an administrative function only (not delivering direct patient care) would have only limited, formal contact with patients. It appeared that Practitioner Services staff had a wealth of informal knowledge about patients; this being interesting in itself. What was it that set these patients apart from the other hundreds of thousands of patients on the GP registration database that Practitioner Services staff did not know anything about (beyond their basic demographic data)? What do Practitioner Services staff know about these patients and what is the nature of this knowledge? It would be useful to compare this with the ideas of the GP key informants too. Hence these questions about characteristics and implications for the

health service were incorporated into the semi-structured interviews with the professional key informants.

3.6.2 National data base linkage

The quantitative aspect of the work that built on the patient removal episode data necessarily followed much later in the study. The removal data required to be condensed, once the definition of a “revolving door” patient had been constructed, to produce a cohort of “revolving door” patients. This could then be analysed to look at patients’ characteristics using a different method with different knowledge claims. A limited analysis of this cohort could therefore be carried out based on the “acceptably anonymised” information looking at such characteristics as age, sex and area of residence. But were there other sources of information that could expand this quite limited analysis? One of the internationally lauded strengths of the Scottish NHS system is that for over 40 years there have been progressive attempts to collate individual patient level data about health service use and outcomes for use in health service audit and research. Data linkage between these and other data sets have been carried out for a large range of purposes (Kendrick, 1997; Walsh, Smalls, & Boyd, 2001). The next step was to investigate what information could be accessed and the process by which this occurred.

The national databases are held by Information Services Division of NHS National Services Scotland (ISD) who manage and develop these sets and carry out approved data linkage requests on behalf of a range of NHS and research organisations. The data schemes available that contain individual patient identifiable data are set out in the following table; those in bold are those that were included in the data linkage request for this project.

Table 3 National databases held by ISD Scotland

<i>Name</i>	<i>Description</i>
SMR00	General outpatient attendances
SMR01*	General acute inpatient and day case discharges
SMR02	Maternity inpatient and day case discharges
SMR04*	Mental Health day cases and inpatient discharges from Psychiatric Hospitals and Units
SMR06*	Scottish cancer registrations
SMR11 (Scottish Birth Record)	Neonatal discharges
SDMD (SMR24)	Scottish Drug Misuse Database; patients who have sought treatment for their drug use for the first time ever or in the last six months since 1990
SMR50	Geriatric long stay discharges
GRO(S)*	Death registrations

* denotes SMR01 linked dataset (SMR01, 04, 06 and GRO(S) death records)

The inclusion of data zones for each patient in the cohort was also requested such that measures of deprivation could be calculated.

The decision to request linkage with these data schemes was based on the early impressions of the characteristics of “revolving door” patients made during discussions with Practitioner Services staff. The request had to balance the desire to obtain a broad range of information but avoid data-overload such that in depth analysis would be difficult and impractical. The

Privacy Advisory Committee of ISD Scotland assessed and approved the data linkage request in July 2006.

I anticipated that these data schemes would provide further demographic detail (eg marital status, ethnic origin) information on patient morbidity and health service activity. Note that A&E attendances, arguably an important aspect of health service activity for these patients (who might find GP access difficult) were not included. This is because patient identifiable data about A&E attendances is not available nationally and hence for data linkage.

3.6.3 Incorporating the experiences of “revolving door” patients

Finally we turn to the fourth research question; what is the impact of being a “revolving door” patient from the patients' perspective?

From the beginning of the development of this study I was keen to learn about the patient's perspectives on being a “revolving door” patient and what this experience might mean for them. I wished to adhere to one of the central philosophical underpinnings of NHS values in this research about an NHS issue; that it is a patient centred service. If I ignored the perspectives of “revolving door” patients, I would undermine this value and perpetuate the exclusion they already experienced with their repeated removal from GP lists.

During the initial discussions with Practitioner Services staff it was apparent that “revolving door” patients would not necessarily identify as belonging to a patient group of “revolving door” patients. Also taking into account the previously described benefits and drawback of the available methods; undertaking semi-structured interviews with individual “revolving door” patients was again considered and thought to be the best approach. A potential stumbling block was recruitment, how to access and recruit patients who may have a poor relationship with general practice and

considering the recruitment difficulties encountered in the single patient removal literature (Stokes, Dixon-Woods, Windridge, & McKinley, 2003)? However since these patients seemed to have a relationship with Practitioner Services staff this could mean it would be possible to recruit patients through the GP registration system. This required the permission of the Caldicott Guardian of the CHI and an application was made at the same time as that for obtaining the patient removal data. The active recruitment of patients via the CHI was scrutinised in depth by the CHI advisory group and necessitated that I make the case for this in person to the committee. The committee agreed to the recruitment of “revolving door” patients by Practitioner Services staff; prospectively, once they had been removed by a practice and came back into the GP registration system. How successful this recruitment strategy was and how I attempted to overcome the issues that came up will be described later.

3.7 Summary

In this chapter I described the aims of the study, the research questions and the principles behind the methods chosen. These were influenced by the literature on single episode patient removals and the research setting. Key decisions and the processes that were required were set out. Chapter 4 sets out the actual conduct of the study in detail.

4. Methods

4.1 Introduction

The previous chapter set out the research by considering the research questions and the methodologies utilised to answer them. This chapter considers the detail of the conduct of the research describing each method used and how it related to the others. Naturally, some portions were carried out in tandem and the data from each method informed others. This is described in the text and also represented in a summary diagram at the end of the chapter.

4.2 Funding, ethics and management approval

Funding was obtained in two stages, the first from the Research and Development Primary Care Division of Greater Glasgow and Clyde in 2007, for transcription costs of the initial key informant interviews and half of the data linkage costs. The second larger grant was obtained from the Scientific Foundation Board of the Royal College of General Practitioners in 2008. This covered half of the data linkage costs and initially the costs of conducting the patient interviews. I had consistent general statistician input from the Research and Development Department of the Primary Care Division of the Health Board but this proved insufficient when the complexity of the linkage data became apparent. The Scientific Foundation Board at my request, allowed me to redirect a portion of these funds for the purchase of statistician input from the Robertson Centre for Biostatistics at the University of Glasgow in 2010. They were expert in working with complex health data sets.

NHS ethics committee approval was sought and obtained for the two phases of the research; the first, on 17th May 2006 (ID number 06/Q1605/74) and the second, on 2nd December 2008 (ID number 08/S0703/165) with only minor changes required. Subsequent minor and major amendment requests were made and approved as required. The NHS Research and Development Management approval process however, led to significant delays in getting the second phase off the ground (almost one year). The important areas scrutinised by ethical review will be considered in appropriate portions of this chapter.

An important overarching consideration when the research was conducted was the handling of the data; processes and safeguards required to be in place early and the ethics application process ensured this was considered explicitly.

I, the professional transcribers and my research supervisors adhered to professional principles of confidentiality, and while the research was in progress data were stored at my place of work and in an anonymised form. Paper records (one copy only) identifying participants were stored in a locked filing cabinet and computerised records were anonymised and secured in a password protected format that only I had access too. With the research completed, the data will be archived securely for ten years according to normal practice and the recommendation of the University of Glasgow's publication "Good Practice in research" (University of Glasgow, 2000).

4.3 Extracting the patient removal data

Prior to 1999, and the integration of the regional patient administration systems, the quality of the CHI GP registration data was not robust across all Scottish Health Boards (Mair, 2005a). Including the year 2005 in the data request, meant that the first full year following the implementation of the of the nGMS (2004) GP contract was captured.

The inclusion criteria for the data request were:

All patients in Scotland removed from GP practice lists at the GPs request due to “breakdown in the doctor-patient relationship” (category B) and “violent patient” (Practitioner Services Division, 2004) from 1999 to 2005.

The “acceptably anonymised” data set contained:

- Unique identifier number as a substitute for CHI number
- Sex of patient: M or F
- Month and Year of birth of patient (eg. 02/45)
- Partial postcode (to postal district eg G12 8) of patient’s residence at each removal date
- ‘Category B’(removal at GPs request due to 'breakdown in doctor/patient relationship') and ‘violent patient’ removal dates tagged to GP practice code from 1999 until 2005
- Reinstatement dates tagged to GP practice code from 1999 until 2005

ATOS Origin (the organisation that manages the CHI data on behalf of the NHS) exported the requested anonymised CHI patient removal data to me in word text file format in April 2006.

I received data about 33,608 Scottish patients that ATOS origin extracted to meet the criteria of having one or more recorded removal or reinstatement dates from 1999 to 2005. There were missing values for removal dates, reinstatement dates and GP practice codes across many of the records. There were also removal and reinstatement dates out of chronology. The data were generated from created “transaction records” and the dates were ordered according to the time they are put onto the system rather than when the dates occur. In some instances the dates may have got further mixed up at the turn of the century. These transaction records were the best available, missing data on these were missing data on the central record and had either been lost or not recorded in the first place (MacKinnon, 2007).

There were five patients who had so many removal and reinstatement dates that their records had to be transferred from Atos Origin on two lines of text-file. As they had so many “on and off” dates recorded in large chunks, it was possible for me to manually make sense of these and reorder these into chronological order.

4.4 Professional key informant interviews

Once ethics and NHS management approval was in place, permission was gained from the director of Practitioner Services Scotland to approach Practitioner Services staff at the three regional offices that provide GP registration services for Scotland (Practitioner Services recruitment letter, appendix 2, Participant information sheet appendix 3, Participant consent form appendix 4). Each of the three regional managers and one administrator from each office (6 participants) agreed and gave consent to be interviewed. All were female and were in their 30s, 40s and 50s. All had worked in GP registration for a number of years; the majority for more than 10 years.

4.4.1 Conducting the interviews

Using semi-structured interviews and a topic guides to collect data allows the researcher to ensure the topic under research is covered, but the method is flexible enough to probe meanings and discuss new themes that emerge. I found the analogy with a “guided conversation” from Lofland and Lofland (1984) (Barbour, 2001; Charmaz, 2006) to be a useful way of thinking about this type of research interview. One of the strengths of being a clinician, trained and experienced in communication skills is that many aspects of the semi-structured interview are similar (Barbour, 2001); asking open questions, using active listening skills and ensuring the participant covered the topic under discussion. However I had to be much more aware about challenging assumptions and probing meanings, words, phrases, areas that were discussed, that the participant and researcher may take for granted as shared understandings. I tried to overcome this by keeping this

issue uppermost in my mind during the interviews. I also talked explicitly about this at the start of each interview by saying something along the lines of;

“As you know I am a GP and although I might know a bit about what I am going to ask you today I am here doing this interview with my social science researcher hat on. I might ask you about issues and you will think; why is she asking that, surely she knows all about this? But I would ask you to bear with me; sometimes I will ask about things for the research record and sometimes to check out what you mean about a topic; is that OK?”

The nature of research interviews is also very different from clinical encounters; they are longer, much less directive and the participant is the expert on the topic under research (Barbour, 2001). The researcher's contribution requires much less talk and much less opinion. I noticed that as the research project progressed and I began to explore the themes in greater depth the participants began to seek more information and opinion from me. I felt I had to allow this to happen to some extent but also to think carefully before making any statements that might influence the participant's own view; very different from clinical encounters where one of the GPs role is to provide an expert opinion that seeks agreement with the patient.

I considered the topic guide to be a map of the areas I wished to cover in the interview. By using the research questions, and thinking carefully about phrasing, I set out a list of main questions with sub questions as prompts (appendix 5). I included the specific phrasing of some open ended questions as opposed to simple topic headings to ensure I would ask open questions and use the techniques I had learned from reading about conducting research interviews (Barbour, 2001; Charmaz, 2006; Ritchie & Lewis, 2003). Examples of these were asking about typical cases, last cases, and cases that don't fit the pattern, that respondents encountered (describing the phenomenon under study). Concrete examples often provided “deep descriptions” and triggers for further discussion (Charmaz, 2006).

In practice all but one of the professional key informant interviews proceeded with a remarkable lack of prompting on my part; the topic guide became a tool for checking, near the end of the interview to ensure I had covered all the areas I wished to cover. I found the prompt questions to be very useful. The interview where I did use the topic guide through out the interview, was with one of the Practitioner Services professional key informants, who- because she had not worked in “allocations”- had very little experience of “revolving door” patients. This was useful data in itself and is further discussed in the results section in chapter 5.

A single audio taped interview was conducted with each participant; for practical reasons of access and travel these were carried out sequentially, in pairs, at each regional office.

Each pair of interview tapes were listened to shortly afterwards; using the Charmazian grounded theory approach. The rationale for this was to identify any possible new themes emerging that required further probing, and hence requiring incorporation into the interview schedule for subsequent interviews (Charmaz, 2006). Two further key informants were identified from these interviews. They were GPs who because of their particular managerial or clinical roles, had experience of “revolving door” patients. They readily agreed to take part in the interviews. One was a male GP in his 50s who had worked as a principal in a deprived area and as a health care manager responsible for primary health care, and the other was a female GP in her 40s who worked in a specialist primary care service for challenging patients. Review of the interview for consideration of new themes was carried out after each of these, too. In practice, no new themes were identified and no major amendments were made for the conduct of the eight interviews. Following review with my research supervisors I judged that theoretical saturation had occurred and that further professional key informants interviews were not required for this portion of the study.

4.4.2 Grounded theory analysis

A professional transcriber transcribed the interviews and I reviewed and edited the transcripts before importing them into ATLAS Ti for analysis. I kept careful research diary notes as recruitment for the interviews started and a record of email and phone contacts with key informants. This informed my reflexivity when considering analysis, and later, theory generation. I analysed the Practitioner Services (PSD) key informant interviews as a group. Because I anticipated the GP interviews may have quite different themes, I analysed these separately after a significant portion of analysis had been carried out for the PSD interviews.

4.4.3 Coding development

Each interview was read and re-read as a primary document in ATLAS Ti in the chronological order in which the interviews were conducted. I used a series of prompts or questions derived from Charmaz (2006) to consider the meaning of what I was reading; including considering what actions and processes were happening as well as the words being used. Charmaz encourages researchers to consider the meanings that participants attribute to these processes; both what they emphasise and what they leave out (Charmaz, 2006). Using this series of prompts I worked through the first interview using “in vivo codes”- codes that use the words and meanings of the participant as closely as possible- to label each discrete happening, or chunk of meaning, in the text. Charmaz discusses a range of possible approaches to coding; from coding individual words, each line of text, or each incident. I assessed that “incident coding” was the appropriate option for this data analysis, as the data is recorded conversations about processes and incidents. Word or line coding is more useful when considering analysis of documents where each word or sentence has been carefully constructed to get over a particular meaning (Charmaz, 2006). Numerous codes were generated by coding incidents using “in vivo codes” and as I read and re-read these, some could be grouped together into families of codes. These families were described and the summary of this description then became a new code that incorporated the meaning of the codes included. This was an

iterative process that involved re-reading the data and checking across the early numerous codes to ensure that meaning was captured and relationships between codes maintained. Once I was satisfied I had reached a stage where new ideas about codes and summarising codes were exhausted for the first interview, I moved onto the second. I used the codes generated from the first interview to code this interview. I paid close attention to gaps in the coding and generated new codes if identified. Careful attention was paid to segments of the interview data that were not coded, or “in vivo codes” that did not seem to fit the new codes that were emerging. At this point, if I was satisfied the data contained in these segments were not relevant to the research project, then these codes were discarded and a note made in the research diary that this data was not directly relevant. This was an explicit exercise aimed at ensuring that I did not ignore data that was difficult to code or that did not fit with my perception of the topic under research. Examples of data excluded; were information about the ways in which practices in localities with lots of new build housing developments responded to increased demand for registration through the allocation system; and discussion about the change in demand for medical cards, as the system changed, and cards were no longer issued face to face at the PSD offices.

I then repeated this coding process for each of the Practitioner Services interviews, moving back and forth between interviews reviewing existing codes and checking out meaning and possible omissions for new codes. I kept research diary notes in the form of memos which recorded process and progress, highlighted issues that needed work and provided action prompts for the next stage of the analysis process. Examples of memos exported from ATLAS Ti set out below describe this initial coding activity.

Process note: 1/11/2006

Description of process to date: edited interview by listening to tape and correcting transcript. Anonymised it too.

Imported rtf doc to make it a PD. Then commenced free coding, line by line, ignoring only those that were my words or not relevant to topic at all.(not much). This was time consuming and a bit boring at times!

Then constructed families to sort free codes into. This allowed me to look at duplicate codes and wording of them. Still trying to capture essence of data quote. Families also help to summarise larger themes.

Process note: 6/12/2006

Over four hours. Now feeling brain dead. Stop for a while and go to edit. Collapsing codes down into broader ones; aiming for about 10. Covering topics asked about in interview and creating some new; like nGMS watershed. merging all that seem to fit. Plan then to make all fit and then go through transcript one again to recode and look for new ones I have missed. These bigger codes then need split to subchapters and fleshed out. Conceptual maps will be helpful. Feel v time poor!

Process note: 21/02/2007

all current PD's : 6 interviews are fully anonymised and imported into Atlas for coding.

Tidied up codes working with idea that codes are like drawers that quotes fit into to.

Then scanned topic guide to glean further codes: influences that produce Rd patients. Made the codes more meaningful and snappy. began process of going thro' pp01 again to check that codes make sense... trying to always bear in mind I may be missing a code.

Need to be careful about significance of extraneous material.

Plan to set aside large chunks next week to get cracking!

Process note: 20/03/2007

Finished coding all PSD interviews. Now need to move to mapping codes and shifting and sorting. When doing the coding I did feel I was not entirely consistent from day to day with what I put where. Will need to review this as I move to the next stage. Exciting though. When the data will reveal itself.

Figure 2 Examples of research diary memos

At the end of this coding I had seventeen codes to work with that I felt captured the meaning of the data and from which to move onto the next stage of analysis. I opted to use ATLAS Ti memos again to consider each code across each interview and summarise the aspects of each code from each interview. I tried to keep to the participant's own words as much as possible. This prompted further interrogation of the data and allowed me to consider views and ideas that the participants expressed both in terms of when they agreed and when they did not. It also prompted me to consider areas that I might wish to consider again in more depth or that I needed to check out the meaning of with the participants. They also provided an

additional check of whether text was correctly coded. Some errors were identified and text was appropriately recoded.

I then worked through each code again summarising the meaning of the “in vivo” ones and moving these summary chunks around again to make sense. These were in headings with their descriptions below those. Some headings were identified that needed to be coded elsewhere.

I felt at this stage that the data was unwieldy; difficult to gain an overview of and in what direction the analysis was going in. I decided to spend some time working on paper copies of these code summaries using coloured pencils to visually split the text into coherent chunks. This task could have potentially been achieved using the network tool on ATLAS Ti but I felt I needed a change of medium to move the analysis forward at this stage. This enabled me to reconsider the code names and some of the coding and make sense of the overall picture of the analysis.

Twelve codes with the summaries of their meanings were produced. They are found below at the end of section 4.4.4.

4.4.4 Incorporating respondent validation

Implicit in the conduct of the research for this thesis has been the principle of rigour with which it has been carried out. Rigour is defined as “to make the validity of each step explicit” (Makins, 1995) and this overlaps with the concept of trustworthiness postulated by Lincoln and Guba (1989) that underpins much qualitative research practice. Trustworthiness encompasses four principles: credibility (or validity); transferability (enough detail to allow comparison with other cases); dependability (of the research process); and confirmability (Koch, 1994). The data were validated by the peer review that my supervisors carried out on portions of the interview data and coding development. The use of respondent validation as a means of checking out with the participants whether the codes captured the meaning of the data, was considered an additional important way of incorporating rigour into the

analysis (Ritchie & Lewis, 2003). I identified some statements that I wished to validate, and some discrepancies between participants' opinions about some topics and viewed this tool very much as, “part of the process of error reduction which also generates further original data which in turn requires interpretation” (Barbour, 2001). There are benefits and drawbacks to using respondent validation; the benefits are described above; the drawbacks include the researcher presenting such a different focus on the data that it is unrecognisable to the respondents, re-presenting data to participants the content of which or the analysis of which may be distressing to them, and potentially, respondents withdrawing statements they had previously made (Bloor, 1992). As this research was conducted using a grounded theory approach “grounded” in the respondents own words and ideas, and as they were professionals talking about an aspect of their work, these drawbacks were not anticipated; nor realised.

I emailed the twelve codes and their summaries (Appendix 6) to the six PSD participants and conducted a follow-up telephone interview with each (two respondents in a joint conference call). One participant also made further comments by email. I asked some questions following broad prompts regarding the participants overall impression of the summaries. All the participants highlighted areas to discuss and my discrepancies and queries were discussed too. No major problems or issues were identified and I found that the clarity of the analysis increased for me.

Following a break from analysis for a period of maternity leave, the two GP respondent interviews were analysed; initially using the codes developed from the PSD interviews. Careful attention was once again paid to gaps in coding; one new code was identified, then merged with a previous one to make a new code (respondent attitudes to “revolving door” patients) and one previous code was split into two. At the end of this process, I was satisfied that the existing coding structure reflected my analysis of the data effectively and I also judged that respondent validation was not required for these key informant interviews. This may be because I had investigated the major discrepancies in the Practitioner Services interviews or because I was

(or thought I was), more familiar with the world of general practitioners, but I felt satisfied that at this stage, data saturation had been achieved and that my analysis of the data represented the data appropriately. The final codes are below:

1. Assignment
2. Characteristics of RD patients
3. Definition of RD patient
4. Impact on general practice
5. Impact on PSD
6. Impact on RD patients
7. Influences producing RD patients: macro context
8. Influences producing RD patients: practice ones
9. PSD background knowledge of RD patients
10. PSD perspectives on general practice
11. Respondent attitudes to RD patients
12. Suggested future changes for system

Figure 3 Twelve codes derived from professional key informant interviews analysis

4.4.5 Moving from analysis to theory generation

Research diary notes containing thoughts and ideas from the interviews and data analysis were used. Initial thoughts were followed up and re-read as I moved into sorting the codes, writing about them, and turning them into draft thesis chapters. Literature areas I had previously explored were revisited and their relevance and fit were re-evaluated in the light of the grounded theory that I generated. Using other's theories to inform and aid development of grounded theory is called employing "sensitising concepts" (Charmaz, 2006).

Here is an example of a memo from early in this stage:

Research diary (theory): 27/05/2009

Norms of the doctor-patient relationship

Medicalisation of behaviour; the doctors and dirty work

What the work of a doctor is; the messy edges beyond the qof.

Tolerance

Boundaries of acceptable use of services

Future changes: enhanced service; patient has to comply with psychological intervention and practice paid. Clear boundaries; a contract between patient and practice about expectations of behaviour and care from both sides. Traffic light system of warnings about behaviour; can move rapidly to red, or return to green after a few months of good behaviour. Assessment and behaviour change intervention then discussion with future GP when re-integration time due.

Need to look at the assignment code and decide how that can be analysed.....

Figure 4 Extract from research diary about theoretical development

4.5 Data linkage and analysis

When a definition of a “revolving door” patient was developed and funding was successfully obtained, data linkage was carried out for the “revolving door” patient cohort. This was in 2009. This set of anonymised information about these patients was re-exported to ATOS Origin who administer the CHI. ATOS “un-anonymised” the patients’ details (appendix 7); reattaching the patients surname, first name, full date of birth and CHI number, whilst retaining the unique study identifying number; and this was retrieved by ISD Scotland for data linkage to be performed. Re-attaching all these patient identifiers allowed for maximum probability matching with the ISD linked datasets. At no time did I have any access to this information.

4.5.1. Probability matching

Much of the development of the ISD data schemes is influenced by Howard Newcombe’s pragmatic approach to record linkage. It has been refined over the years by the range of information requests to ISD made by the NHS and

researchers, and as information technology has developed (Walsh, Smalls, & Boyd, 2001).

Probability matching is “the comparison of two records and the decision as to whether they belong to the same individual” (Walsh, Smalls, & Boyd, 2001). The two records (the data scheme file records and the “revolving door” patient cohort records) were compared and a score was assigned to each by the analyst at ISD Scotland. The extract from this linkage scoring process follows:

Extract from ISD standard programme for assigning Linkage Variable Scores:

If soundex matches, score = 15

If first initial of forename matches, score = 10

If first 2 letters of forename match, score an extra 2.

If first initial of forename does not match, score = -7.2 (males) and -6.61 (females)

If gender matches, score = 1

If gender does not match, score = -6.5

If first 8 characters of surname do not match, score = -2.5

If year of birth matches, score = 6.3

If year of birth does not match, score = -7

If month of birth matches, score = 3.56

If month of birth does not match, the score depends on how far away from each other the 2 months are.

If day of birth matches, score = 4.9

If day of birth does not match, the score depends on how far away from each other the 2 days are

Maximum score for postcodes matching = 14.53

There can be various scores for postcode depending on how much of it matches

If CHI matches, score = 10

If Case Reference Number matches, score = 10

(Hopkins, 2010)

Figure 5 Extract from ISD standard programme for assigning linkage variables

“The threshold above which we agree that the 2 records belong to the same person is set and then pairs of records are checked manually to ensure the score is sensible and will maximise the number of links whilst minimising the chances of bad links occurring” (Hopkins, 2010).

It was not possible to obtain the linkage cut off scores for each data set as this information was embedded in patient identifiable data and hence in a format that I could not have access to. It is not normal practice for ISD to provide detail of thresholds as part of linkage work (Hopkins, 2010).

I received the data linked patient files in three portions; SMR00, SMR01 and SDMD.

The SMR00 file contained the data on acute hospital outpatient attendances and the SMR01 linked data set, data on acute hospital admissions, psychiatric hospital admissions, cancer registry information and death records. 96.48% and 96.26% of the patients linked with the ISD data schemes. The Scottish Drug Misuse Database (SDMD) file which is the record of drug misuse treatment episodes has less data contained in it so to maximise linkage, ISD linked the SDMD both to the SMR01 file and the patient file using both linkages to maximise linkage. Because this linkage was done in two parts, it was not possible to obtain the linkage scores (Hopkins, 2010). In the final exported extract 54% of patients linked with the drug misuse database. Of course the percentage of patients who link with the database depends both on the accuracy of the probability matching and whether the “revolving door” patients had activity recorded in those NHS service areas.

4.5.2 Measuring deprivation

As each patient's postcode of residence was recorded with each outpatient attendance and hospital admission; this meant patients' data zones could be assigned and measures of deprivation applied. Data zones had been developed for Scotland and were based on small stable geographical areas. They were developed to contain households with similar social

characteristics, aiming to accommodate physical boundaries and local authority areas (around which most services are constructed). This meant that statistics could be collected and analysed across a range of policy areas, and followed over time. Measuring population statistics that were meaningful for local communities and service planners, is a tension between ensuring sufficient numbers to persuade that an issue needs tackled, versus numbers being so large that quite large variation in characteristics is obscured by large numbers. The development of data zones attempted to address this. 6,505 data zones covered all of Scotland, and contained between 500-1000 household residents each based on 2001 Census data. Hence there were clusters in densely populated areas. Ensuring they would provide a stable geography and provide a robust base for measures of deprivation was an explicit aim of the team who developed it on behalf of the Scottish Government (Flowerdew, Graham, & Feng, 2004).

The Scottish Index of Multiple Deprivation (SIMD) 2006 was used to describe deprivation for the “revolving door” patient cohort. This was based on seven measures; income, employment, education, housing, health, crime, and geographical access combined to give an overall measure of deprivation (Information Services Division NHS National Services Scotland, 2007b). This can be split into deciles so that 10% of the Scottish population are in each decile; decile 1 being the most affluent and 10 the most deprived. It is worth noting that the most up to date SIMD 2009 opted to reverse this order, so more recent statistical reports on deprivation in Scotland report the opposite (Information Services Division NHS National Services Scotland, 2010a).

4.5.3 Getting underneath the complexity

Initial descriptive statistical analysis that I attempted, in order to characterise the “revolving door” patient cohort and its data-linked information on hospital admissions, outpatient appointments and drug misuse treatment episodes; led to a thin description of the group; which skimmed over the complexity of individual patients. This was partly because

quantitative description necessarily collates group characteristics but also the technical expertise required to manipulate the large and complex data-linkage data sets was lacking in my skill set, despite lengthy and frustrating attempts to obtain them sufficiently. Quantitative analysis was subsequently conducted by the Robertson Centre for Biostatistics statistician. Their analysis was based on a series of questions I devised to interrogate the data (appendix 8) and we worked collaboratively, revisiting the questions as the work progressed. The results of this are presented with attribution throughout the results chapters. I also “qualitized” (Sandelowski, 2003) the “revolving door” cohort which is described next.

4.6 Qualitizing the “revolving door” patient cohort

My decision to qualitize (Sandelowski, 2003) the quantitative data on the “revolving door” patient cohort was made with some trepidation; I worried that I was transgressing paradigm boundaries by using an interpretivist approach to analyse routinely collected quantitative health service data. However, this intuitive move felt the only way that I could get underneath the data, and bring into focus the images I had glimpsed as I read through column after column of patient data. I followed my hunches, and what follows is the description of the development of this analysis.

As my reading about mixed methods research deepened I discovered that this was “an emergent analysis decision”, not uncommonly made, that sat firmly within the qualitatively dominant (type) mixed methods tradition and is a type of secondary data analysis because it is analysing a set of data that is not naturalistic (Onwuegbuzie & Combs, 2010).

4.6.1 Qualitized sample

This qualitative analysis of the routine linked data set remained restricted to the second cohort of “revolving door” patients (see table 6 in section 5.1). This was viewed as a purposive sample of patients and issues of bias

were considered. The sample may have excluded patients whose GP registration records were poorly recorded. The Robertson Centre statistician reviewed all the patient records when generating statistical imputation options and could identify no pattern, by year of record, or Health Board area, to explain systematic differences in recording (Johnson, 2011c). In addition, the explanations for the errors described by the administrators of the CHI in section 4.3 had no implications for systematically biasing patient characteristics that I could think of. The results should be interpreted as for all the qualitative data in this thesis; they are not seeking to be generalisable; these are a partial but valid view when all the conditions of the research setting are taken into account.

4.6.2 Patient profiles

A profile of each patient was constructed as a synthesis of 4 sources of data; the information retrieved from the Community Health Index data on patient removals before the data was successfully imputed, the linked Scottish Drug Misuse Database data (SDMR) the linked hospital admissions data, and the linked outpatient attendance data. This profile was viewed as a way of summarising the unwieldy data contained in the linked data sets and sought to represent patients' demographics and health service interaction; not the person behind the profile.

Only ICD10 codes were used for the diagnoses; meaning clinical data from 1998 onwards only are taken into account. Each profile was then turned into a "primary document" for coding and analysis using Atlas Ti (the qualitative software package used to support analysis for other portions of the project). Each profile was identified both by the unique ID number that each patient had, and a chronological number to ensure that I kept track of the order of the cohort and progress with coding.

Patient's unique id,

Age (at June 2005) , sex, marital status, first and last date removed GP list, number of removal episodes (original cohort), fast or slow revolver (original cohort), entry on Scottish Drug Misuse Database, dates of first and last treatment episode, drugs misused, in prison during treatment, Health board of residence, SIMD (Scottish Index of Multiple Deprivation) decile score.

Number of hospital admissions, clinical diagnoses (often using medical note abbreviations) where (check dates) is noted this indicates two very similar records which may represent transfer between units (eg ITU and general medical)(this was not checked against the records) If patients have many admissions and if a pattern was discernable a summary was recorded. If no hospital appointments this was recorded. If lots of missing clinical codes this was noted (may be pre 1998 admissions)

Outpatient attendances (OP) speciality attended, number of appointments recorded, number of DNA's (did not attends), date of first and last appointment, clinical codes if available (rarely) comments on data including whether referred by prison or courts.

Sometimes additional notes about information that stood out during profile construction

Figure 6 Key to patient profiles

4.6.3 Initial codes

The profiles were then read and re-read and free text coding was applied using the same Charmazian grounded theory approach. Data segments were coded according to the themes that emerged. Some codes were straightforwardly determined by the presence or absence of information contained in the profiles, such as coding for presence or absence on the Scottish Drug Misuse database. Others required consideration about deciding boundaries between codes and the use of sensitising concepts. Knowledge such as the definition of a “revolving door” patient used in this study and what is normally considered to be high utilisation of inpatient care were examples of sensitising concepts in this context.

GP removals	Hospital admissions	Outpatient appointments
5 or less removal episodes 6 to 10 removal episodes 11 to 20 removal episodes more than 20 removal episodes	no hosp admissions 5 or less admissions 10 or less admissions 20 or less admissions 30 or less admissions 40 or less admissions 50 or less admissions 60 or less admissions 70 or less admissions 80 or less admissions 90 or less admissions 100 or less admissions 110 or less admissions 130 or less admissions 160 admissions or less 200 or less admissions 300 or less admissions	no OP appts 5 or less appts 10 or less appts 20 or less appts 30 or less appts 40 or less appts 50 or less appts 60 or less appts 70 or less appts 80 or less appts 90 or less appts 100 or less appts 120 or less appts 140 or less appts 160 or less appts 180 or less appts 200 or less appts High DNA rate
Scottish Drug misuse database		
SDMD No SDMD		

Figure 7 Initial codes for patient profiles

The clinical coding was a more complex process. I used knowledge and assumptions from my clinical background to interrogate the data and characterise the clinical presentations that the patient profiles contained. These clinical codes were applied if the patient had evidence of a condition relating to that code from their hospital admissions or outpatient attendances. Most of the clinical information was contained in the hospital admissions data as this was where many of the health service contacts had an ICD 10 code applied on discharge. From outpatient information a few psychiatry and substance misuse clinical codes were obtained.

Addiction codes

alcohol intoxication without dependency
 drug intoxication without dependency
 alcohol dependency without drugs
 drug dependency without alcohol
 alcohol and drug dependency
 high suspicion of additional substance misuse related physical harm
 physical complications of alcohol dependency
 physical complications of drug dependency

Mental health codes

dementia
 learning disability
 clear severe and enduring psych diagnosis
 sporadic psychiatric diagnosis
 shifting psychiatric diagnosis
 definite personality disorder diagnosis
 evidence of self harm
 referral or contact with psychiatry without diagnosis
 no evidence of any psychological issues
 non compliance with medical treatment

Physical health codes

additional unrelated physical health problems
 only physical health problem
 violence related

Additional codes

Child
 Dead
 Evidence of court, prison or forensic involvement

diagnoses too, in such a way that all clinical diagnoses were included in these codes. This allowed me to be satisfied that all clinical diagnoses retrievable from the “revolving door” patient cohort were considered and that all this information was integrated in a way that no areas were missed or ignored. These codes were refined as the process of coding each profile proceeded. For example other psychiatric codes were developed in addition to the psychiatric diagnosis code of “clear severe and enduring psychiatric diagnosis” which was a clinically interpreted code implying a diagnosis of a chronic psychotic illness or an established bipolar illness. One of these was “evidence of shifting diagnosis” that suggested the patient’s clinical presentations changed over time or there was difficulty in making a firm diagnosis. This often means that after repeated periods of assessment a personality disorder diagnosis is made. Another one was when patients had occasional psychiatric diagnoses recorded during some admissions such as

depression or anxiety. An additional code of “ad hoc psychiatric diagnosis” was added to capture these.

Some additional codes were used to consider special groups; children in the cohort and the patients who died. Unexpectedly there was information about patients’ contact with the courts, prison or having forensic involvement. This was information that had been considered important in the early stages of the study’s development but plans to obtain it had been abandoned because of the additional resource that would have been required.

The Robertson Centre statistician matched the children in the cohort with their families for the qualitative analysis, using the following method:

Groups of patients likely to be family members were identified by network analysis. A family was defined as a group of patients including at least one child where each member is linked to the group by having been either removed or registered at the same practice on the same day while having the same postcode. Each family had to have at least one member who was a child (< 16 years of age) for at least one record. Not all members needed to be linked directly - it was sufficient that each family member was linked to at least one other family member.

(Johnson, 2011e)

Figure 9 Method used to identify families in the "revolving door" cohort

The clinical codes provided a useful descriptive scan of the information range and provided the detail of the scope and boundaries of information contained in the data set but they occurred in many combinations between patients. They helped delineate the next level of analysis and were then used to move between levels of analysis to check out subsequent hunches.

What follows is an introduction to the sensitising concept of “illness scripts” (Charlin et al., 2007) that was utilised to support the next level of analysis and the qualitised description of the “revolving door” patient cohort.

4.6.4 *Illness scripts*

This explanatory information is drawn from a review article that distils the current research knowledge and explains the different terms (Charlin, Boshuizen, Custers, & Feltovich, 2007). In cognitive psychology, “Scripts (schemas) arise from repeated experiences with real-world events, as a result of which certain types of information come to be organised in specific ways.” They are:

“integrated networks of prior knowledge [that] lead to expectations, as well as to inferences and actions... Expectations and actions embedded in scripts allow subjects to make predictions about features that may or may not be encountered in a situation, to check these features in order to adequately interpret (classify) the situation, and to act appropriately”(Charlin, Boshuizen, Custers, & Feltovich, 2007).

Script theory has been investigated in medical education to help understand and explain clinical reasoning. Clinicians, in their mental processes, formulate a set of “illness scripts”; templates of symptoms, signs and characteristics encountered during their medical training and clinical practice, which they refine with clinical experience.

During a clinical encounter the doctor gathers information and without conscious thought “activates” an illness script or number of scripts. In the majority of “routine case,” if the pattern of information fits with the “illness script”, this process remains unconscious. A diagnosis is made and predetermined action is taken. This is known as “non analytic script activation” and increases with clinical experience and is associated with expertise. In a “non routine case”, when diagnostic uncertainty is experienced; when the information gathered does not fit well with the activated illness script or a series of scripts, this is when “deliberate script induction occurs”. The clinician seeks further information and uses a range of clinical reasoning skills to determine which illness script best fits and what action to take. It is the incorporation of these “non routine cases” that lead to refinement of the clinician’s repository of illness scripts (Charlin, Boshuizen, Custers, & Feltovich, 2007).

Can this theory of “knowledge structures” that lead to “expectations, inferences and actions” (Charlin, Boshuizen, Custers, & Feltovich, 2007) be applied in a similar way to how doctors think about their patients? No literature could be found that explored this area further.

An example of what happens in general practice may help us to reflect on this possibility. Consider how GPs may use the general practice patient summary record before meeting a patient for the first time. The patient summary is contained in the patient’s notes and is a series of one line summaries of clinical conditions from birth and over time, which also sometimes has other information recorded eg. “Looked After and Accommodated child” or “history of domestic violence”. Before a GP sees a new patient he/she will scan the patient’s up to date summary and process the information. A picture or shape of the patient may be immediately in the GPs mind. These could be considered a “patient script”. Or the information contained in the summary may evoke a number of possible “patient scripts”. The purposes of these are to help the GP be sensitised to what the patient may bring to the consultation or what range of responses may be required. They do not that restrict the range of scripts that may be invoked should new information become available after listening to the patient’s presenting issues. This is distinct from invoking stereotyping judgements about patients which remain fixed even when new information becomes available. The same process of non analytic and deliberate script induction may be relevant too.

However, what is the status of “patient scripts” in the context of analysing the “revolving door” patient profiles? As the analysis process proceeded and I applied the initial codes and became familiar with the content of the profiles, I became aware I was categorising patients in the same way as I did when receiving information about patients in day to day clinical work; I was activating “patient scripts”. For some patients, the script was non analytically activated, for others inductive reasoning was required, and for others it was not possible to find a “patient script” that fitted. As I read the profiles and began the analysis process I found myself recalling “revolving

door” patients described both by the key informant interviewees and patients I had worked with.

4.6.5 Predominant health problem codes

I opted to go with this inductive hunch and in the next level of coding analysis sought to delineate the “patient scripts” for the “revolving door” patient cohort. These were typified as the predominant health problems that the patient had. By summarising the cohort using these, it was hoped that this could provide a more in depth description of the overall complexity of the “revolving door” cohort; and help to gain some descriptive depth about individual patients too.

Described below is the process by which the patient profiles were analysed to ascertain the “patient script” for each. In order to retain rigour I moved beyond non analytic activation of a patient script for each patient profile, and hence made each category decision explicit.

The analysis was carried out using a graded evidence approach; strong to weak evidence, with diagnostic codes used in hospital admission data viewed as the strongest. For example, if a patient had evidence of hospital admissions in their patient profile where a psychiatric diagnostic code was applied then this was viewed as strong evidence of psychiatric illness. When this became a pattern (with or without evidence of other health issues) then this was viewed as the patient’s predominant clinical profile. An example of weak evidence is if there were psychiatry appointments in the patient’s outpatient record. The assumption was made that a clinician or the patient had been concerned enough to refer/self refer to psychiatric services. It is not possible to know for certain whether this was referral for psychiatric assessment or for assessment of addiction issues; as how much psychiatry is involved in addiction assessment and treatment varies across time and geography. This was therefore coded as referral or contact with psychiatry diagnosis not known and was not considered to be the predominant clinical

picture. Instead it was used in conjunction with the other clinical diagnoses codes and other information to help shape the picture of the patient.

Whether information was accorded strong or weak evidence was governed by my medical knowledge and understanding of the health service. I have attempted to draw distinctions thus; strong evidence where diagnostic labels have been applied to patients; weak evidence when information may be interpreted in a diagnostic way but other options are possible. An important example of this is the status conferred of having treatment episode(s) recorded on the Scottish Drug Misuse Database (SDMR). A detailed analysis of number of episodes and substances misused was not carried out; so although having SDMR treatment episodes may (and from clinical experience often does mean) that the patient has a significant substance misuse health problem, it may also mean that the patient had one treatment episode but then went on to become substance misuse free. Treatment services have varied over time and geography in their thresholds for treatment and the substances they offer treatment for too. If however the patient then goes on to have hospital admissions that relate to drug dependency; if they have diagnostic codes for such, or problems that usually directly relate to drug dependency, such as phlebitis or bacterial endocarditis, then the predominant clinical picture is seen as substance misuse. All of the information and its range or strong and weak evidence status is then integrated and coding applied.

Clearly this was based only on secondary care data, as there was no access to primary care data. As these were profiles of real patients; and real people have a range of illnesses over their life course, in several instances patients had occasional or minor problems out-with the dominant code they were allocated too. This too replicates the real world use of “patient scripts”; in that the shape of the patient is about the health dominant conditions or issues that doctors create their script about.

An experienced GP and a medical sociologist (my thesis supervisors) initially reviewed 10% of the patient profiles having been furnished with limited

information about the coding hierarchy and detail. They achieved 45% agreement using this approach and it was concluded that the difference was because I used a more strict application of the level of evidence considerations set out above. The same reviewers reviewed a further 10% of the sample once they received this detailed information about the coding hierarchy and background. They achieved 70% and 60% respectively. The difference was again attributable to degrees of levels of evidence; for example when each of us decided how strong the evidence was to attribute a “substance misuse combined physical illness” script to a patient rather than “drug dependency problems” alone. The level of agreement was felt to be robust enough to allow these patient scripts to have the status of shaping analysis of the cohort. The dominant health problem codes with a description of their meaning follows:

Table 4 Predominant “patient scripts” with description

Predominant health code “patient script”	Description
Psychiatric illness	Clear evidence with absence or weak evidence of substance misuse or physical illness
Drug dependency problems	Predominantly drug misuse related admissions including drug overdoses and physical consequences of injecting such as cellulitis, phlebitis, HCV infection. Prescribed medication overdoses other than benzodiazepines and heroin are considered to be self harm
Alcohol related harm	Predominantly alcohol related admissions either intoxicated or dependent, and can include physical health presentations directly caused by alcohol misuse
Substance misuse combined psychiatric illness	when the two clearly coexist and both trigger admissions (alcohol and or drugs)
Physical illness	not related to substance misuse; predominantly admissions are for physical illnesses of significant morbidity usually that have a repeating pattern
Psychiatric illness combined physical illness	when the two clearly coexist; both triggering admissions
Substance misuse combined physical illness	when the two clearly coexist and the physical illness is not related to substance misuse; both triggering admissions
Injuries	admissions predominantly related to injury; usually, but not always, apparently violence related
No clinical code possible	it is not possible from the information presented to decipher what the patient’s predominant (if any) health problems are; eg having an SDMR drug misuse record is not sufficient to confer a predominant drug misuse code

This analysis was dialectically integrated with the rest of the data that helps inform the results about the characteristics of “revolving door” patients in chapter 6.

4.7 “Revolving door” patient interviews

The philosophical perspective or values underpinning this study would have been undermined if the perspectives of “revolving door” patients themselves had been ignored when seeking to investigate and understand more about this neglected and excluded group of patients. Moreover there was potential to gather rich data and reach deeper theoretical insights too. I was keen too to gain experience of conducting research with patients who are not usually included in health service research.

4.7.1 Research setting

From the analysis of each of the “revolving door” patient cohorts around half of the patients remained resident at the same address over the 6 year period of the study interval. The key informants' interview data also revealed that a subset of patients reported problems leaving their own home to attend GP appointments due to psychological or physical health issues. The key informants also felt that individual “revolving door” patients would not conceptualise themselves as belonging to a group of “revolving door” patients, they felt too that many of the patients may have poor communication skills (including literacy) and coping strategies.

For these reasons, semi structured interviews with individual participants were chosen as the data collection method. The benefits and technical aspects of conducting semi structured interviews have been set out in chapter 3 and earlier in this one.

4.7.2 Recruiting participants

“Revolving door” patients

Caldicott Guardianship permission stipulated that recruitment of patient participants from the CHI data had to be prospectively through Practitioner Services; as patients are removed from a GP practice list and Practitioner Services allocate them to a new practice.

The following definition, derived from the second definition of a “revolving door” patient (see table 6 in section 5.1) was used for recruitment:

A revolving door patient has been removed more than three times from practice lists. Each removal episode should be no longer than six months apart; including this episode.

It was thought that many “revolving door” patients would fit this criterion from superficial scrutiny of their registration record by PSD staff, and a recruitment sheet was devised for this (appendix 9). The PSD staff member was asked to contact the patient by letter on my behalf asking the patient to consider participating in the study (patient recruitment letter, appendix 10, information sheet, appendix 11). The letter was accompanied by an audio CD version of the letter and information sheet as the standard recruitment technique of contacting the patient by letter only, has potential bias against successful recruitment of patients with poor literacy skills. The letter and audio recording asked patients to contact me by telephone to agree to take part or for further information about the study. I held a mobile phone for the purpose of recruitment for the study.

Recruitment began on 1st November 2009; the regional office registration managers and allocation staff were enthusiastically involved, and made a lot of effort to find patients who fitted the criteria; even contacting me about patients who had been removed twice so that I could decide whether to include them or not. The national manager also checked the preceding months for “revolving door” patients; but no patients fitted the criteria. At my request they also sought out patients with whom there were special arrangements with individual Health Boards to move GPs at regular intervals (this had been described during the key informant interviews). We were all surprised to discover that patients were simply no longer being repeatedly removed. Practitioner Services staff had intimated that the number of allocated patients had gone down further from when I conducted the key informant interviews but they had expected to find some patients, what we

all thought may represent the “hard core” of patients who were entrenched in a pattern of “revolving”. Recruitment was ended on 31st May 2010 at the end of a six month period which would have captured any patients fitting the inclusion criteria.

This radical development in the analysis of “revolving door” patients in general practice deserved further investigation. Was it that my definition of a “revolving door” patient was inaccurate, was it that somehow Practitioner Services staff had missed “revolving door” patients coming into the system? I doubted the latter given the strong evidence from the key informant interviews conducted in 2006 that Practitioner Services staff knew these patients well. Moreover it was their ideas about the definition of a “revolving door” patient that had been its cornerstone.

I contacted ISD Scotland again, and obtained the data on patient removals that is collected by them annually. This provides an update on the repeated removals data for 1999 set out in table 1 in the introduction to this thesis.

Table 5 Number of repeatedly removed patients by frequency removed from 1999 to 2010 (to end of March) in Scotland

Year til March	Number of patients removed per number of times									As percentage of total removals
	2	3	4	5	6	7	8	9	10 +	
1999 ³	264	71	24	9	12	11	6	2	7	13.3
2000 ⁴	90	20	4	3	8	8	8	1	4	6.5
2001	149	32	13	12	1	0	0	1	4	9.4
2002	256	59	26	7	3	1	1	0	1	12.4
2003	147	33	10	2	3	0	0	0	2	7.0
2004 ⁵	159	35	9	5	1	1	3	0	3	7.1
2005	154	29	4	6	2	0	0	2	2	6.0
2006	102	15	6	3	0	0	0	0	2	6.0
2007	118	15	4	0	0	1	0	0	0	5.1
2008	106	9	4	2	0	0	0	0	0	4.6
2009	121	9	0	1	0	0	0	0	0	4.3
2010	74	8	1	0	2	1	0	0	0	2.8

(Information Services Division NHS National Services Scotland, 2010c)

It is assumed that for the four patients who revolved 4 or more times to March 2010 did so sufficiently out with the study interval. Note that these are annual figures and the same patients may be represented across the years.

This table provides additional quantitative evidence that the numbers of “revolving door” patients had reduced dramatically and this adds weight to the evidence from attempts to recruit current “revolving door” patients that they may have in effect disappeared.

³ Excludes repeat data for Greater Glasgow, Fife and Dumfries and Galloway Health Board

⁴ Excludes repeat data for Greater Glasgow and Lanarkshire Health Board

⁵ 2001-2004 inclusive excludes repeat data for Greater Glasgow Health Board

“Ex-revolving door” patients

Whether “revolving door” patients have indeed disappeared and what the causes may be are re-visited in chapter 5, but at this stage I remained focussed on the final research question. What is the impact of being a “revolving door” patient from the patients’ perspective? From the quantitative analysis of the “revolving door” patient cohort (1999 to 2005), it was possible to map the possible geographical locations of where ex-“revolving door” patients might live. These were patients who had stopped “revolving”. Was it possible that GPs themselves may feel positive now about helping me to recruit patients with whom they had succeeded in stopping “revolving”? I utilised a pragmatic recruitment technique for this. Based on the quantitative data I looked at the proportions of the “revolving door” patients who came from different Health Board areas. These were

- Greater Glasgow and Clyde: 46%
- Lanarkshire 28%
- Ayrshire and Arran 14%
- Lothian 6%
- Forth Valley 3%

I opted therefore to select a purposive sample of 30 GPs to approach, proportionately based on this distribution of patients but concentrating on those towns or areas of cities where patients may live in;

- 10 in Glasgow
- 4 in Argyll and Clyde (now part of Glasgow and Clyde)
- 9 in Lanarkshire
- 4 in Ayrshire

- 2 in Edinburgh
- 1 in Forth Valley

Where possible I targeted individual GPs whom I knew professionally. This was judged a positive recruitment strategy that might increase GP engagement in recruitment but which I did not think would bias the recruitment of “ex-revolving door” patients (GPs recruiting patients letter, appendix 12).

I asked each GP to identify patients using the following statement:

“patients who have been removed more than three times from practices but who may have “settled” in your practice. These are patients who in the past have been removed at GPs’ requests for “breakdown in doctor-patient relationship” or “violence”; not patients who have moved out of the practice area.”

I asked them to select one patient on my behalf and send them a patient recruitment pack (with only minor changes from the one devised for Practitioner Services “revolving door” patient recruitment)

Fourteen GPs agreed to participate; 1 refused; and 15 did not reply despite a follow up email or letter within one month. Of the 14 participating 7 practices were subsequently unable to identify any “ex-revolving door” patients on their list, including 1 who gave up due to time constraints; as the possible patient files were so big to search through for evidence of allocation letters; and 2 practices made no further contact.

Five practices identified patients; for one of these the GP subsequently felt it was inappropriate to interview the patient, as her husband had just died. One patient was difficult to make contact with, and it subsequently emerged that she was serving a long term prison sentence. One patient removed himself from the practice list just as we were about to arrange an interview (following a mismatch of expectations about benzodiazepine prescribing), and one patient was removed after two years on the practice

list, when the practice had had enough of sustained aggression issues. One patient was successfully contacted and was subsequently interviewed.

4.7.3 Safety considerations

The results from the professional key informant interviews had suggested that some “revolving door” patients may display inappropriate behaviour at times. It was not possible to gather independent risk assessment information for individual patients (such as that ordinarily gained in clinical encounters; from clinical notes, professional carers, social work alerts, etc) as Caldicott permission and ethics approval allowed no research access to this information to protect the confidentiality of patients. I therefore used the principle of “universal precautions” for each potential participant and devised a researcher safety protocol which is found as appendix 13. I used an accompanier and had an initial telephone contact with prospective participants (patient contact sheet, appendix 14).

The researcher safety protocol was based on literature on the topic, (Davidson, 2008; Paterson, Gregory, & Thorne, 1999; Social Research Association, 2008) discussion with research colleagues experienced in research in risky settings, and my own clinical experience in risky settings (which includes working with clinical chaperone accompaniers). I was surprised to find no similar published protocol in the primary health care research literature. It covered safe travel to the research site, appropriate clothing and equipment, positioning inside the interview space, the use of personal pin alarms, and the notification, follow up of the start and the end of the interview with a colleague at the University, and set out the specific triggers of concern that would necessitate the interview being abandoned.

Using research accompaniers is a recognised method of promoting researcher safety in risky research settings (Social Research Association, 2008) but unusual in health research settings. This became apparent when NHS management approval was sought, successive Health Boards attempted to understand and approve the accompanier's role in the research in a

variety of ways which contributed to the lengthy delays in reaching full NHS management approval. The role of the accompanier was to be quietly present for the conduct of the interviews, alert to, and prepared to communicate risk concerns to me at any time. I was expected to immediately act on those concerns. The accompanier taking part in the study was another experienced GP colleague.

The initial telephone contact was planned when the potential participant phoned me for further information or to agree to take part in the study (patient contact sheet, appendix 12). Apart from providing information and answering questions about the study I covered practical issues like the patient's address, directions for getting to the house and who else might be present at the interview. This may alert me to inappropriate language or intention at this stage and I planned to follow this up, record any concerns and if need be decline to interview the patient.

In practice the patient who was recruited for interview only agreed to be interviewed when his GP gave him reassurance that I was a safe person to talk to. The GP characterised this by explaining that I was a GP whom he knew well (through my teaching role and through both being participants in drug misuse training) who could be trusted, and that I worked with drug users and had a positive attitude towards him. The GP (unbidden) also provided me with an informal risk assessment of the patient.

4.7.4 Conducting the interview

The interview took place in the participant's own home in August 2010 using a topic guide devised as described before (Topic guide for patient interview appendix 15). It was intended that two interviews should take place a couple of weeks apart to encourage a rapport; as it was considered that "revolving door" patients may be distrustful of professionals (including researchers) and be reluctant to discuss their experiences during the first interview. I thought it might also provide time to reflect on what was discussed. A second interview might also allow a second opportunity to

observe the participant's interaction and to further reflect on my response to the participant and to explore further theoretical areas of interest from the first interview. However only one interview was conducted. This was due to two factors; the first and overriding one was that I felt on completion of the first interview that I had gained rich data. Concerns about the patient being reluctant to talk were unfounded (I suspect the GP who recruited the patient had this in mind) and I therefore judged that conducting a second interview would not capture more than I had already of the patient's perspective on the issue. The second reason was that practically, because of the previously unanticipated recruitment strategy direction I had had to take, time to complete the study was running short.

4.7.5 Analysis of a single interview

When approaching analysis of this single patient interview I tried to set aside my hard won sense of preciousness about it. I knew that recruiting patients to take part in any study is usually difficult, but it became apparent both from the responses of the organisations I had to seek permission from, and from the lack of literature on managing safety in health research settings, that recruiting patients who are known to struggle to engage with health professionals and for whom there may be risk concerns is not at all common. This is at least the case in Primary Care research; as I received some of my key guidance from research colleagues working in psychiatry and drug misuse research. The many issues encountered are important and will be reviewed in more depth in the final discussion chapter.

My initial response on completion of this interview was validation. I felt that the layers of knowledge I had built up over the previous years about "revolving door" patients was confirmed by the interview. However acknowledging this response, I actively sought to be reflexive, taking a step away from the data, and then began analysis. I thought it was important to locate the interview in the context of the professional key informant interviews and their analysis, in order to explicitly compare similarities and

differences, so began incident coding utilising the 12 codes previously identified. These codes did cover a portion of the data, using “definition of RD patient” and “impact on RD patients” but most of the data remained uncoded. Most of what the participant talked about was their life experiences and their roles and relationships, data which could not be captured by these codes. I looked at the data afresh and returned to the principles of grounded theory as set out by Charmaz (2006) that is described earlier in this chapter. The following codes which cover the patient’s life experiences and particularly his roles and relationships were subsequently devised:

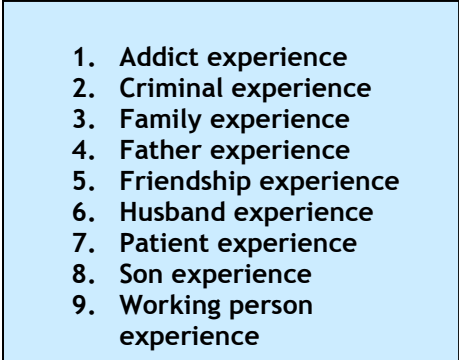
- 
1. Addict experience
 2. Criminal experience
 3. Family experience
 4. Father experience
 5. Friendship experience
 6. Husband experience
 7. Patient experience
 8. Son experience
 9. Working person experience

Figure 10 Patient interview additional codes

The results of this analysis of the patient interview are described in chapter 9 as a single account.

4.8 Following up the disappearance of “revolving door” patients

Building on what had been discovered about the possible disappearance of “revolving door” patients, I decided to further explore this as a new emergent theme. One of the strengths of a mixed methods study that uses a qualitative approach as its dominant methodology is that surprise findings can be viewed as an opportunity to deepen insights and understandings of the topic under study.

4.8.1 Further professional key informant interviews

I opted to seek further professional key informants using semi-structured interviews and to continue using a grounded theory approach. This approach had provided rich data before with all its advantages previously described. It also practically meant only a minor amendment request to the ethics committee as an extension to the grounded theory study.

Having been encouraged by discussions I had with the GPs involved in recruiting “ex-revolving door” patients on my behalf, I decided to approach this sample theoretically. Who might have the best idea about why “revolving door” patients had disappeared? Where had the hotspots (of patients “revolving”) been? Which GPs might have a good idea about what had changed? I decided to begin by carrying out 4 additional interviews; recruiting by letter (appendix 16) two GPs in geographical areas where “revolving door” patients used to be common (in areas that I had not worked in as a GP, no insider knowledge), one GP with Community Health Partnership (CHP) managerial responsibility (with the service redesign that had occurred during the six year conduct of the study, they had responsibility for registration issues) and one GP with Local Medical Committee (LMC) responsibility. The LMC often deal with contractual queries from GPs and was involved in Health Board negotiations about service delivery issues, and it was hoped these two former key informants would be able to bring knowledge from their extended roles to the topic under study.

The two GPs who had service roles only helped recruit “ex-revolving door” patients. One was male, in his 50s and was a GP principal in a moderately sized practice in deprived area in a town; and the other was in his 40s and was a GP principal in a mixed affluent/deprived area, large sized practice in another town. The GP who had a city CHP role was also a GP principal in a deprived moderately sized practice in an area of that city. I opted to target the LMC GP in a Health Board area that had responded poorly to the patient recruitment request. It took a lot of effort to get access to a GP from the

LMC. I had to employ the persuasion of a senior colleague with links in the area, to effect this in the end. The GP with the LMC role was male, in his fifties and a GP principal in a small practice in a deprived town. All four GPs took part in a semi structured interview; which took place where they worked (topic guide for additional GP interviews, appendix 17).

4.8.2 Data saturation and closure

The interviews were conducted over the latter half of 2010 in the same manner as the other key informant interviews. They were analysed using the same grounded theory generated codes for the previous key informant interviews. Gaps and omissions, new themes and unusual perspectives were searched for. However only one new code was generated: **disappearance of RD patients**.

New depth to the historical perspective of the generation of “revolving door” patients was revealed, and local examples of how they were both generated and reduced in number were described, but with remarkable congruence of ideas overall. I concluded that data saturation had been reached and after discussion with my supervisors we agreed that no further interviews need be conducted.

4.9 Summary

This chapter has described in detail how the study was conducted. It commenced with the retrieval of Scottish patient removal data from the CHI, and the conduct of professional key informant, semi structured interviews with six Practitioner Services staff and two GPs. The data linkage with routine NHS data was carried out on the first cohort of “revolving door” patients and the subsequent second cohort was qualitisied. One semi-structured interview was carried out with an “ex-revolving door” patient and finally the interviews with a further four GP professional key informants. Diagram 4 which follows summarises in a diagram format, these different portions of the study and how they interacted with each other.

This format is based on the work of Morse who utilised these diagrams when designing and describing mixed methods studies (Morse, 2010).

The next chapters 5,6,7,8 and 9; set out the results from the analysis of the data that using these methods produced. Because of the emphasis given to a dialectic approach to analysis, the results in chapter 5 are necessarily woven together. The results about the apparent disappearance of “revolving door” patients are included here too because it was important when considering the definition of a “revolving door” patient and the influences that produced them. The results for chapters 6, 7, and 8 follow the convention of reporting the results from the professional key informant interviews first then the quantitative and then qualitative analysis of the “revolving door” patient cohort

Chapter 5,6,7,8 deals with each of the four research questions in turn. However I decided with symbolic intention that the results from the single patient interview should be presented in its entirety in chapter 9. This could be viewed as privileging the patient’s perspective; but attempts to integrate the account into the other chapters diminished it.

Chapter 10 is the final chapter which concludes the thesis. Throughout the text direct acknowledgement is made when graphs or diagrams are not my original work.

An Integrative Study with a Sequential Design

THEORETICAL
inductive

DRIVE

RESEARCH QUESTIONS

1. What is the definition of a “revolving door” (RD) patient?
2. What are the characteristics of RD patients?
3. What is the impact of RD patients on the NHS?
4. What is the impact on RD patients themselves?

◀••• = Result point of interface

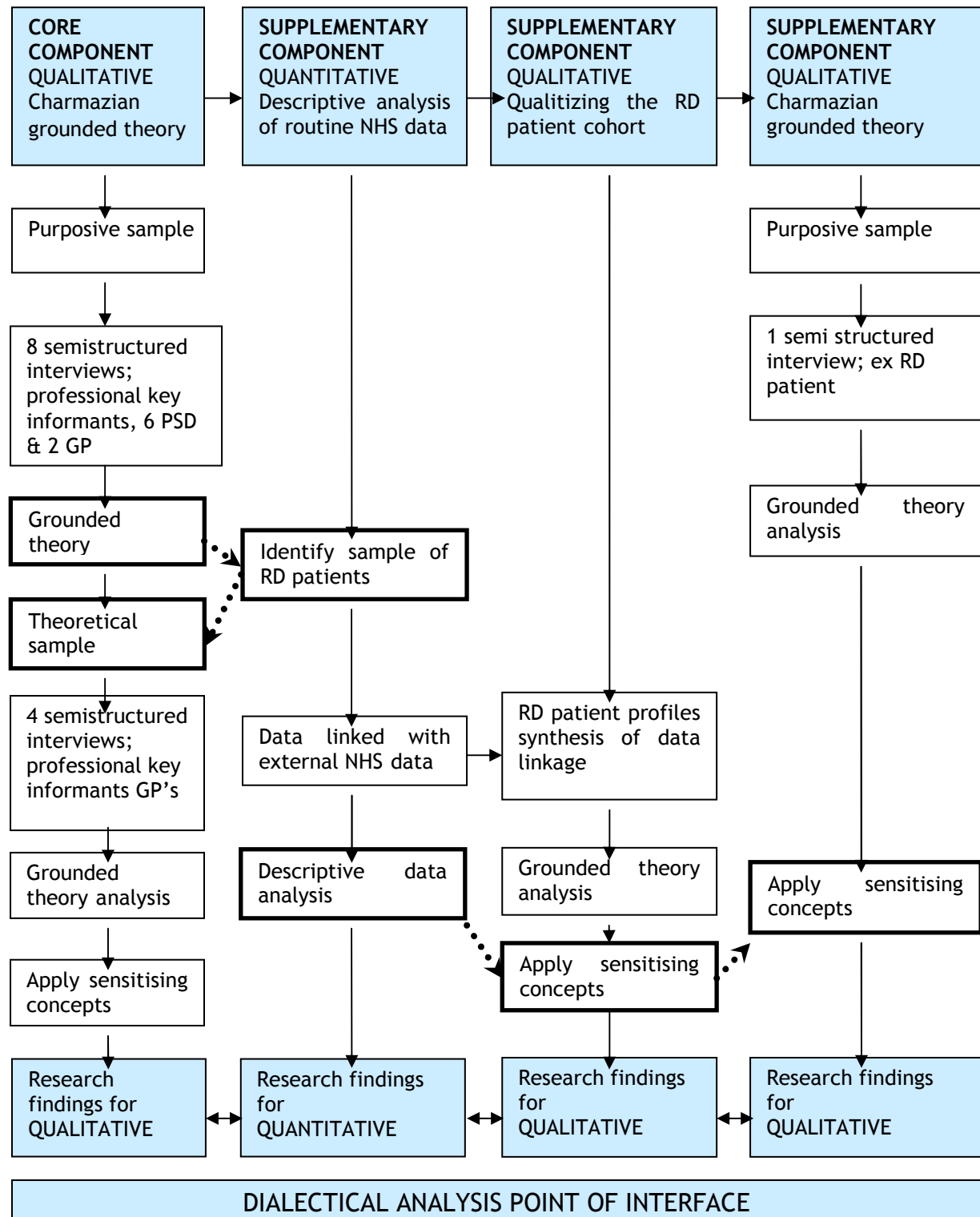


Figure 11 Diagram of mixed methods study design

(Morse, 2010)

5. Results: Defining “revolving door” patients in general practice and their apparent disappearance

For this chapter the results from the professional key informant interviews and the CHI patient removal data are woven together in the text. The first part explores how to define “revolving door” patients in general practice, the second goes on to consider the influences that produced “revolving door” patients, thereby bringing into focus the themes and theories that may influence their definition, and the third part reviews their apparent disappearance.

5.1 Defining “revolving door” patients

33,560 patients had one or more removal episodes for the reasons “breakdown of GP/patient relationship” or “violence” from Scottish general practices during 1999 to 2005. This was the time interval during which individual patient removal data were retrieved. The number of these registration episodes extracted from the CHI by each year studied is illustrated in the following graph:

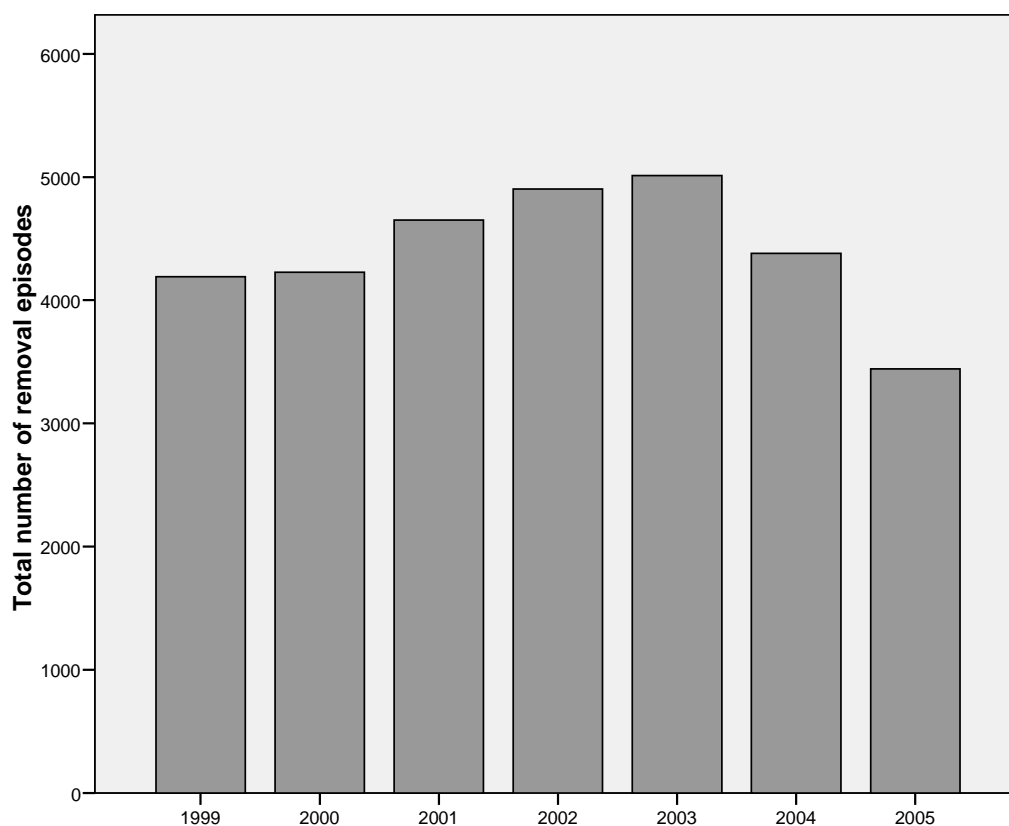


Figure 12 Patient removal episodes in Scotland extracted from the CHI, by year; 1999 to 2005 (breakdown in GP relationship and violence)

“Revolving door” patients in general practice were described by the professional key informants in 2006 as a small group of patients that professionals working in primary care would recognise. They thought that “revolving door” patients themselves would not necessarily identify with the label. In 2010 one GP described coming across 20-30 “revolving door” patients during a 15 year partnership in an urban area that used to generate a lot of repeat removals (GP respondent 3, (GP3)).

The majority of “revolving door” patients were removed because practices opted to remove them, although occasionally a patient would persistently remove himself, because they wished to register with another practice. Occasionally a patient was not happy with any practice they were allocated

to. Patients do have a right not to be registered, and there were examples of one or two “revolving door” patients who resisted being registered despite having significant health needs. An example was a patient who needed daily administration of insulin by the district nurses. She would be removed for behavioural issues, and the district nurse would phone Practitioner Services to ensure she was quickly re-allocated a new practice (and hence a new district nurse team who would administer this essential treatment) (Practitioner Services respondent 4, (PS4)).

Practitioner Services respondents agreed that a patient who was ever removed once or twice, was not a “revolving door” patient, but three times was starting to look like a “problem”. There was a range of opinion over what time period this would need to be. As a first step to refining the CHI data set therefore, all the patients who had 3 or fewer removal episodes over the 6 year interval of the study were removed from the data set. This left around 10% of the patients from which to further refine the definition.

Three distinct attempts to refine the definition were made, each definition building on the previous one, and each attempting to operationalize, in numerical format, the professional key informants’ ideas about the definition of a “revolving door” patient.

Practitioner Services key informants made a distinction between two groups of “revolving door” patients. “Fast revolvers” were regularly and routinely removed as frequently as every seven days as illustrated by the following quote:

“Well I would say it was someone who is consistently removed from a GP practice and has difficulty re-registering, even if they don’t have difficulty registering they are changing their GP practice on a very regular basis. And that can be down to seven days in extreme cases or that may go on for a period of time until it is resolved but they can actually change practice quite quickly because they are consistently removed from each practice you put them to.” PS3

In contrast “slow revolvers” were removed after some months. They sometimes stopped “revolving” for months or years at a time after going through bursts of removal activity:

“they might go to a practice and they might stay there for a year or a couple of years and they might be removed and say three months down the line they might be removed again get another practice and they will stay on that one a bit longer. We do seem to have a set of patients that are removed and assigned but maybe not on a three monthly basis. I have worked for the team for about twenty odd years so you get to know the names and somebody will say “Mr Whatever” and you think “oh yeah”, and they say “how do you know?” and its “he’s an assigned patient” so you know names; but it might not be on a three monthly basis it might be six months, eight months, a year.” PS2

The versions of the numerical definitions attempted to accommodate these two distinct groups of “revolving door” patients. Definitions of “fast” and “slow revolving door” patients were devised. As the numerical boundaries of these developed, I identified a further group of patients; those who had been removed 4 or more times in 6 years but who revolved too slowly to be “slow revolving door” patients. These were called “non core” patients.

Following subsequent analysis of the linked data when the characteristics of the three groups of “fast”, “slow” and “non core revolving door” patients were compared, the conclusion was that there was no descriptive statistical difference between them. What was distinct were the characteristics of these groups when compared with the usual general practice population. These characteristics are described in detail in the results chapter 6, characteristics of “revolving door” patients.

The attempts to make a complex activity fit a numerical definition felt uncomfortable throughout the process of seeking one; however by the end of the analysis, including the collaboration with the Robertson Centre statistician; this discomfort made sense. It was simply very difficult to make the status of being a “revolving door” patient fit a discrete numerical definition. Hence the final definition of a “revolving door” patient for the

purpose of this study was a patient who was removed 4 or more times from a GP practice list in 6 years.

Table 6 summarises each of the three definitions and how each cohort of “revolving door” patients was utilised in the analysis of the data. The detail about each definition and the descriptive statistical summary of the patients in each cohort are described in appendix 1.

Table 6 Description of the three definitions and cohorts of "revolving door" patients in the study

	First definition	Second definition	Third definition
	First cohort	Second cohort	Third cohort
Use of the cohort	Exported for linkage with hospital admissions, outpatient appointments and SDMD data	Patient profiles that were qualitized	Quantitatively analysed by the Robertson Centre statistician
Number of patients	673 patients	368 patients	586 patients with demographic data from the CHI 436 patients with additional linked data available
Definition of a "revolving door" patient	"fast": median "days on list" less than 100 days AND "slow": median "days on list" less than 366 days "non core" not included	"fast": median "days on list" less than 100 days AND "slow": median "days on list" less than 180 days "non core" not included	"fast": median "days on list" less than 100 days AND "slow": median "days on list" less than 180 days AND "non core": 4 or more removals in 6 years
Data imputed	no	no	yes
Patients moving cohort	-	305 from first cohort are excluded	7 patients from second cohort are excluded 75 patients from first cohort re-enter 150 patients are new from the original patient removal data as a result of imputing the data

5.2 The role of assignment

Respondents described all the patients who went on to become “revolving door” patients as being assigned (or allocated; the words were used interchangeably) to practices; that is Practitioner Services staff had to find them a new practice when they were removed from their previous one. Practitioner Services had a list of GPs in a defined geographical area and they simply worked through the list assigning the patient to the next GP on the list. In this way “revolving door” patients made their way round practices, sometimes several times. One Practitioner Services staff member interviewed had no direct experience of “revolving door” patients because she had never worked in GP assignments.

All the GP respondents felt that being an assigned patient had a stigmatised status. They were sensitive to this as soon as the letter or phone call allocating a patient came into to the practice. One Practitioner Services respondent felt that practices had a low tolerance for assigned patients, with some seeing it as a licence for removing “bad” patients.

Some practices also removed assigned patients before they saw them; either because they didn't feel they should have any patients assigned or sometimes because they didn't wish a particular patient to come back to the practice after previous difficulties:

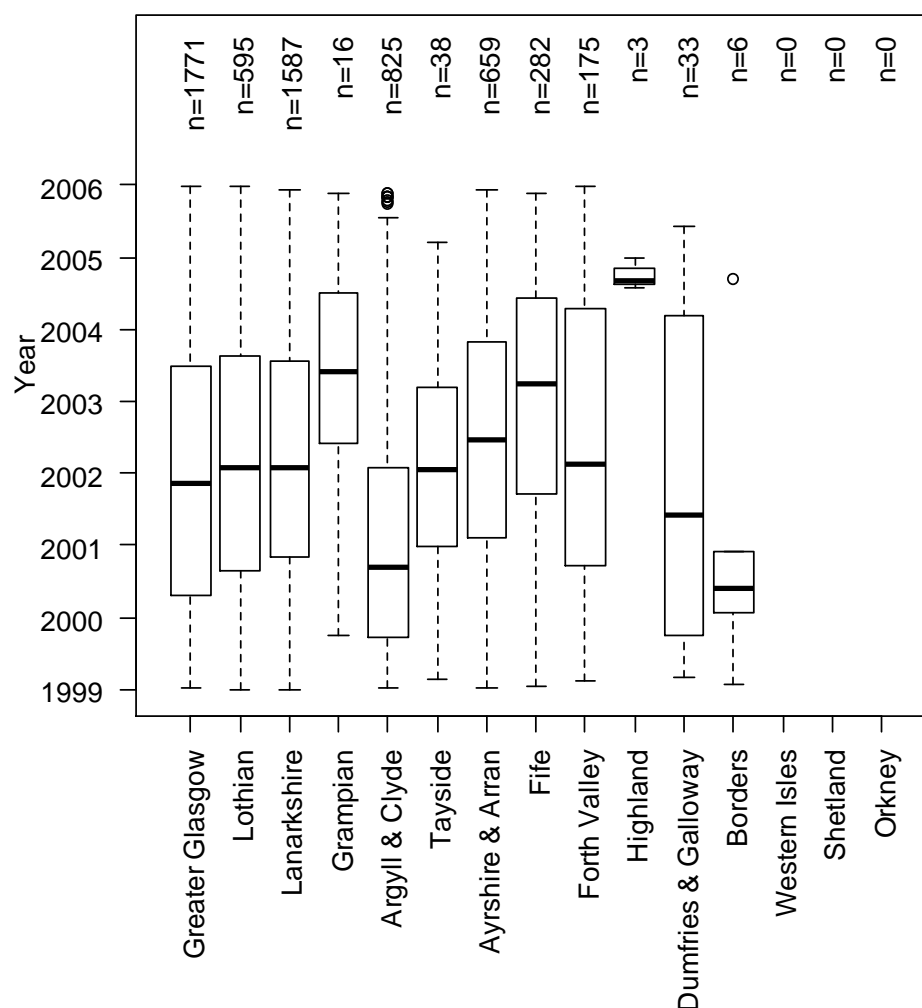
“Well we could assign the patient and twenty- four hours or two hours later we can get a fax saying remove them; they haven't seen the patient yet, but they just don't agree with the allocation. They're almost like, “it can't be my turn again, shouldn't that be somebody else's”; possibly they know the patient from before; or maybe it's a patient that's coming back to them; you know, and they think, “oh not him/her again”. But yes they can definitely, and still do occasionally, remove patients without seeing them.” PS3

In one Health Board area assigned patients did not have the same right to remove themselves from a practice as did other patients. Historically this was put in place in the mid 1990's when patients viewed moving round practices as a means to accessing drug treatment services more quickly.

5.3 Health Board area removal activity

The distribution of GP list removal and reinstatement activity for each Health Board area for the “revolving door” patient cohort is set out in figure 13 below. This was part of the analysis of the third cohort of “revolving door” patients, but excludes the imputed dates. It is set out as a box plot so that the range in scale of Health Board activity can be compared on the one graph. Five numbers divide the data into four parts each with equal numbers of the data from the lowest 25% to the highest. The first and last dates when patients were removed or reinstated in the study interval (within 1.5 interquartile range (IQR) of the box) are the whiskers at each end of the plot, with dates lying beyond these limits plotted individually as points. The quartiles are the ends of the box and the median is the thick black line. If these dates occurred at a constant rate from 1999 to end of 2005 these five points would be spaced evenly over the years (eg Ayrshire and Arran). The total number of removals and reinstatements is given in numbers above the plot. The order of the plots is in descending order with the Health Board with the biggest population first (Johnson, 2011a).

Box plot of removal and registration dates by health board



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 13 Box and whisker plot of dates of removal and registration activity excluding imputed dates for the third cohort of "revolving door" patients by Health Board between 1999 and 2005

The removal and reinstatement dates in 1999 are underrepresented because a proportion of these were imputed. The graph shows that the majority of Health Board areas had consistent removal and reinstatement activity over the time interval that the "revolving door" patient cohort was derived from. The Highland data represent one patient who when the imputed data were included, did not remain in the third cohort of "revolving door" patients.

From this third cohort the rate of “revolving door” patients per Health Board area were devised as set out below:

Table 7 Numbers of “revolving door” patients in the third cohort and number per 10,000 population of patients by Scottish Health Board

Health Board	Number of “revolving door” patients	Total adult pop	Number of “revolving door” patients per 10,000 population
Greater Glasgow	183	713349	2.57
Lothian	70	653703	1.07
Lanarkshire	116	448961	2.58
Grampian	4	430540	0.09
Argyll & Clyde	55	338032	1.63
Tayside	8	320327	0.25
Ayrshire & Arran	67	299751	2.24
Fife	28	290623	0.96
Forth Valley	19	229886	0.83
Highland	0	173997	0
Dumfries &	4	122235	0.33
Galloway	1	89420	0.11
Borders	0	21610	0
Western Isles	0	17437	0
Shetland	0	15935	0
Orkney	0		

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Lanarkshire Health Board and then Glasgow had the highest rates, with Ayrshire and Arran third and Lothian fourth.

An exploration of the factors that might have influenced the production of “revolving door” patients now follows.

5.3 External influences producing “revolving door” patients

The next section describes what respondents said about the macro factors that influenced revolving, such as the way that general practice as an organisation tended to organise its appointment system .

5.3.1 Geography

The capacity that a geographical area had to absorb “revolving door” patients, the respondents felt, influenced whether patients began to revolve and if they did, whether they were left alone to move round practices simply through being removed and allocated. In areas where there was a high number of practices then the patient moved around and the practices coped; in contrast to a practice in a rural area described below:

“R (respondent):...there is one doctor, who is right out in the sticks; he can't remove anybody basically, because he would get them back; so they don't remove as far as I know; because there is no purpose in it; because they are going to get them back anyway.

I (interviewer): But (city) has a big enough conurbation to absorb people basically?

R: Yes we can absorb them no problem!!" PS4

In areas with smaller numbers of practices then it became more difficult for both practices and Practitioner Services when the patient is reallocated to the same practice frequently.

5.3.2 History of regulations governing removals

The respondents described that regulations required that practices kept all patients registered for a minimum of seven days, except when they are removed for reasons of violence. These patients were managed differently; they entered Health Board specific arrangements for care of violent patients. If a patient requested removal they must be kept on for 14 days by the same practice.

Frequency of removal however did vary across health board areas: in some areas a previous “gentleman's agreement” (that preceded current legislation) of keeping assigned patients for three months was still adhered to by practices and in others, Practitioner Services staff understood that patients would be kept on for thirty days before removal.

These perceptions influenced how long “revolving door” patients stayed with practices before removal. Some practices routinely removed assigned patients after the agreed time scale even if they experienced no problems in that time:

"But one of the things that probably is consistent is that if a patient is assigned, they may only be assigned for a three month period; and so when that three month period is up-there could be no difficulty what so ever with the patient-but some practices may see it as being, “right we have had our turn”, and remove the patient and pass them on. So that is the bit about behind the scenes, in the sense that they still communicate with us, but there has not been incidents; which is the perhaps the more unfortunate part; which is that the practice will stick to the administrative process." PS5

5.3.3 Health Board involvement

The respondents reported that Health Boards varied in their approach as to how much they would get involved in managing a “revolving door” patient’s registration episodes. Some would intervene and set specific agreements in place with a number of practices to rotate a patient over a specific time frame:

"I think for the area that she stays in, it [the agreement via the Health Board] started at twelve practices. So I mean before, it was certainly that she could be assigned in the morning, and by afternoon she would be removed, and she would have to get another doctor. So we were going through a lot more practices that way. So at least now they are thinking; they might get her two or three times a year for two weeks; (brief pause) which to start off with looked pretty good; (brief pause) but lately- I don’t know if she is getting worse than what she was to start off with- but a few practices have now decided to pull out of the area that she is now in. So my numbers are getting less; so I think they are going to have to look at the contract again to see whether or not they can do something." PS2

One Health Board had a specific practice set up to see “challenging patients”, assess them over a period of time, and then transfer them back to mainstream general practice. In contrast some Health Boards did not get involved in managing “revolving door” patients at all. This was related

partly to how much a local area was able to absorb “revolving door” patients without causing too much difficulty to practices, or Practitioner Services staff; but also how key individuals within Practitioner Services and Health Boards opted to deal with patients who presented problems.

5.3.4 The GP appointment system

There was a view that some general practices removed patients who serially did not attend appointments. In support of this approach was the idea that patients had to get a clear message that appointments were precious and that attendance was one of the unwritten rules of being a patient. A contrasting view was that patients with chaotic lives could not always be expected to make it to their appointments. Moreover some patients had such chaotic backgrounds they could not cope with booking appointments and when they then turned up to the practice unexpectedly, confrontation occurred and they would be removed. Some of these patients became “revolving door” patients. One of the Practitioner Services respondents described this as follows:

"The one big area that I think no one addresses very well, is the someone who persistently DNAs [does not attend] and I think that that person probably isn't seen as being a challenge. The person who screams and shouts; the person who is violent; the person who is a real challenge; will probably be identified and may, well, be-ok we need to look at it a different way- but the person who perhaps has no trust in the NHS, and of a certain GP service, and doesn't turn up for health visitor appointments; all of these kind of things. That's the person who could perhaps be removed more often than isn't; and we don't have the continuity of care, and everyone just sees it as being-oh for goodness sake this is a nuisance." PS5

One respondent felt that there had been a population change with regard to expectations about receiving a home visit, helped in part by out of hours centres who expected patients to attend (GP6). This had reduced expectation and hence conflict over what was termed inappropriate requests for home visits.

5.4 Tolerance

A theme that was central to the accounts of all the professional key informants was tolerance; tolerance by individual GPs and tolerance by practices. There were lots of factors that either promoted or reduced tolerance and these will be described in turn. They were, the quality of the doctor-patient relationship, being tuned into complex patients, having the skills to work with complex patients, the effect of time pressure, the effect of spreading the burden of care across professionals, the notion of the legitimate work of general practice, and the perception of violence.

5.4.1 Established doctor-patient relationship

What emerged unanimously was that knowing the patient or the patient's family is a protective factor in preventing a patient from starting to revolve around practices. GPs were more likely to tolerate negative behaviour by a patient if they were known to them. This might be because they know it is possible for them to behave in a more acceptable manner, they may have some understanding of what led them to this behaviour, or it might be an awareness of the possible impact a removal may have on the patient's family. The patient's wider context is understood and taken into account as illustrated sequentially in these three quotes:

"I think if the patient is already known to the practice and if their behaviour is known to be normally acceptable, then if they were out of order one day or if they were shouting or aggressive in some way, people would think; "Oh, why are they behaving in that way? Something must have happened to make them behave this way." And they would maybe take them aside or write them a letter and give them an opportunity to talk about it. A different way than somebody who is unknown but has a history of being removed; they would just be removed I think, and there wouldn't be an attempt to try and see the hidden reason for their behaviour." GP1

"having a whole family registered with the practice helps because generally if they are independent lone wolves out there, there is less of a stigma loss. Or less of a, not stigma; the other; less of an embarrassment factor of being put off the doctors list; because

the doctor-patient relationship gets devalued because you are not one of the family. While if you are the family GP and you get put off but; your mammy knows about it.” GP3

“you don’t really want to offend the family, certainly not by striking someone off, if you want to call it that; although sometimes the family can be quite supportive towards the doctor as well; because if someone is giving the doctor grief, as it were, they are most likely giving the family grief too. Because even though I’ve talked about family beliefs [health beliefs learned from the family that affect interaction about illness] and so on, sometimes the very, very demanding person can also be a bit of a black sheep within the family too.” GP6

This was further illustrated by the Practitioner Service respondents’ perception that once a patient started “revolving” around practices where there has been no established relationship it was much harder for them to stop “revolving”.

5.4.2 Being tuned into complex patients

It was the Practitioner Services respondents’ view that the setting GPs worked in was important, that GPs working in areas of high deprivation had more experience of working with patients who presented in challenging ways. They felt this led them to cope better, and remove patients less often. The GPs had differing perspectives on this, some feeling it was useful to have the “thinking tools” required to deal with patients who are complex in this way in controlled, predetermined slots, whilst others found it helped them to be able to see a mix of patients and switch between these:

“obviously we are used to changing our thinking quickly between patients in general practice. And we all know that we, you can deal with someone with cancer and you can deal with someone with a cold in the next consultation. It might be wailing about the fact that they have a cold and they think it is terrible; and sometimes you know; you feel like saying -my previous patient to you came in here and you know- they have two weeks to live- sort of thing- but I think its easier sometimes when you have very, very high demand patients to have those thinking tools, as you say at the forefront of your mind. So you are on a roll as it were really; when you are dealing with them and you don’t [have] the more reasonable demands of your other patients as well” GP6.

“because there was only one or two or three at a push per day. Having five or six per surgery would I think grind most receptionists down; and having five or six extremely challenging behaviours per surgery is; having one or two; I can just about cope!” GP3.

5.4.3 Having the skills to work with complex patients

This was viewed as being about individuals having the interest and attitude that promotes working with challenging patients; Practitioner Services respondents saw this as part of what led GPs to work in deprived areas. Individual GPs who were positive, saw it as a core task of general practice but they also viewed it as being to do with their character as a person. They could also see how their skill set and “stock phrases” (GP6) had evolved over time and with experience in a positive way.

5.4.4 Time pressure

The GP respondents felt that stress and a lack of time to deal effectively with patients' problems and their behaviour, as a major factor in reducing tolerance and triggering removals:

“I do think some people obviously lack that skill [ability to see things from the patient's perspective]; not necessarily lack it all the time; but if they are stressed and overworked and running late; then they want to take a short cut rather than take time. I think that you need to have time as well; which is one luxury that I have; because I have half an hour appointments “ GP1.

5.4.5 Burden of care spread across professionals

One respondent felt that the burden of looking after patients who were difficult was now more spread across the primary care team and hence improved the tolerance of GPs and practices towards patients:

“Maybe because the pressure isn't so great as it was; that they were the only people who could see patients. Now you needn't be seen by the GP; you can be seen by any member of the practice team staff. You can be seen by the pharmacist; you can get information from NHS 24. The GPs are now not working out of hours that's; was it 2003 or 2004; there was the out of hours co-operative set up; so they have more time in the day to deal with

patients. So a whole load of initiatives have come together I think" PS1.

5.4.6 Core values of general practice

The respondents considered that GPs varied in what they viewed as the proper work of general practice; underpinned by a difference in values which led to a difference in tolerance towards "revolving door" patients:

"Well it is the difference between professionalism and business (laughs) to an extent and personality types that they are more sympathetic. There is the people who want to help the underdog, there are others who are only interested in clinical medicine, only interested in running a successful business; who really don't have time for people, that really don't have in their opinion, interesting clinical problems. And who are abusing the service from their perception, and who are preventing them from having three or four other patients on the list that could generate income for them. That is simplistic; if you were to parody; to take the two types; you would have the leather sandaled person who is in the community and wants to understand the problems, sees the psychosocial, is more of a public health doctor as well as an individual- patient doctor. Then you have got the pin- stripe suited GP with very middle class values who is out to earn one hundred and fifteen grand a year and who is not going to let this person stand in their way who clearly does not deserve any input" GP2.

5.4.7 The role of the perception of violence

Respondents reported that individual GPs and practices collectively had differing ideas about what constituted threatening or violent behaviour and hence how they chose to deal with it. This was connected in part to whether dealing with that behaviour represented the legitimate work of the practice (as they saw it); and at an individual level was influenced by the prior relationship they had with the patient. In some practices a patient raising their voice was viewed as a violent act and may trigger a removal (particularly if other reasons for reduced tolerance were apparent) whereas in others it would be seen as challenging behaviour and an issue to sort out. Practitioner Services respondents gave as an illustration of this, when the legislation about removals for reasons of violence came into being. Marked

variations in perception were highlighted when practices had to provide some detail about the circumstances for removal:

"there are some practices that remove more than others. It's just a zero tolerance and they say well, we just don't put up with this kind of behaviour, or maybe there is one particular doctor within a practice that is prone to do that" PS3.

On the other hand they described some practices as being reluctant to make a removal a "violent" patient one, as they did not wish to get the police involved. This means that the subsequent practice may not have been aware of potential risks.

Respondents perceived that this variation in tolerance of behaviour also made it difficult for patients to understand what acceptable behaviour was, as they revolved round practices.

5.4.8 The tipping point

All of these influences came into play about whether the patient became a "revolving door" patient or was removed and continued "revolving" to another practice. Reaching the tipping point, expressed what could be the culmination of a long number of incidents or negative interactions, or a sudden major trigger incident, and this was described by all GP respondents who provided GMS services to patients. This tipping point is described by this Practitioner Services respondent quote:

"...sometimes the practices put up with patients; and because they know them; and they have had them for a long time - maybe they are not your ideal patient- but they cope with it. And then they have just had enough one day, and they get put off; and that can start it. They have maybe been there no bother, because the doctor knows how to handle it; but then they get put off. And it's not as easy going somewhere else, because maybe they are not going to tolerate the same level of behaviour." PS3

5.5 The disappearance of “revolving door” patients in general practice?

5.5.1 Introduction

That “revolving door” patients were reducing in number was evident from the data when I conducted the Practitioner Services professional key informant interviews in 2006. However neither I nor staff at Practitioner Services, expected to recruit no “revolving door” patient in Scotland over a six month period in 2009-10 (section 4.7.2). The routinely available data from ISD Scotland on patient removals to March 2010 added weight to the evidence that “revolving door” patients had reduced dramatically but not completely disappeared. Moreover from the GP professional key informant interviews carried out in the summer of 2010, there was an account of a patient being repeatedly removed. The patient had recently moved from England (not part of the Scottish CHI recording system) and this was the third practice she was removed from after being registered for nine months:

“R: There would be one that I could think of that most recently left with mild learning difficulties and significant mental health...who again had the difficult way of interacting with the staff at our of hours, and inappropriate requests for things that were insoluble...Unfortunately her son verbally, well no physically threatened a parking attendant; tried to run him over; which was something that we couldn’t really tolerate. And so because he drove her here, all the time on a daily basis; generally that it was something we could not sustain. So she was already on a warning for behaviour and she apologised for it; her behaviour about verbally abusing several members of the reception staff at the front door as they left to go home from work. ...she crossed the line it was just unacceptable....”GP3

As already described in section 4.7.3 these dramatic reductions in patient numbers led me to change the study’s direction; I sought to recruit “ex-revolving door” patients and I undertook further professional key informant interviews (including GP3 above) to investigate this apparent disappearance.

The results from these data integrated with the previous key informant interviews and utilising some quantitative data are presented below.

There were two influences that were unanimously put forward as contributing significantly to this reduction in repeatedly removed patients, the first were changes in the treatment of drug misuse, and the other was the impact of the 2004 nGMS contract. The GP respondents also discussed the influence of external organisations.

5.5.2 The treatment of problem drug use and development of services

There were two strands to respondents' accounts about the influence that problem drug use had on the production of "revolving door" patients. The first was a historical account of general practice's response to the injecting drug use epidemic of the 1980s and 1990s. One GP respondent gave a bleak description of the impasse experienced at the time when patients would come seeking treatment and GPs lacked the knowledge and skills to know what to do:

"..it really kicked off about 92, 93, a lot of people started appearing, we had no training in it, we didn't know what to do. GPs didn't know what to do, there was no hospital base, there was an alcohol service but there wasn't a drug service and more people were appearing and we didn't know what to do with them. Over time, some of these patients became so insistent and abusive and demanding of practices that eventually they would, we would try our best with them but they would cross a line. They would go to another practice, they would repeat the same behaviour, they would cross a line and eventually, they've gone round all the practices in the area and their behaviour would still continue. So what the practices in this area ended up doing was utilising a thing called "Regulation 16" which is an old thing in the old "red book" of regulations. And I can't remember the exact wording, but basically if someone was allocated to you that you had reason to believe that they would be threatening or abusive towards you, you could move them on immediately. So we had groups of people that were moved on, we would be allocated them and we would immediately re-allocate them so within about a week to 10 days they've gone to somebody else; that they had also had trouble with, who would move them

on...when we got a drugs service which was effective and people were getting into treatment, and they were being stabilised, then a lot of these patients problems disappeared” GP4.

When GPs began to provide structured treatment (methadone maintenance therapy) this stopped individual patients “revolving” and contributed to a large reduction in numbers of “revolving door” patients overall. This account came not just from the GP respondents who demonstrated an early and persisting positive attitude to drug misusers but was perhaps most starkly described by those GPs who admitted they were not so positive-at least in the early days:

“...more people are deciding that perhaps it is manageable within primary care so that was the first step; methadone. We started finding methadone; because there was a lot of people dying. I thought well I know they are obnoxious and a pain; but they are someone’s mother someone’s daughter. And there’s no doubt that methadone is sedating, there’s no 2 ways about it, it does sedate you, you can argue whether it’s a good thing or a bad thing; it makes life infinitely, infinitely, more manageable” GP5.

The second strand, which was the more recent, had been the expansion of community treatment services which included integrated working between GPs (including an enhanced service payment), community addiction teams, hospitals and prisons, which led to a further improvement in patient’s stability. Waiting lists for treatment in the community reduced, and hospitals and prisons began to continue prescribing when patients were admitted or imprisoned. This led to patients interacting with their GPs in a way that allowed their other health needs to be met. Hence patients whose primary reason for becoming a “revolving door” patient was their difficult interaction with GPs about their drug misuse treatment, stopped “revolving”.

This was one of the issues that “revolving door” patients used to discuss frequently with Practitioner Services staff. What the Practitioner Services accounts revealed when they discussed the timeframe of services developing was the geographical differences in the development of

treatment services in the different areas of Scotland. This quote describes one of the Health Board areas coming late to these:

"Whether he obviously got the medication he was after this, I mean this one has been a drug abuser for fifteen- twenty years; so it's something that he just couldn't stop. So I think he put him on a programme that he could live with, and instead of him trying to reduce it he kept him on it, and it's worked wonders. If he hadn't gone there and got that, I think he would have been one of my other ones that would have been two weekly, whatever; because he had been round near enough every GP in (rural/urban HB area)." PS2

5.5.3 The impact of the 2004 nGMS contract

The 2004 General Medical Services contract which governed how GP practices delivered services and were paid, was thought by all respondents to have had a big positive influence on practice removal activity and the production of "revolving door" patients. This quote is from a Practitioner Services respondent in 2006:

"I(interviewer): this idea of "revolving door" patients do you think that's a valid one?

R (respondent): I might have a couple of years back but I don't think so much now. The GP contract changed in 2004 and my allocations have literally gone down to zilch so the contract has been great for me. I do have the offenders, my ones that are continually going round the system but in saying that they stay longer with a practice now before they are put off; they are no longer a seven day removal; so it's working for me." PS4

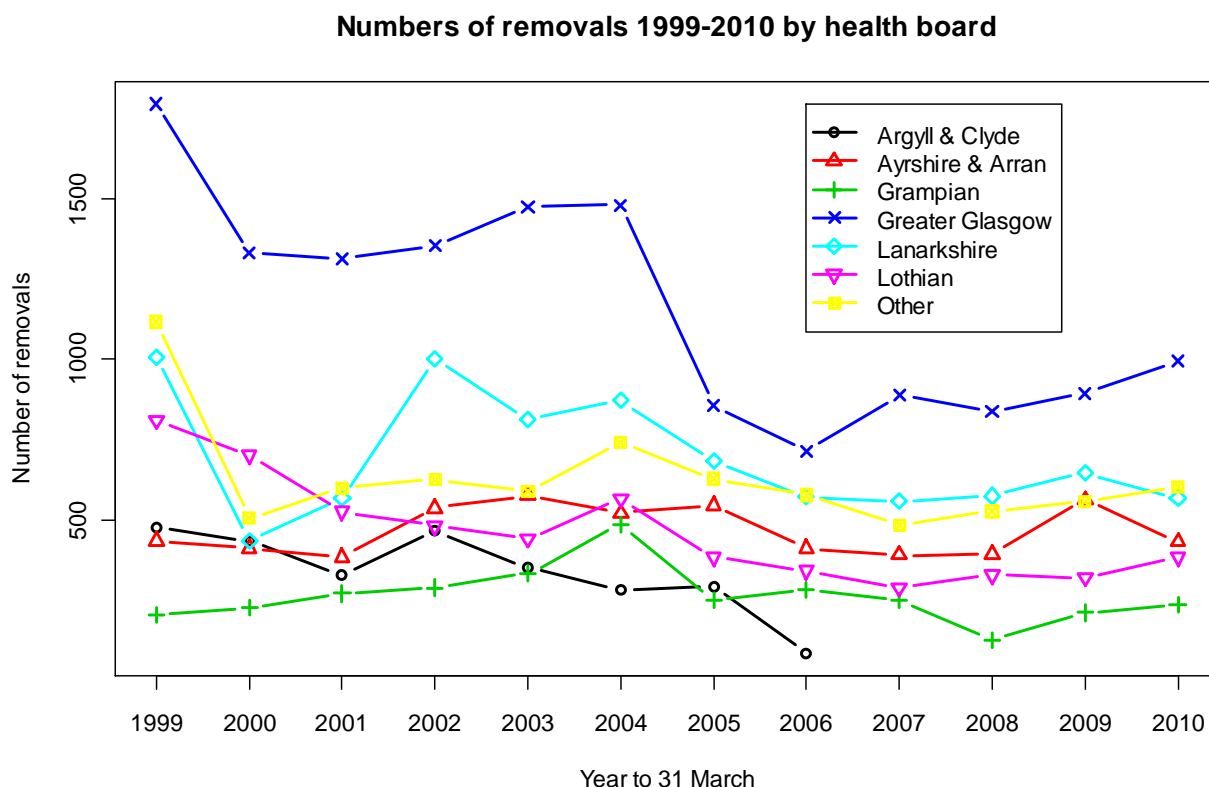
The most important aspects were the non discriminatory tone and accountability for removal decisions that the contract introduced. Patients now had to be warned before removal; had to be informed of the reason for removal (unless there was an overriding reason for not doing so) and the practice had to keep a record of this for external scrutiny.

Another change was that payment for GP out of hours care was no longer linked to patient contacts. GPs now paid a flat rate from their "global sum"

irrespective of how many contacts their practice generated. This meant that patients who had frequent (and perceived as inappropriate) out of hours consultations were no longer removed from GP lists.

The removal of target incentives linked to practice payments for screening tests or vaccinations was acknowledged by the respondents to have had an impact. Some practices no longer felt the need to remove patients who defaulted cervical smear screening or vaccination appointments.

A plot of removal episodes (excluding geographical removals) by Health Board in Scotland showing the removals from 1999 to 2010 (the most complete data available):



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 14 Plot of number of all CHI patient removals due to breakdown of doctor patient relationship or violence by Health Board from 1999 to 2010

Glasgow (and Clyde) dominates the picture being the largest Health Board in Scotland; however the trend does appear to change after 2004.

To investigate this further a Chi squared test comparing the number of all patients removed in 2003 and 2005 in Scotland, the last year of the 1990 GMS contract and the first full year of the nGMS contract respectively, was calculated. 4576 patients were removed in the last full year of GMS compared with 3640 in the first full year of nGMS. (The Chi squared = 114.522 with one degree of freedom. The two tailed p-value was < 0.001 for the removed patients). This difference in observed versus expected removals was highly significant supporting the finding that the 2004 nGMS contract significantly reduced GP patient removal activity.

5.5.4 Influence of external organisations

Some GP respondents described attempts that had been made by other agencies to discourage repeated patient removals. In one locality one of the GPs described efforts by a colleague to bring about change:

“The reason it ended round about here is that we had; as I say we had these patients who were going round and round the practices, nobody wanted them, they were difficult, they were demanding... one of the Health Board officers had a quiet word with her [GP in local area] that although we weren’t doing anything illegal, there were some whispers going round that (urban town) wasn’t pulling its weight, we were getting a bit of a reputation for not addressing these difficult- other areas would just get on with it- but we had this merry-go-round, that people were getting punted round. And about that time (GP in local area’s) practice wanted to get practice accreditation and they realised that this system that was in place would be a barrier to them achieving that. So she called a meeting, and we all sat down, and we all thought “yeah, it was a bit fishy really, this system that we had”. So what was going to happen was, that the next time one of these patients was allocated to us we would keep them. We would not get rid of them; we would keep them for 3 months which was the other length of time you could have under the red book; keep them for 3 months and if they behaved themselves and didn’t cause a hassle then we would keep them going at that point” GP4.

Another respondent described how the Royal College of Practitioners began to discourage the practice of removing patients, and a couple cited the activity of the Health Service Ombudsman which flagged practice removal activity as a problem; they felt this was influential in changing attitudes too.

5.6 Summary

I have described how a numerical definition of a “revolving door” patient was sought and then discarded; taking into account the complexities of patient, practice and administrative factors based on the data from the professional key informant interviews. The final definition was that a

“revolving door” patient had been removed four or more times from GP lists in six years for the reason “breakdown in the doctor-patient relationship” or “violence”. This recognised that it was the status of being repeatedly removed that set these patients apart from the usual general practice population rather than detail about the range of time scales. All “revolving door” patients were assigned to practices and this was a stigmatised status.

There were a number of external influences that determined whether patients would start or persist in “revolving” around practices. The geography of the area was important as “revolving door” patients did not occur in places with insufficient practices to move around. The history of regulations governing removals influenced how long practices in different Health Board areas held onto patients before removal. The amount that Health Boards were willing to intervene to support patients who were being repeatedly removed had a role in some areas, with a rota of practices with a specific time frame set up. Finally the GP appointment system was seen to be a problem for patients whose chaotic lives meant they struggled to keep appointments and this triggering repeated removal for patients who persisted in defaulting appointments.

Tolerance was a central theme in considering what influenced the production of “revolving door” patients. Central to this was the importance of an established doctor-patient relationship either with the patient or the patient’s family. If this was the case patients were less likely to revolve; but once they did start “revolving” a lack of this relationship made them more likely to continue “revolving” around practices. GPs who were tuned into more complex patients and who had the skills to work with them, had higher tolerance, but time pressure had a negative effect on this. Recent changes in the delivery of care which meant that patients could see a range of health professionals about their problems also has had an effect in reducing the burden of caring for challenging patients and this was thought to promote tolerance by GPs. Underpinning all of this was what different GPs considered to be the legitimate work of general practice, with a role of the perception of violence bound in with this too. However GPs or practices did

reach a tipping point with patients, either from an accumulation of a lot of triggers or one major incident leading to their removal again.

There had been a decline in the number of “revolving door” patients in Scotland and as the study progressed there was a dramatic decline in patients being removed repeatedly. The development of treatments for problem drug use and then improvements in the delivery of services for problem drug users varied geographically, but had an early and sustained positive influence, alongside the influence of external bodies who discouraged patient removals. But it was the positive, ethical, regulatory, and financial climate of the 2004 nGMS GP contract that appeared to be the final push to encourage all practices to hold onto “revolving door” patients and keep them on their list.

5.7 Discussion

5.7.1 Tolerance

That tolerance was such a central theme in what led to, or reduced the production of “revolving door” patients merits further examination. Its dictionary meaning is “the ability to accept things that one dislikes or disagrees with”, or “the ability to endure specified conditions or treatment” (Compact Oxford English Dictionary, 2005). Tolerance, however, is also a social, value-based construct;

“typically conceived as an individual virtue, issuing from and respecting the value of moral autonomy, and acting as a sharp rein on the impulse to legislate against morally or religiously repugnant beliefs or behaviours” (Brown, 2006).

In this light it is viewed as a professional value to be encouraged and praised. This would appear to be the meaning with which it is used, when the respondents are describing tolerant GPs or practices. However, a sociological perspective that examines the penetrance of tolerance into every sphere of public and private life sees a dark underbelly to this

discourse. By the act of being tolerant the tolerator “iterates the normalcy of the powerful and the deviance of the marginal” (Brown, 2006). The tolerator is asserting their own mainstream status and defining as different some aspect of the tolerated. What is it about “revolving door” patients that GPs might be trying to tolerate which by this view gives them the status of deviant? This will be considered in the next chapter when I examine the characteristics of “revolving door” patients.

5.7.2 Stigma and stereotyping

For now I will turn to the common characteristic of “revolving door” patients that has been described in this chapter, which is that they were assigned patients. That is the status which describes a patient who has been unable to register with a practice themselves, and who has to make a request for Practitioner Services to register them on their behalf. It is not just “revolving door” patients who are assigned, all patients who struggle to find a new practice may need to be.

All the respondents viewed this as a stigmatised status to the point where Practitioner Services staff would strongly advise a patient to try as hard as they could to find a practice themselves so that they did not have to become an assigned patient. There was a sense from all respondents that this view of assignment was a reasonable one, as inevitably attached to it was the understanding that the assigned patient was in some way “trouble” as described by this respondent:

“I(interviewer): ... any patients who have been “revolving door” patients, that have known, that, you’ve just thought; what on earth is going on now; why are they “revolving”; I don’t get it?

“R (respondent): No, they all had a reason, and it was kind of like; oh here we go. Generally they are allocated, that’s warning sign one; and there were some stories of practices where, somebody; if you were a man in your 20’s allocated; you would be put off after 7 days without even thinking about it- because there must be something wrong with you- that didn’t happen here...” GP3.

The onus was on the patients to disprove that they were trouble. But it was also generally agreed that patients would not understand that assignment had this status.

Stigma is defined by Scambler (1998) as:

“any attribute, trait, or disorder that marks an individual as being unacceptably different from the “normal” people with whom he or she routinely interacts, and that elicits some form of community sanction”

This is operating as “enacted stigma” when the stigmatised are behaved towards in a certain way, because of that stigmatised identity (Scambler, 1998). This could also be viewed as stereotyping, the identity of being assigned is seen as having fixed attributes that in this social context are the dominant identity of the patient. At best this is until the GP meets the patient, and at worst for the length of their (short) doctor-patient relationship. This is distinct from categorisation. They both operate to seek to impose a sense of social order on the social world but crucially as Pickering (2001) points out “stereotyping.... attempts to deny any flexible thinking”. Moreover from a conceptual viewpoint across disciplines:

“stereotypes operate as distancing strategies for placing others in such a manner that they will serve to point up and perpetuate certain normative boundaries of social conduct, roles and judgement, separating what is seen as threatening and disturbing from what is regarded as acceptable and legitimate” (Pickering, 2001).

5.7.3 Proper work and core values of general practice

What is acceptable and legitimate in the work of general practice? In one of the quotations above about general practice, the GP respondent talks about, how wearing either “sandals” or “pinstripes” are the two extremes of how general practice can be, and this is (acknowledged as) a stereotype. But this vivid description represented what underpinned all of the accounts, both by the GP and the Practitioner Services respondents. For the GPs it was an account of how they saw themselves as adhering to the core values of

general practice (as best they could), and for the Practitioner Services respondents it was about describing those GPs who either did, or did not embody those values. One of the GP respondents describes how their practice sees their role:

“Yes I think it is, in that you do the best for people of all shapes and sizes and all personality types you, we have a GMC [General Medical Council] type responsibility to do our best for patients irrespective of that; but individual tolerances for what people will be able to put up with are going to be different. We have, I know here, our group[GPs in the practice], we have a very similar ethic of trying to get them [patients] to stick,[stay registered] to try and get a depth of relationship such that the noise disappears and we can actually start to deal with some stuff.[health issues]” GP3.

Numerous attempts have been made over the years to set out what is the proper or legitimate work of general practice (Mechanic, 1970). Advances in clinical medicine and hence changes to what was considered the clinical territory of primary and secondary care, and the Quality and Outcomes framework of the 2004 nGMS contract have all contributed to a resurgence of this articulation. This seems to always return to what was essentially both a description of the technical biomedical aspect of general practice and the centrality of the interaction or relationship GPs have with their patients (Loxterkamp, 2008; Sweeney & Heath, 2006). Inextricably tangled in this was the articulation of the core values of general practice (Gillies, Mercer, Lyon, Scott, & Watt, 2009). The respondents in this study echoed the view put forward by these commentators and the Royal College of General Practitioners, that to attend only to the biomedical aspects of a patients care is to neglect the core values of general practice (Gillies, Mercer, Lyon, Scott, & Watt, 2009; Loxterkamp, 2008; Sweeney & Heath, 2006). Moreover, in the case of “revolving door” patients, having an established doctor-patient relationship was seen as the major protective factor against patients becoming removed and then beginning to revolve. Therefore, what was special about the case of “revolving door” patients? What was it that allowed GPs to neglect a patient’s medical needs, suspend

their core values, deny a doctor-patient relationship and remove patients repeatedly?

5.8 Conclusions

This chapter described the definition of a “revolving door” patient, a patient who was removed four or more times from GP lists; recognising that it was the status of being repeatedly removed that set these patients apart from the usual general practice population. All “revolving door” patients were assigned to practices and this was a stigmatised status.

The external influences that produced “revolving door” patients were the geography of the area, the history of regulations governing removals, the amount that Health Boards were willing to intervene to support patients who were being repeatedly removed and the GP appointment system.

Tolerance was a central theme that influenced the production of “revolving door” patients. Higher tolerance and less removal activity was promoted by an established doctor-patient relationship with the patient or the patient’s family, GPs who were tuned into more complex patients and who had the skills to work with them, and patients being able to see a range of professionals about their problems. Lower tolerance and more removal activity were more likely if GPs had high time pressure or were stressed in other ways. What GPs considered the legitimate work of general practice including how they perceived violence was an important influence on tolerance. However GPs did reach a tipping point with patients and removed them.

There was a dramatic decline in the number of “revolving door” patients in Scotland during the time frame of the study. This was perceived to be due to the development of treatments and improvements in the delivery of services for problem drug users as an early and important factor, along with pressure from a number of professional bodies for GPs to change removal

behaviour. The positive, ethical, regulatory, and financial climate of the 2004 nGMS GP contract brought the numbers to almost zero as the study concluded.

All “revolving door” patients were assigned to practices and this was a stigmatised and stereotyped status to have. How the so-called underbelly of tolerance; that the tolerator is asserting their own mainstream status and defining as different some aspect of the tolerated; relates to assignment was explored. The professional key respondents and the general practice literature agreed on what constitutes the core values and proper work of general practice as being both the biomedical sphere of caring for patients and the doctor-patient relationship.

The next chapter describes the characteristics of “revolving door” patients and investigates further what might constitute the legitimate work of general practice.

6. Results: Characteristics of “revolving door” patients

As well as drawing on data from the interviews with the Practitioner Services and GP professional key informants, this chapter sets out a descriptive analysis of “revolving door” patients who revolved between 1999 and 2005. These patients’ hospital admissions, outpatient attendances and drug misuse treatment episodes are explored using a quantitative analysis of the third cohort of patients, and then the qualitative analysis of the second cohort (as described in table 6, section 5.1); each being used to inform the other. This seeks to answer the research question, what are the characteristics of “revolving door” patients?

6.1 Professional key informant interviews

6.1.1 *Memorable patients*

Practitioner Services staff had an administrative role in the NHS. They were based in large administrative buildings in the three large cities in Scotland and for a number of years (since patients were no longer required to collect copies of medical cards from their premises) had no face to face contact with patients. Much of their workload was computer record based but they did speak to patients on the phone. From the many thousands of patients whose records they processed, the “revolving door” patients stood out. They stood out because the staff “knew” (PS4) them, or they certainly could recall lots of information about them. This was in part because “revolving door” patients made frequent contact with Practitioner Services, to request a new allocation, to talk over their problems, or once they got to know staff members, for a chat. It was also because general practice staff would phone or write and describe situations or problems that related to the reasons why patients were being removed, to Practitioner Services staff. Practitioner Services respondents acknowledged that their view may be missing those patients who do not contact them or those whom practices didn’t provide

additional information about. The GP respondents remembered “revolving door” patients because they stood out as patients.

There were three characteristics that “revolving door” patients all shared; respondents were unanimous about these. They were all required to create the circumstances which would start a patient on a “revolving door” path, bearing in mind the influences that produced them set out in the previous chapter. These are described in turn. Then I describe the aspects of patient characteristics that were not uniform across all patients but which help to add flesh to the necessary characteristics.

6.1.2 Unreasonable expectations

Respondents perceived that all “revolving door” patients had unreasonable expectations from the Health Service in a range of ways. They requested consultations for perceived health needs very frequently and it was the perspective of respondents that they often could not distinguish between a minor and major illness. Respondents perceived that the subsequent response these patients expected from the practice was unreasonable including having unrealistic preferences for one GP. Some patients even phoned the practice or other services repeatedly after they have just been seen. Overriding this was the practice’s experience that they cannot hope to meet the patient’s perceived needs.

“You start off, and you try and sort out some of their problems; but then you realise with some of them; unless there’s a change in their perceptions and so on, things aren’t going to get better. Some of them have got chronic diseases they’ve just simply not accepted. How do you get them to realise you aren’t going to get better; you’re always going to have some sort of disabilities? Are you going to have changing perceptions of what we expect here, what we can and cannot try for you there?” GP5.

This was often described in terms of house call interactions as illustrated below:

“He played the piano in the house and he wasn’t asked to, switched the light on and she didn’t give permission to do that in

her bedroom. But she will find fault with anybody because she wants someone particular; there is only one[GP] that she likes particularly...so everybody that goes in there she finds fault with...she calls out ambulances all the time, day and night, she makes 999 calls, which the practice inevitably get involved in, and she is exceedingly demanding. And she demands house calls all the time; and then she won't open the door because she is having her tea... there are problems there and she requires medication.... she is not very mobile now either..."PS3.

And in the interactions taking place in the practice as illustrated by this quote:

"...literally couldn't pass the health centre on the bus without stopping and coming in and that was very difficult really.." GP6.

The group who were described differently when considering this characteristic were drug users seeking treatment. There were some GPs who when they discussed the historical context of the development of drug treatments and services, viewed previous patient behaviour as inappropriate and some Practitioner Services respondents who did too, usually when a request was made for dihydrocodeine or benzodiazepine prescriptions. There was seen to be a change over time, however, as knowledge and skills about treating problem drug use altered and respondents moved to perceiving most problem drug users requests for treatment as reasonable. There was a perception by some respondents that some GPs were being inappropriate now, in not meeting the requested treatment needs of drug misusing patients.

6.1.3 Inappropriate boundaries of behaviour

There was also a perception that "revolving door" patients were patients whose boundaries of behaviour were difficult for others to accept. This was apparent as soon as the patient began to interact with the practice and they made health staff feel threatened or exasperated, including Practitioner Services staff who administered the registration system. Exasperation was bound up with perceived inappropriate demand when the patient seemed

unwilling or unable to change their pattern of behaviour relating to this, aggression and violence are considered below.

Verbal aggression

Respondents felt that patients who were persistently abusive or impolite to reception staff and health professionals, became “revolving door” patients. Some “revolving door” patients struggled to control their anger and blew up easily.

"Yes the ones [“revolving door” patients] that I have met have a tendency to become very quickly verbally abusive, and I think that’s why people want to back away from them. So I think that would be their main common characteristic. On the phone as well they quickly become out of order with their language and insults, inappropriate insults very rapidly." GP1.

One Practitioner Services respondent felt it was the older “revolving door” patients who are more abusive:

"One woman she is just (ehm) diabetic but she won't inject herself; so nurses have to go out every day. That’s nothing to do with the doctors; it’s the nurses that she abuses; and that’s usually where you find these [older] ones that go around the system because of the abuse that they give to others that are coming into their home." PS4.

Drug users who became verbally aggressive when they made requests for treatment and were unable to accept the response they get from practices were also described. This example was from a Health Board area that was late in developing their treatment services compared to other areas:

"Because we have had patients that have been assigned on a regular basis; probably between a lot of them; is just the fact that they are drug users, and it's often not the treatment that they are getting from the practices. You know the doctor may want to try and reduce their methadone or whatever; but because the patient doesn't want that, they then become aggressive, annoying, whatever you want to call it. Just so the

doctor will say right; I have had enough of you; you're being removed."PS2.

Mismatch of expectations and the tolerance of the GP or practice were important too.

The role of violence

The respondents mostly had the same view about whether “revolving door” patients were violent or used threats of violence; in the majority of Health Board areas violence was not thought to be a significant factor:

" P: Unless they are removed as an immediate removal because of violence in which case they come off immediately that day.

I: And does that happen for the” revolving door” patients?

P: Not often; it depends on the patient. There could be a patient in that category but they are not all like that; they are not all like that at all; definitely not; no." PS3.

In a minority of Health Board areas; and this was in areas where “revolving door” patients were least common, they were a significant proportion of “revolving door” patients where violence was considered to be a factor:

"I think for us probably the “revolving door” ones have been more violent, really. Fairly abusive everywhere; I certainly know of two or three patients here who persistently with every practice they went in to, they would produce a knife and they would do this, and that is very difficult because you not going to put up with that. "PS5.

The GP respondents felt the reason was that GPs were actually less inclined to remove patients who were a serious threat, they tended to try and manage such patients themselves. They placed some emphasise on GPs not wishing to pass on serious risk to other practices and moreover felt that because they knew the patient over a long period of time (an emphasis on established relationship again) they were better placed to manage serious

risks. This was supported by Health Board specific arrangements for management of violent patients.

"...some violent patients aren't put off lists, people think well I'm just displacing a problem to someone else and it is better the devil you know."GP2.

Responsibility for behaviour

All respondents got across either implicitly or explicitly in the interviews that it was theirs and the NHS's role to provide care to all patients equally (an expression of core values again). However the respondents also articulated with varying degrees of criticism that "revolving door" patients were unable to share this view. Many of the respondents felt that "revolving door" patients were unable to see the impact of their behaviour on the professionals they interact with, and on other patients:

"Certainly demanding, a little bit selfish probably, about their needs, and not understanding that the GP has probably got another two thousand patients on his list." PS1.

There was a range of interpretations of this behaviour. Some respondents viewed it as patients asserting their rights as patients:

"But the kind of challenging who will, perhaps constantly challenge in the sense that they are non compliant; and they are often quite intelligent; and its "I don't want to do this and I'm quite aware of my rights."" PS5.

But some respondents viewed this as moving towards a more selfish sense of individual entitlement:

"I: So you get a sense of that: they are unable to see the bigger picture?

R: No they are not interested in the bigger picture; they just want what they think they are entitled too. I suppose some of them they see drug addicts get this, that, and the next thing; and they

think they should be getting it. And I say; “that’s not necessarily the way it works.” PS4.

Many of the Practitioner Services respondents felt the “revolving door” patients had a remarkable understanding of the assignment system and would anticipate consequences to certain actions as set out in this example:

"In the past before we had the violent patient clinic they could be removed immediately and we had to assign them immediately and some of the patients even became aware of that service. And if they didn't like where they were put, they would maybe start a fight; so they would get taken off immediately so we would have to put them somewhere else. You know they get to know these things; its not in the papers or anything, so I don't know how they get to know it; that's what I mean by smart." PS4.

Others saw the problem as a manifestation of the mismatch between patient's behaviour and how professionals expected patients to interact with the system; “I don't think there is one who plays the game properly” (PS4). One cited example was the use of language, and underlying these discussions was the class differences between patients and their GPs:

"...I think if you put it in context they probably don't regard them [swear words] as particularly insulting where they come from; but for your average person they take huff quite quickly because it isn't normal language; whereas for them it is probably nothing; peanuts. Again you have to get into their shoes to try and understand what they are saying, don't you?" GP1.

"I think people's unreasonableness in terms of their expectations requesting their behaviour from the GPs; they expect they act in certain way; that maybe a very middle class expectation from the GP. I think anyone attending a professional looking for help, support, counselling and all the rest of it needs to act in a reasonable way with them; not to be threatening physically or verbally to them. "GP2.

Permeating all of the attempts at understanding where responsibility for behaviour lay, was how much it was to do with the patients' underlying health problems meaning they could or not change; as illustrated here:

"The other chap is still bad but not nearly as bad as he used to be; he sort of turns up at casualty repeatedly. (ehm) Yeah, they are very difficult to deal with actually, because you can speak to them and say how unreasonable they are and they agree with you but then the next day they are doing it again and it seems to be very difficult for them to get over that feeling of anxiety; of, I need help now." GP1

This linked in with whether patients were able to change.

Ability to change behaviour

Respondents ranged in their opinions about patients' ability to change the behaviours that led them to be removed repeatedly; but a sense that if this could be achieved they would stop being repeatedly removed. This view on the ability to change was partly dependent on the reasons behind why patients revolved and partly due to the respondent's experiences and views about patients' willingness and ability to make behaviour change. Some respondents were clear change was not possible:

"...I think that these people either have a complete disregard for the professional advice of the doctors, they want what they want and don't get it, most professionals will not just give in to demands for things, and therefore, they don't learn from the interaction to change their behaviour; they just keep going the same way, and no doctor I think will work within that relationship for very long when the demands are completely unreasonable..." GP2

Some made the link between the underlying diagnoses the patients had and the possibility of whether professionals would be able to engage therapeutically with the patients, the GP respondents were more hopeful and could give examples of patients who had mainly problem drug use problems who had stopped "revolving", and they all gave accounts of patients with established or likely personality disorder diagnoses who they had struggled with. The first quote explores this generality:

"I think if you begin to engage with them meaningfully you are likely to keep them; so they will stop becoming "revolving door";

so these people are just too difficult to fathom and too difficult to work with... They themselves may not want to engage with a proper therapeutic relationship anyway so it is not the GP's fault; but partly it could be if: it's attitude from the GP as well. But I think in the main, I never know obviously what goes on behind closed doors in surgeries; most GPs are reasonable individuals; and I think would try their best to engage with someone; but if they saw that they weren't getting very far and they knew the patient's already been through seven or eight, ten practices whatever, they would probably not think it was worth putting a huge amount of effort in." GP2.

And the second quote gives an example of a patient the respondent had difficulty working with:

"just couldn't get a rapport with this woman at all; you just could not get into find out what on earth was behind all this. And she was also one of these patients who would come in and park themselves and give you 12 things to deal with, ...we try all the tricks you say 'well look that's an awful lot of stuff you've only got 10 minutes so if you tell me the 3 things that bother you most' so she would tell you that; and then she would just go on. And I said "look I've got other people to see"- "but you still haven't fixed such and such." Or it would be; one thing I remember she did have; is I think she had a broken nose at some point; and she was forever going on about the appearance of this nose. And there were 20 letters in her file from various ENT or plastic surgeons all over the country, saying; we cant make this nose any better that's the way it is. But she would not accept that it couldn't be made any better....when you are talking to somebody and you know you have no mutual points of reference if I can put it like that, you just don't click at any sort of level, its like they are half a pace apart from my reality if you like -which I assume is everybody else's- and they just don't see other peoples point of view...they are completely wrapped up in themselves and they don't see anybody else's viewpoint." GP4.

All respondents were able to give examples of patients that had been "revolving door" patients but who had stopped "revolving" and settled down and many GP respondents were proud of the effort and progress they had made with these patients. These tended to be patients with problem drug use problems; but they often had other challenges as well. Clear signalling and setting of boundaries about what was reasonable to expect seemed to underlie progress. But it was slow and sustained effort was required.

"Sometimes you can see them biting their lip and actually changing what they are saying, other times it slips out and they apologise. I say, "oh don't worry. It is not necessarily the words, is it; it is the way it is said." If it is the odd swear word thrown in, in the conversation you do not really take any notice but if somebody is directing it in a forceful and aggressive way to you that's quite different. I suppose I try to get that across. One particular patient who the social work department will not meet with at all because he has behaved so badly; and I try to get him to understand how he makes people feel; and I think he is getting an idea of that and realising that he is not going to get anywhere with them unless he toes the line. Maybe he will one day (laughs)." GP1.

6.1.4 Unmet health needs

The third necessary characteristic that the respondent reported was that "revolving door" patients had health needs that required to be met. These may be physical, psychological or needs that relate to the medical aspects of benefits or insurance, otherwise they would not be in contact with general practice or would simply avoid re-registering with another practice once removed. A respondent described an example of such a patient:

"Categorically will not have another practice until such time as she needs a job reference or needs a medical, has applied for a visa and wanted that to happen; so she needed to register. But she doesn't want to register with the practice; she will just go there and get that; and they weren't happy to do that; and then something else will happen, maybe she will stay there for three weeks and then she wants access to her records and then there will be a big (pause), something will go wrong with that, and she will be removed again.." PS3.

Practitioner Services respondents knew about many "revolving door" patients having specific high dependency needs such as being housebound and requiring regular nursing input for their medical problems or having agoraphobia and requiring house calls.

Patients with mental health problems

Respondents described “revolving door” patients whom they felt had mental health problems. This was articulated in different ways by the Practitioner Services respondents and the GP respondents; the first describing how patients interacted but not explaining behaviour in mental illness terms, the second providing more explanatory and medical model examples. Practitioner Services respondents described patients who behaved bizarrely, seemed to have conversations with themselves, were demanding, appeared delusional, and even displayed inappropriate sexual behaviour. Here is an example of a description:

"This patient is a bit; I use words like delusional , and I am not medically qualified, but she has odd ideas about patient data and doesn't want to go to the practice across the road because of some programme she heard on radio four which suggested that obviously they would tell everybody all this information sharing within the NHS. And she feels that there is no privacy. She doesn't want to go to the practice that's nearest to her because she doesn't want her neighbours and everything knowing all her business which of course the GP practice is going to tell them. She refers to things she has read and to consultants that she knows personally who have given her advice about this, that and the other, and she is quite difficult. And she makes accusations against the practice when she is there which is quite difficult for them and unsubstantiated. And therefore ends up going to the next one. They get fed up with her as well, she goes back. There have been quite a few issues with her."PS3.

The GP respondents felt that the majority of “revolving door” patients had personality disorders, likely to have been discharged from psychiatry services, and for who general practice is ill equipped to work effectively with:

“...the last one we had it was particularly frequent, inappropriate house calls; demanding; aggressive; playing one person off against the other; being abusive verbally to staff. That was the last one we had; it was somebody who had learning disabilities and was in a home, and refused to cooperate with all treatments. She used to have numerous complaints and was over investigated.... And

her case notes were horrendous; large part of them were personality problems."GP5.

Patients who were anxious and expressed their symptoms through physical complaints and health seeking behaviour were a subset of these patients. GPs also gave examples of a few patients who had milder spectrum learning impairments and some described patients with major mental health illnesses who became "revolving door" patients as described in this example:

"One patient was moved on a few times when she had several periods of actual physical aggression when she was psychotic. She was schizophrenic and she had quite a few serious assaults actually."GP1.

Patients with drug dependency

Patients with problem drug use had a historically important role in being the majority of "revolving door" patients before problem drug use treatments and services were developed. This pattern changed at different times in different Health Board areas as GPs began to prescribe maintenance methadone treatments and treatment services were set up and became accessible. For the GP respondents, this was the main explanation for the reduction in patients with drug problems becoming and remaining as "revolving door" patients. The Practitioner Services respondents generally agreed with this, but some also took the view that many of the patients with problem drug use were getting older, becoming physically more unwell and maybe quite naturally their perceived aggression and drug seeking behaviour had settled down.

"But I think my worst ["revolving door" patient] had serious problems internally and he had to go in to hospital. And when he was discharged I think- now- the guy is pretty ill and he had been a drug addict since he was about fifteen. And I think he's something like fifty now; and only up to about three years ago I finally got rid of him [the patient stopped "revolving"]...But like that; a lot of them are getting older now and I think they are dying off; or if they just can't take it the same; so I don't know if that's part of it as well."PS4.

One unusual “revolving door” patient with a problem drug use history was described by a Practitioner Services respondent. The patient used two CHI numbers (one was a dead relative’s) and was being prescribed addiction medication from his long term registered practice and additionally from a series of second practices that he was “revolving” around:

"Well he was getting prescribed from his GP and he was getting prescribed from all the other doctors that we were assigning him too. And seemingly the amount he was getting would kill him so he must have been dealing. So he was getting his own to keep him going and he was- it was only when we assigned him to his own practice that the practice realized- because they have got his records and they had a description or whatever, was on it. But he hadn't approached us as the other person and it was the practice that married the two together and said that he is one and the same person. It had been going round the system for at least three years anyway at least." PS4.

Further evidence of this unusual scenario was discovered in the subsequent portion of work qualitisng the “revolving door” patient profiles. Two apparent patient’s outpatient records matched identically with two CHI numbers and they were resident in the same Health Board area. The assumed explanation is that when the patient’s dual identity was discovered the outpatient records were merged.

Patients with alcohol dependency

Patients with alcohol dependency problems were thought not to usually become “revolving door” patients. GP respondents felt that this may be because GPs were able to form reasonable doctor-patient relationships with most alcohol dependent patients. The perception was that they tended to have periods of relative stability and positive contacts with general practice in between more chaotic times and even in those chaotic times made more reasonable demands of general practice:

“R:...if someone is merely drinking themselves to death at home, they don't want help, there's not a lot I can do. Someone who is bouncing out of hospital up and down to casualty, fine; there's

nothing I can do about it, we can offer you X, Y, Z but if you don't want it you don't want it. The ones who will cause problems, who annoy you are the ones who, you know are repeatedly phoning you out late at night and so on, most of them aren't great; there's addictions services they can see. What I reckon is that tolerance has gone up and up and up; what will we do with their physical problems? Most of them come in and are pleasant enough to you, they will tell you what life is, and what they want; their benzos [benzodiazepines] and all that; and this is going to make it so much better; and they are going to cure themselves and so on.

I: So their interaction's ok?

R: By and large- unless there's underlying problems there -and most of them; if you; where we work; if you can't always deal with the alcohol problems you would put a lot of people off the list!" GP5.

6.1.5 Social contexts

The social contexts that "revolving door" patients were in were discussed by all respondents and were viewed as important factors in the patient's background difficulties.

Families

Some families become "revolving door" patients when usually the main caregiver, often the mother, had problems with the practice; either because of demands made on behalf of herself or her children. The mother was removed along with the whole family, although some practices did keep the children registered when the caregiver moved to another practice. A GP respondent described "revolving door" patients he had come across in this way:

"Parents who have got unreasonable expectations about managing their children's illnesses and they keep coming and coming and coming with what the doctor sees as self limiting trivial complaints but if they don't get the antibiotics, they are not referred to hospital, then that leads to an aggressiveness on the part of the parent and that is something that may just spill on to the next practice and the next practice. Again people just think I

can't stand this person for more than three [months], whatever short period of time, get them off." GP2.

Children who had repeat removals such that they were defined as “revolving door” patients will be described later in the chapter. At no time during the key informant interviews was there a suggestion that children themselves caused sufficient difficulty to trigger removals and become “revolving door” patients.

Conversely as already described, being part of a family registered with a practice was also an important protective factor for patients who were challenging to work with.

Relationships

Most respondents viewed typical “revolving door” patients as isolated and alone, because they had difficulty maintaining personal relationships:

"I would say they are almost entirely on their own; 95% anyway; maybe 100% actually, live alone. So they are isolated; almost invariably have difficulty keeping other relationships going. Ehm, none of them work; all unemployed or off sick, so a very, and they frequently have had very disturbed childhoods as well, so they come from a very sad background generally."GP1.

Some Practitioner Services respondents perceived that “revolving door” patients' needs may change as they get older, as their families grow up, or their spouses die, their social networks shrink and they become more dependent on the health service.

For some “revolving door” patients there was evidence that this difficulty with relationships also spilled over into their interaction with other agencies that patients had to interact with; the local authority, housing, social work, for example, as illustrated in the following quote:

"I have a gentleman on the go at the moment [being repeatedly removed] who has made accusations of various people being racist and there was going to be a sort of meeting arranged with

social work and the race equalities board and things like that; and there were a lot of people involved; a lot of third parties involved in dealing with this gentleman we were speaking to. So it was quite obvious he had issues with a lot of people; about things, so sometimes there might be social work involvement or another third party...."PS3.

6.1.6 Unusual “revolving door” patients

Practitioner Services respondents felt that for a very small number of patients who become “revolving door”, a one off break down in the doctor-patient relationship (themselves or another family member) meant they got caught in the system of assignment-removal. But they did not have the major underlying problems that usual “revolving door” patients had. These patients were usually articulate and respondents reported that when they gave their side of the story it was surprising they have been removed. On the other hand the GP respondents felt that “revolving door” patients all conformed to the description of patients having unrealistic expectations and inappropriate behaviour with underlying health issues.

6.2 The third “revolving door” patient cohort: quantitative perspective

6.2.1 Children first

Table 8 is an overview of the demographic descriptors of the children and the adults who were in the third cohort of “revolving door” patients. Taking into account the results from the key informant interviews and a subsequent detailed qualitative analysis of their hospital and outpatient activity, the children were excluded from the subsequent analysis of “revolving door” patient characteristics. This was because it was trigger events with the adults in their family that led them to revolve around practices.

Table 8 Sex, SIMD decile, median time on a list, overall and in age subgroups (child vs adult) for all “revolving door” patients in the third cohort

		Total	Age (years) at first removal		p ⁶
			0-15	16+	
Sex	N _{OBS} (N _{MISSING})	586 (0)	31 (0)	555 (0)	0.117
	Female	199 (34.0%)	15 (48.4%)	184 (33.2%)	
	Male	387 (66.0%)	16 (51.6%)	371 (66.8%)	
SIMD decile at first removal (1 is least deprived)	N _{OBS} (N _{MISSING})	432 (154)	23 (8)	409 (146)	0.835
	Mean (SD)	8.2 (2.1)	8.7 (1.2)	8.2 (2.1)	
	Median (IQR)	9.0 (7.0, 10.0)	9.0 (8.0, 9.0)	9.0 (7.0, 10.0)	
	[Range]	[1.0, 10.0]	[6.0, 10.0]	[1.0, 10.0]	
SIMD decile at first removal	N _{OBS} (N _{MISSING})	432 (154)	23 (8)	409 (146)	0.064
	1-5	55 (12.7%)	0 (0.0%)	55 (13.4%)	
	6-7	60 (13.9%)	3 (13.0%)	57 (13.9%)	
	8	64 (14.8%)	5 (21.7%)	59 (14.4%)	
	9	107 (24.8%)	10 (43.5%)	97 (23.7%)	
	10	146 (33.8%)	5 (21.7%)	141 (34.5%)	
Median days on GP list	N _{OBS} (N _{MISSING})	586 (0)	31 (0)	555 (0)	0.278
	Mean (SD)	124(130)	108 (121)	125 (131)	
	Median (IQR)	85 (25, 173)	60 (18, 154)	86 (26, 174)	
	[Range]	[1, 809]	[3, 396]	[1, 809]	
Median days on GP list	N _{OBS} (N _{MISSING})	586 (0)	31 (0)	555 (0)	0.453
	Fast (0-100)	330 (56.3%)	21 (67.7%)	309 (55.7%)	
	Slow (101-180)	117 (20.0%)	4 (12.9%)	113 (20.4%)	
	Non-core (181+)	139 (23.7%)	6 (19.4%)	133 (24.0%)	

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

⁶ P-values are from Wilcoxon Rank sum tests of equal medians (continuous variables) and Fisher exact tests of equal proportions (categorical variables). For categorical variables with more than two categories, P-values were approximated from 2,000 simulations.

Thirty-one children were removed 4 or more times from GP lists from 1999 to 2005 in Scotland. There was no sex preponderance and they lived in deprived areas. The distribution of their “revolving” activity was not different from the adults, providing further evidence that their removals were linked to adults.

6.2.2 Demographics of the third cohort of “revolving door” patients

The demographic data for this portion of the analysis was drawn from the analysis of the adults in the third cohort of “revolving door” patients. The results from the data on hospital admissions, outpatient appointments, and treatment episodes on the SDMD (Scottish Drug Misuse Database) follows. The age of the patient calculated for this analysis was age when the patient started “revolving”.

		Total
Sex	N _{OBS} (N _{MISSING})	555 (0)
	Female	184 (33.2%)
	Male	371 (66.8%)
Age at first removal (years)	N _{OBS} (N _{MISSING})	555 (0)
	Mean (SD)	34 (13)
	Median (IQR)	31 (24, 39)
	[Range]	[17, 88]
Age at first removal (years)	N _{OBS} (N _{MISSING})	555 (0)
	16-24	156 (28.1%)
	25-34	197 (35.5%)
	35-44	119 (21.4%)
	45-54	43 (7.7%)
	55-64	22 (4.0%)
	65-74	9 (1.6%)
	75+	9 (1.6%)
Married at first removal	N _{OBS} (N _{MISSING})	392 (163)
	Yes	62 (15.8%)
SIMD decile at first removal (1 is least deprived)	N _{OBS} (N _{MISSING})	409 (146)
	Mean (SD)	8.2 (2.1)
	Median (IQR)	9.0 (7.0, 10.0)
	[Range]	[1.0, 10.0]
SIMD decile at first removal	N _{OBS} (N _{MISSING})	409 (146)
	1-5	55 (13.4%)
	6-7	57 (13.9%)

	8	59 (14.4%)
	9	97 (23.7%)
	10	141 (34.5%)
Health Board at first removal	N _{OBS} (N _{MISSING})	555 (0)
	Greater Glasgow	183 (33.0%)
	Lanarkshire	116 (20.9%)
	Lothian	70 (12.6%)
	Ayrshire & Arran	67 (12.1%)
	Argyll& Clyde	55 (9.9%)
	Fife	28 (5.0%)
	Forth Valley	19 (3.4%)
	Tayside	8 (1.4%)
	Dumfries & Galloway	4 (0.7%)
	Grampian	4 (0.7%)
	Borders	1 (0.2%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Table 9 Third cohort of adult “revolving door” patients by sex, age, marital status, SIMD decile and Health Board

Two thirds of the patients were male, and the mean age was 34 years (range of 17-88). Only 15.7% of patients were married when they started “revolving”, compared to 49% of 30-34 year olds in the general Scottish population in 2005 (General Register Office for Scotland, 2010). Most patients lived in areas of high deprivation (as measured by Scottish Index of Multiple Deprivation deciles) and most “revolving door” patients also lived in Health Board areas in the central (urban) belt of Scotland.

Scottish NHS records are known to poorly record ethnic status; for example 30.9% recording was achieved across Scottish Health Board admission and day patient records for the first quarter of 2009. This was following a drive to improve recording (Information Services Division NHS National Services Scotland, 2010b). There was a similar pattern found in these patients records, ethnicity recording was less than 30%, so was not reported.

6.2.3 Removal histories and stability of residential address

The number of removal episodes and the number of weeks that patients revolved, were calculated and then the stability of the patients' residential address was examined, by summarising the number of postcodes of residence that were recorded over the time patients revolved (each removal and reinstatement date on the CHI is tagged to the patients postcode of residence).

Table 10 Number of removals, length of time “revolving” & postcode of residence for the adults in the third “revolving door” patient cohort

		Total
No of removals	N _{OBS} (N _{MISSING})	555 (0)
	Mean (SD)	6.6 (7.1)
	Median (IQR)	5.0 (4.0, 6.0)
	[Range]	[4.0, 92.0]
No of removals	N _{OBS} (N _{MISSING})	555 (0)
	4	258 (46.5%)
	5	112 (20.2%)
	6	52 (9.4%)
	7	40 (7.2%)
	8	16 (2.9%)
	9	12 (2.2%)
	10	13 (2.3%)
	11-20	38 (6.8%)
	21-50	11 (2.0%)
	51+	3 (0.5%)
No of postcodes while on removals database	N _{OBS} (N _{MISSING})	555 (0)
	Mean (SD)	2.3 (1.5)
	Median (IQR)	2.0 (1.0, 3.0)
	[Range]	[1.0, 11.0]
No of postcodes while on removals database	N _{OBS} (N _{MISSING})	555 (0)
	1	192 (34.6%)
	2	167 (30.1%)
	3	98 (17.7%)
	4	53 (9.5%)
	5	26 (4.7%)
	6-10	17 (3.1%)
	11+	2 (0.4%)
No of postcodes per year	N _{OBS} (N _{MISSING})	555 (0)
	Mean (SD)	1.2 (1.6)
	Median (IQR)	0.8 (0.5, 1.3)
	[Range]	[0.1, 22.8]
No of weeks on removals database	N _{OBS} (N _{MISSING})	555 (0)
	Mean (SD)	163 (91)
	Median (IQR)	158 (92, 231)
	[Range]	[5, 360]
No of weeks on removals database	N _{OBS} (N _{MISSING})	555 (0)
	0-50	67 (12.1%)
	51-100	91 (16.4%)
	101-150	97 (17.5%)
	151-200	108 (19.5%)
	201-250	82 (14.8%)
	251-300	64 (11.5%)
	301-350	35 (6.3%)
	351+	11 (2.0%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

The majority of patients were removed 4 times (range 4-92) and the frequency data provides a useful summary of the removal activity of the individual patients. Note that three patients were removed more than fifty one times.

6.2.4 Hospital admissions

The focus in this area was on the patient's interaction with the health service and the clinical information that could be analysed across their life course, rather than restricting the scope to the time when they were "revolving door" patients. The number of admissions, timeframe of admissions, and the admissions rate that patients had when they were admitted to hospital (from 1981 to December 2010, the time interval available) are described. I then explore the reasons why patients were admitted to hospital.

Table 11 Number of hospital admissions by years recorded, number of admissions per year and irregular discharges for the adults in the third “revolving door” cohort whose record linked to SMR01

		Total
In SMR01 (hospital admissions)	N _{OBS} (N _{MISSING})	410 (0)
	Yes	351 (85.6%)
No of admissions	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	19 (29)
	Median (IQR)	9 (3, 22)
	[Range]	[0, 295]
Admissions data timeframe (years)	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	21.8 (5.9)
	Median (IQR)	22.7 (16.9, 28.1)
	[Range]	[7.0, 28.6]
No of admissions per year	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	0.8 (1.2)
	Median (IQR)	0.4 (0.1, 1.0)
	[Range]	[0.0, 14.9]
Any irregular discharges	Yes	210 (51.2%)
No of irregular discharges	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	2.0 (4.2)
	Median (IQR)	1.0 (0.0, 2.0)
	[Range]	[0.0, 45.0]
No of irregular discharges per year	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	0.09 (0.18)
	Median (IQR)	0.03 (0.00, 0.12)
	[Range]	[0.00, 1.61]

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Most patients had hospital admissions, but the number of admissions and rate of admissions varied between patients. No statistically significant links were found between admissions, irregular discharges and the number of times patients' revolved.

For each hospital admission up to ten ICD codes, that is codes that could be used to describe a discharge diagnosis, could be recorded. This meant a lot of data was obtained. An initial scan and the subsequent qualitative analysis found that there was a lot of inconsistency of recording between the ordering of these codes in their groups of ten. This was partly due to trying

to describe in a diagnostic (and multi-layered in itself) coding framework, the complex reasons why someone has been admitted to hospital and what happened during the admission; but also due to recording patterns that varied between clinicians, units and specialities. However each admission did have at least one diagnostic code applied to it. There have also been efforts by ISD working with hospital staff in recent years to improve recording consistency (Information Services Division NHS National Services Scotland, 2007c).

Table 12 summarises the main admission reasons. Explanation and further analysis of these follows that. “Diagnostic label not applied,” groups together codes that do not provide a clinical diagnosis reason for admissions and are further described immediately.

Table 12 Hospital admission categories, number (and percentage) of patients with at least one hospital admission for that category for the adults in the third “revolving door” cohort whose record linked to SMR01

	Total
Linked to SMR01 (hospital admissions)	410 (0) 351 (85.6%)
Diagnostic label not applied	321 (78.3%)
Physical illness	320 (78.0%)
Substance misuse	278 (67.8%)
Poisoning	215 (52.4%)
Intervention or procedure	202 (49.3%)
Psychiatric illness	157 (38.3%)
Learning impairment	4 (1.0%)

*Statistical analysis conducted by Paul Johnson statistician
Robertson Centre for Biostatistics, University of Glasgow*

“Diagnostic label not applied”

“Diagnostic label not applied” was the category that included ICD10 diagnostic codes that were not clinical codes. These were for admissions due to an incident; often injury linked (1737 out of those recorded), admissions with symptoms and signs (1332), admissions for social and environmental problems (84) and admissions for the sequelae of an accident (84). Clinical diagnostic codes may have been attached to these but it proved difficult to model the combinations of these to produce a coherent picture.

Physical illness

“Physical illness” was the category that described codes that were clinical codes that related to physical illness. The commonest 10 codes were:

Table 13 Number of adult “revolving door” patients in the third cohort with at least one hospital admission for the commonest physical illness categories (records linked to SMR01)

Physical illness (linked SMR01)	Total
Gastrointestinal disease	179 (43.7%)
Respiratory disease	150 (36.6%)
Infectious and parasitic diseases	133 (32.4%)
Skin and subcutaneous disease	122 (29.8%)
Cardiovascular disease	118 (28.8%)
Musculoskeletal and connective tissue diseases	86 (21.0%)
Genitourinary system disease	85 (20.7%)
Nervous system disease	78 (19.0%)
Female reproductive organ disease	53 (12.9%)
Sense organ disease	51 (12.4%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Additionally admissions that were coded for the remaining 5-10% of reasons were diseases of blood and blood forming organs, oral dental disease, a code for “prosthetic body part”, acquired absence of body part, and endocrine/immune system disease. Admissions coded for less than 5% of reasons were: pregnancy/childbirth/puerperum problems, endocrine immune disease, benign neoplasms, malignant neoplasms, nutrition, metabolism disease, social development disorders and congenital disorders. This analysis provides a very broad description of the physical illness categories encountered. These physical illness categories will be explored later in the qualitative analysis.

Substance misuse

Two thirds of patients (across all groups) had hospital admissions (at least once) with a substance misuse problem recorded. This was only for a diagnosis that was coded as a dependency, it did not take physical consequences into account. Some physical health problems related to

alcohol dependency only, were extracted in an additional review of the data presented later. There is currently no ICD10 coding that describes direct physical consequences of drug dependency (eg. skin abscesses as a result of injecting). These results are the proportion of patients who ever had an admission diagnosis code, so some patients may be represented in all groups.

Table 14 Number of adult “revolving door” patients in the third cohort with at least one hospital admission with drug dependency, alcohol dependency or physical consequences of alcohol dependency (whose records linked with SMR01)

Substance misuse (linked SMR01)	Total
Problem drug use	233 (56.8%)
Alcohol misuse	153 (37.3%)
Physical consequences of alcohol misuse	46 (11.2%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

More than half of the “revolving door” patient cohort had ever had an admission with a drug dependency problem, over a third with an alcohol dependency problem, (this does not include intoxication) and over one in ten with an admission with physical evidence of alcohol misuse.

Poisoning

Just over a half of the cohort had an admission following exposure to a substance that had the potential to cause them harm. This code did not distinguish between intentional and accidental exposures (usually overdoses) and included street drugs, alcohol and prescribed medicines.

Intervention or procedure

Nearly half of patients had at least one admission when an intervention or procedure was carried out. This included admission for a medical examination (including psychiatric), surgical procedures, and administration of medicines.

Psychiatric illness

Over a third of patients had at least one admission where a psychiatric diagnostic code was applied. This was not described in more detail, because making a firm diagnosis of a psychiatric illness is not reliably made on one hospital admission with only ICD10 codes for information. For example making diagnoses over time are usually important to make the decision that a patient has a severe and enduring psychotic illness (e.g. paranoid schizophrenia). One hospital admission coded thus could mean this diagnosis, but if repeated admissions had different codes then this could evolve into another diagnosis such as personality disorder or drug induced psychosis. To model ICD codes in such a way to achieve some validity in this context, would have been complex and was outwith the scope of this study. In many respects this complex interpretation of the data was the function of the qualitative analysis of the cohort.

Two themes from the key informant interviews data were brought in to this analysis too. Personality disorder was described as being the underlying diagnosis for many of the “revolving door” patients so the ICD codes which corresponded to personality disorder diagnoses were extracted. Deliberate self harm was identified as a theme in the qualitative analysis of the “revolving door” patient cohort too, and is also associated with personality disorder so this was included too:

Table 15 Number of adult “revolving door” patients in the third cohort with at least one hospital admission with a personality disorder diagnosis or self harm episode (whose records linked with SMR01)

Specific psychiatry codes (linked SMR01)	Total
Personality disorder diagnosis	75 (18.3%)
Self harm	197 (48.0%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Around one in six patients had at least one admission where a definite diagnosis of a personality disorder was noted and hence the assumption made that the diagnosis had a part to play in the admission. The general population prevalence of personality disorder is estimated to be around one in ten increasing to around one to two in three patients in inpatient psychiatric hospital settings (Burns, 2006).

Nearly half of patients had at least one admission with a self harm episode, these were admissions when an overdose of medicines or an injury, were coded as being intentionally self inflicted.

Learning impairment

Four patients had a diagnosis of learning impairment made on at least one hospital admission.

Additional categories

Two additional categories were identified from the qualitative analysis of the cohort. The first were non clinical codes related to expressed negative behaviour and included a range of codes with labels that ranged from “irritability and anger” to “malingerer”. The second were injuries where the patient had been a victim of violence.

Table 16 Number of adult “revolving door” patients in the third cohort with at least one hospital admission with negative behaviour recorded or violence victim (whose records linked with SMR01)

Additional category codes (linked SMR01)	Total
Negative behaviour recorded	20 (4.9%)
Violence victim	161 (39.3%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Twenty patients had negative behaviour recorded at least once during a hospital admission and two in five patients had at least one admission when they were a victim of violence.

6.2.6 Outpatient appointments

The clinical coding data for outpatient appointments were poor; with 96.8% of outpatient appointments having no clinical diagnosis recorded (Johnson, 2011b). Appointments and non attendances are described along with referrals made by the prison or judiciary.

Table 17 Number of outpatient appointments (& per year), number of DNA's (& per year) and referrals from prison or judiciary for the adults in the third cohort of “revolving door” patients whose records linked with SMR00

		Total
In SMR00 (outpatient appointments)	N_{OBS} (N_{MISSING})	410 (0)
	Yes	404 (98.5%)
No of appointments	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	28 (35)
	Median (IQR)	15 (8, 35)
	[Range]	[0, 249]
Outpatients data timeframe (years)	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	13.0 (1.9)
	Median (IQR)	14.0 (13.0, 14.0)
	[Range]	[4.7, 14.0]
No of appointments per year	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	2.1 (2.5)
	Median (IQR)	1.2 (0.6, 2.8)
	[Range]	[0.0, 17.8]
Any missed appointments	Yes	379 (92.4%)
No of missed appointments	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	11 (14)
	Median (IQR)	7 (3, 13)
	[Range]	[0, 146]
No of missed appointments per year	N _{OBS} (N _{MISSING})	410 (0)
	Mean (SD)	0.8 (1.0)
	Median (IQR)	0.6 (0.2, 1.0)
	[Range]	[0.0, 10.4]
Any prison or court referrals	Yes	81 (19.8%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Almost all the “revolving door” patients had outpatient appointments; with the majority having one or two per year and a minority more than that. Almost all the cohort had missed appointments too. However the majority missed one or an average of less than one per year with a minority having a high DNA rate per year.

Around one in five of the cohort had at least one outpatient referral made by prison services or the courts. This gives an indication of the proportion of patients who had some level of forensic involvement.

6.2.7 Substance misuse and the SDMD

Linkage with the Scottish Drug Misuse database (SDMD) was investigated in addition to hospital admissions data and outpatient attendances. These were records of patients having treatment episodes for substance misuse that are logged by the clinical service they attended and collated nationally. The proportion of patients who had treatment episodes recorded and the substances misused is in table 18 below:

Table 18 Substance misuse treatment episodes and number of “revolving door” patients in the third cohort with at least one treatment episode for each listed drug of misuse recorded on the SDMD

	Total
Treatment episode on Scottish Drug Misuse Database	412 (0) 245 (59.5%)
Heroin	207 (50.2%)
Benzodiazepines	53 (12.9%)
Other opiates	40 (9.7%)
Cannabis	23 (5.6%)
Stimulants	13 (3.2%)
Alcohol	10 (2.4%)
Other drugs unspecified	4 (1.0%)
Minor analgesics	3 (0.7%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Heroin accounted for over half of patients' problem drug use with benzodiazepines, and other opiates common too. This was high compared to the estimated Scottish population prevalence of problematic opiate and/or benzodiazepine use which in 2006 represented 1.62% of 16 to 65 year olds (70% male and 30% female) with Glasgow and Clyde Health Board area having the highest prevalence at 2.53% of residents (Hay et al., 2009).

The SDMD is a record of patients who seek treatment for dependency and this is generally regarded to underreport the prevalence of problem drug use (Frischer et al., 1997). Note that the data here of patients presenting for treatment of alcohol dependency are likely to be an even poorer proxy for prevalent use; because from clinical experience, patients presenting for alcohol dependency treatment episodes were not often recorded on the SDMD.

By gathering all the available evidence of substance misuse from the hospital admissions, outpatient attendances and SDMD recording for the “revolving door” patient cohort, I sought to examine the gaps and overlaps between the three databases in Table 19 below:

Table 19 Evidence of substance dependency by source of information for the third cohort of “revolving door” patients

		Total
In SDMD	N _{OBS} (N _{MISSING})	410 (0)
	Yes	245 (59.8%)
Source of diagnosis	SDMD only	58 (14.1%)
	(SMR01) hospital admission only	94 (22.9%)
	SDMD & admission or (SMR00) outpatients	191 (46.6%)
Evidence of substance dependency	SDMD or admission or outpatients	343 (83.7%)

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

14% of patients had treatment episodes on the SDMD without having any admissions or outpatient attendances for substance misuse and 23% of patients only had hospital admissions-with no evidence of treatment episodes. Overall 83.5% of patients had evidence of substance dependency from all the linked data sources.

6.2.8 Deaths

Table 20 summarises the patients from the third “revolving door” cohort who died.

Table 20 Survival and age at death for the third cohort of “revolving door” patients as recorded in the SMR01

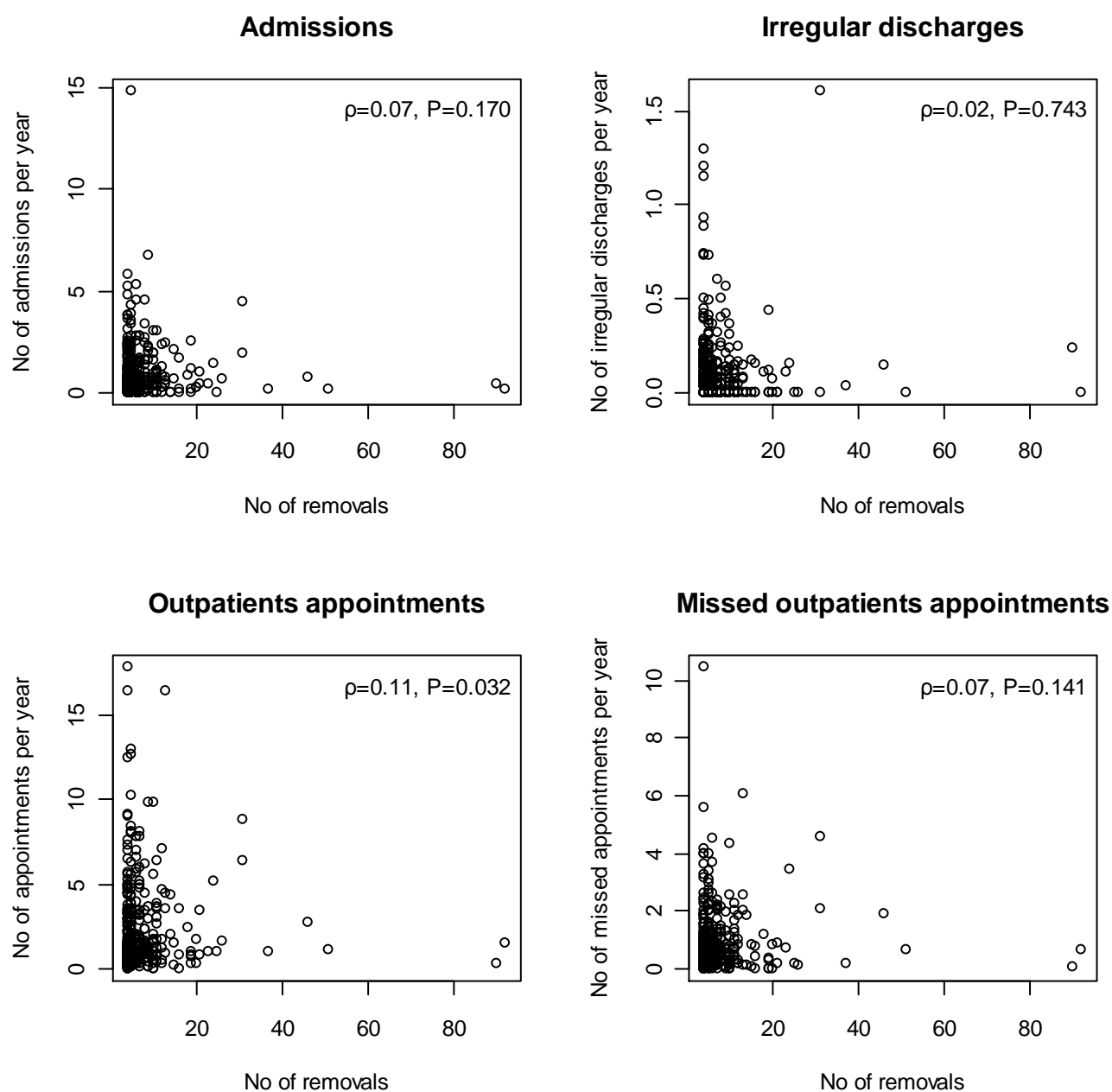
From SMR01		Total
Survival from 01/01/1999 to 30/04/ 2009	N _{OBS} (N _{MISSING})	410 (0)
	Alive	336 (82.0%)
	Dead	74 (18.0%)
Age at death(in years)	N _{OBS} (N _{MISSING})	74 (336)
	Mean (SD)	49 (17)
	Median (IQR)	43 (35, 62)
	[Range]	[23, 95]

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

18% of the cohort died between 1999 and April 2009. The mean age at death was 49 years of age with the youngest being 23 years old and the oldest 95 years old. It was not possible to carry out a more in-depth analysis of these death data due to resource constraints. The average age of death of the Scottish population in 2005 was 75.1 years old (General Register Office for Scotland, 2009b). This can not be directly compared with the “revolving door” patient cohort because the sample’s age, sex and deprivation measures were skewed from the total Scottish population. Its mean age was also calculated over a 10 year period compared to one year.

6.2.8 Removal from GP lists and other health service interaction

Whether there was any relationship between the number of times “revolving door” patients were removed from GP lists and the other ways in which they interacted with the health service was explored in the following scatter plots:



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 15 Scatterplots of admission, irregular discharge, outpatient appointment and missed appointment rates per year against number of removals for the third cohort of "revolving door" patients as recorded on SMR01 and SMR00

⁷ Estimates of Spearman's rank correlation coefficient (ρ) are given, with P-values from tests of the null hypothesis that $\rho = 0$.

As described before the majority of “revolving door” patients have around 4 removal episodes from GP lists. The majority also had low numbers of hospital admission, irregular discharge, outpatient appointment, and missed appointment rates per year. There is only a positive statistical correlation between patients’ number of removal episodes and their annual rate of irregular discharges from hospital.

These scatter plots also provide a useful summary of the small number of “revolving door” patients who are outliers when different variables are taken into account; for example the patient who had more than 80 removal episodes but low rates of other activity or the patient who had 4 removal episodes but missed appointments for more than ten outpatient appointments per year.

6.3 Qualitative analysis of the second “revolving door” patient cohort

The qualitative analysis was carried out using the second cohort of “revolving door” patients and as in the development of the quantitative analysis I analysed the data in groups initially; “fast”, “slow revolving door” patients and “non core” patients. However as with the quantitative analysis I found no qualitative difference between them when analysing the themes that emerged. In addition before the quantitative analysis was concluded I could discern no qualitative patterns that linked number of removal episodes to patient characteristics, or to hospital admissions, or outpatient attendances. Hence the results are presented for the “fast”, “slow” and “non core revolving door” patients together.

Some patient profiles have been “translated” into prose and presented in text boxes as each category or theme is described. This is to add further depth to the description of the patients in the “revolving door” cohort.

6.3.1 Children first

During the initial stages of analysis children (patients who were children when they revolved) were included with the adult (aged over 16) members of the cohort. Their patient profile was constructed in the same way using the same data and their profiles were then analysed using the same codes; including the predominant health issue codes. However, when reviewing each child's profile it became apparent that their "patient scripts" were distinct from the adult ones and heterogeneous. Each child's profile was then reviewed again and a description of their patient profiles follows. Patients who were children are then excluded from the adult patient analysis that follows.

Seventeen children were included in the qualitative analysis and their removal dates were all identical to at least one adult with whom they shared an address, within ten families. When this was with a single adult they were female, apart from one male whose apparent adult partner was found in the overall removal data but. She had insufficient removal episodes to be in the "revolving door" patient cohort. There were two sets of couples. The profiles of the adults followed the pattern of the "revolving door" patient profiles overall, and they all had significant health issues including one female adult who died. She had two young children.

Twelve children had hospital admissions. Five of the children aged 3, 5, 6, 7 and 15 had admissions for chronic health problems; asthma and respiratory problems (first two patients), feeding and gastro-intestinal problems, recurrent dental caries requiring admission for treatment, and an admission for chest pain respectively. A 5 year old child had an admission with extensive facial injuries and then a later ingestion of medicines at home. One 12 year old girl had admissions for a scalp injury, ingestion of a substance at home, abnormal vaginal bleeding aged 10 and then a medicines overdose aged 16 (the linkage data was retrieved up to the last available date that could be retrieved). This last patient profile would suggest a patient script of an adolescent with a history of childhood sexual and

physical abuse but there was no direct clinical evidence. A 19 year old (who was under 16 when he revolved) had 6 admissions with a range of non suspicious injuries except one for toxic effects of gas inhalation at home. One 9 year old boy had appointments with child psychiatry but no hospital admissions.

If on reviewing these children's profiles described so far, I were to apply patient scripts then a number of script options would be activated and these would include ones that consider social deprivation or family conflict as important. For children's "patient scripts", family context is very important.

More typical of the children patient scripts that general population children profiles would activate as options were the remainder of the children in the cohort; that of a "healthy-and-no-obvious-concerns child" patient script. A 9 year old with one admission for dental caries, one 11 year old with an admission with tonsillitis and febrile convulsions, and an 8 year old with an admission for a head injury occurring outside. One 16 year old boy who had been a child during the period he revolved had 5 admissions but no clinical diagnostic information. Two remaining children, aged 9 and 11 had only outpatient attendances; and 2 children, aged 3 and 4, had no admissions or outpatient appointments. Five out of eight of these children were siblings of the children who had patient scripts activated that suggested they came from deprived or difficult family circumstances.

6.3.2 Predominant health needs

The predominant health needs are the "patient scripts" that were activated when each adult patient's profile was analysed for the 351 adult patients in the "revolving door" patient cohort. Recall that the patient profile was a summarised account of the information contained in the NHS linked dataset for each patient.

For 71% of the “revolving door” patients it was possible to review the information in their profiles and reach a conclusion about their predominant health needs and activate a “patient script” for that patient. The number of patients who were coded using these is set out below. Nine predominant health codes or patient scripts included all of these patients including the group of patients for whom no predominant health code was able to be applied

Table 21 Number (% proportion) of predominant health code “patient scripts”, and number of deaths for “revolving door” patients in the second cohort

Predominant health code “patient script”	Number of patients (%)	Number of deaths
Substance misuse ⁸ combined psychiatric illness	61 (17%)	7
Drug dependency problems	51 (14%)	0
Psychiatric illness combined physical illness	35 (10%)	7
Substance misuse combined physical illness	21 (6%)	3
Alcohol related harm	25 (7%)	6
Psychiatric illness	22 (6%)	0
Injuries	18 (5%)	1
Physical illness	15 (4%)	2
No clinical code possible	103 (29%)	0

The conclusion that can be reached from the data presented in this table is that substance misuse is the commonest feature of the “patient scripts”, with psychiatric health problems an important feature for many. These will be explored in more detail shortly as each “patient script” is explored in more detail including the apparently deviant cases; the patients who did not explicitly have substance misuse, or psychiatric problems contained in their “patient scripts.” These are the “patient scripts” of predominant injuries and patients with only physical health problems. The patients who died in each “patient script” code are considered too.

⁸ Substance misuse includes alcohol and drug related harm

6.3.3 *Substance misuse combined psychiatric illness*

Patients who had the “patient script” of substance misuse combined with psychiatric illness; were the largest group of patients who were profiled. Patients were included in this “patient script” if they had both psychiatric and substance misuse problems contributing to their predominant health problems.

Self harm was a prominent feature in three quarters of these patients. The evidence was mainly admissions for medication overdoses (heroin or benzodiazepine overdoses were excluded as they may represent accidental overdoses relating to substance misuse). Strong evidence of self harm episodes is what led the sixth of patients who had no formal psychiatric diagnoses to be placed in this predominant health category.

A third of patients had a shifting diagnosis which meant that the patient had a range of psychiatric diagnostic labels applied over time; such as depression, anxiety, or transient psychosis. This implied a range of presenting symptoms and changes over time that represent patient with complex presentations who may have psychological trauma backgrounds or features of personality disorder. A sixth of patients had a definite personality disorder diagnosis (usually from inpatient admissions records). Another sixth had a sporadic diagnosis which meant the patient has a psychiatric diagnosis from a few admissions; often one depression or anxiety diagnosis. Only around a sixth of patients had a severe and enduring psychiatric illness which was defined as schizophrenia, bipolar mood disorder, depression with psychosis, and in one patient’s case a somatic disorder that persisted throughout the patient’s admissions.

More than a half of the patients with this patient script had evidence of alcohol and drug dependency, a third were drug dependent and the remainder were alcohol dependent; except for one patient who stood out as unusual. She had recurrent admissions with methadone and medicines overdoses but had no problem drug use treatment episodes, no formal

psychiatric diagnoses, no definite drug dependency diagnosis and was intoxicated with alcohol on some occasions.

The following patient profile provides a description of a patient with this predominant health code:

31 year old male patient with around 40 admissions. He had a severe and enduring diagnosis of paranoid schizophrenia. He had a personality disorder, evidence of self harm from medicines overdoses and laceration injuries to his forearms. He was alcohol and drug dependent, had one pulmonary thrombo-embolism, and recurrent pancreatitis which made a minor contribution to his admissions. He DNA'd 16/22 outpatient appointments. He was removed 10 times from GP lists.

Seven patients in this group of patients died; all except one had many hospital admissions (between 40 and 290) and had been removed from GP lists 5 or 4 times. The remaining patient who had around 20 admissions was removed from 43 GP lists. None of the patients who died had a severe and enduring psychiatric diagnosis. All the patients had evidence of self harm and alcohol dependency and their deaths were related to the physical consequences of their dependency. This is illustrated by the following patient profile:

52year old female patient with around 300 admissions. There were no diagnoses recorded until admission 210. She had a shifting psychiatry diagnosis; depression, anxiety, with personality disorder, self harm and alcohol dependency. She also had drug misuse treatment episodes for opiate dependency, and additional physical health problems, cerebral palsy and epilepsy. She DNA'd 3/23 outpatient appointments. She was removed 5 times from GP lists.

6.3.4 Drug dependency

One fifth of patients had the “patient script” of drug dependency which means that the majority of their health problems related directly to drug dependency problems; the second most common patient script.

Nearly four in five patients in this “patient script” had evidence of physical consequences of drug dependency such as phlebitis, abscesses or acute hepatitis C infection. They represent patients who had hospital admissions as a result of drug dependency (so of course they will have more physical health problems relating to drug dependency) but they do not have other serious physical or psychiatric health problems triggering admissions. Only two patients in this group did not have treatment episodes recorded on the drug misuse database, one of them having had admissions for physical consequences of problem drug use.

About a fifth of these patients had evidence of alcohol dependency in addition to their drug dependency; one patient exhibiting physical complications of alcohol dependency, alcoholic liver disease; but with drug dependency being the biggest feature of his admissions. An additional two “revolving door” patients had only possible evidence of co-dependency with drugs and alcohol, and five additional patients had admissions where they were alcohol intoxicated.

A third of patients with drug dependency as their “patient script” had additional physical health problems (unrelated to substance misuse) that triggered admissions. They tended to be minor and ranged from a lower respiratory tract infection to an in-growing toenail. Nearly a third of these patients had admissions with violence related injuries.

A quarter of patients with “drug dependency” as their dominant script had evidence of self harm on admissions; with one of these patients having a personality disorder diagnosis and another patient who had a diagnostic code that he was “not compliant with medical treatment”. Over a half had had referral or contact with psychiatry but no diagnosis; recall that it is not possible to say whether this psychiatric contact is for psychiatric or substance misuse reasons. One third had no evidence of any psychiatric problems. More than three quarters of these patients had high DNA rates and a quarter had prison or court involvement.

Here is a patient profile which represents this group of profiles; although he stands out because he was removed from GP lists many times:

41 year old male patients with around 20 admissions. He was opiate dependent with drug misuse treatment episodes, admissions with recurrent cutaneous abscesses, chronic hepatitis C infection and occasionally asthma mentioned. He DNA'd 11/14 outpatient appointments. He was removed 22 times from GP lists.

No patients representing this “patient script” died, despite the majority having admissions directly relating to physical consequences of drug dependency.

6.3.5 Psychiatric and physical illness

There was a sense from the majority of patients in this group that the patient’s psychiatric health problems had an impact on their physical health and how this was perceived by hospital staff. For some this was explicit when symptom codes rather than disease codes were repeatedly applied and for a few, words like “malingerer” and “functional” were included in amongst physical health diagnoses.

Only a third of patients had evidence of self harm (overdoses or injuries), and a third of patients had a definite diagnosis of personality disorder.

A third of patients had sporadic psychiatric diagnoses and a third had shifting diagnoses. Only four patients had severe and enduring psychiatric diagnoses. Half of patients had evidence of substance misuse but this was not a predominant issue from their admissions data.

Three patients with this patient script are set out below to represent the complexity of these patients’ presentations:

49 year old male patient with around 18 admissions. He had a diagnosis of somatoform disorder which was stable across admissions so accorded severe and enduring status. He had a personality disorder diagnosis too. He had admissions with headache, pneumothorax, pain disorder, intra-vertebral disc displacement, oesophagitis, injury and a disorder of male genital organs. He DNA'd 3/14 outpatient appointments and was removed from 27 GP lists.

39 year old female patient who had around 130 admissions. She had a shifting diagnosis of anxiety, phobic anxiety, depression, depression with psychosis and agoraphobia. She had many, many admissions with chest pain and type 2 diabetes; many with abdominal pain; a few with Crohns disease; gastro-intestinal haemorrhage. HIV and hepatitis C infection were noted once. Drug dependency was mentioned although she had no drug misuse treatment records. She DNA'd 31/45 outpatient appointments. She was removed 32 times from GP lists.

21 year old female patient who had around 18 admissions. She had admissions with recurrent overdoses, nausea and vomiting, gallstones, abdominal pain and jaundice. She had opiate treatment episodes recorded on the drug misuse database but no admissions directly attributable to substance misuse. She DNA'd 12/28 outpatient appointments. She was removed 5 times from GP lists.

Patients with a learning impairment or with a dementia diagnosis were considered as psychiatric diagnoses for the purpose of the coding. Of the two patients in the cohort who had a diagnosis of learning disability one had insufficient information and was coded "no clinical code possible" and the other triggered this patient script. Her profile was:

26 year old female patient who had around 60 admissions. She had hereditary spherocytosis, epilepsy and a learning disability diagnosis. She had evidence of injuries, self harm and had treatment episodes recorded on the drug misuse database. She was removed 4 times from GP lists.

Five of the six patients with a dementia diagnosis in the cohort were in this patient script too. They were all over 70 years old and had no other evidence of psychiatric or substance misuse problems in their patient

profiles. They all had unrelated physical health problems; they had between 11 and 35 admissions. Three had 4 GP removal episodes, one had 8 and one had 10 removal episodes. They accounted for three of the seven deaths in this group. Two of the profiles of the patients who died are set out:

44 year old male patient who had around than 80 admissions. He had a sporadic diagnosis of conduct disorder, had evidence of self harm, and was alcohol dependent. He had many admissions due to being paraplegic after a spinal injury. He was removed 4 times from GP lists.

68 year old female patient who had around than 50 admissions. She had shifting psychiatric diagnoses including depression, panic disorder, non compliance with treatment and some alcohol intoxication episodes. She had serious complications of diabetes including a limb amputation and renal failure amongst many physical health issues. She DNA'd 25/70 outpatient appointments. She was removed 31 times from GP lists.

6.3.6 Substance misuse and physical illness

For the patients who had a predominant diagnosis of substance misuse and physical illness; this meant they had a “patient script” of serious physical illnesses that led to hospital admissions that were unrelated to their substance misuse problems.

Four patients were alcohol and drug dependent. They had valvular heart disease; peripheral vascular disease; chest pain/angina; and recurrent pancreatitis (it was not clear that it was alcohol related).

Nine patients were drug dependent. They had diabetes and its complications (three patients); epilepsy and gastro-intestinal disease; polycystic kidneys; epilepsy; a lung neoplasm and irritable bowel syndrome; sick sinus syndrome; and chest pain.

Eight patients were alcohol dependent only. In addition to the two patients described below they had respiratory problems and atrial fibrillation;

angina, right bundle branch block, and complications of alcohol dependency; bladder problems; ischaemic heart disease; limb amputation and complications of alcohol dependency; and ischaemic heart disease and complications of alcohol dependency.

Only four patients had no evidence of psychiatric referrals or contact.

Three patients died; they all had alcohol dependency; and two of their profiles are described below; the first had a short serious illness in addition to alcohol dependency and the second a lot of serious health problems that may have been related to alcohol dependency but this was not clear.

52 year old male patient with around 9 admissions. He had a malignant tumour of his testes and was alcohol dependent with physical complications of alcohol dependency. He was removed 10 times from GP lists.

70 year old male patient with around 60 admissions who was alcohol dependent and who had alcoholic liver disease, chronic pancreatitis, poor mobility and duodenal obstruction. He was removed 9 times from GP lists.

6.3.7 Alcohol related harm

Alcohol related harm was the “patient script” when alcohol and its dependency consequences dominated the patient’s clinical picture, although for some, other health problems were apparent.

Just more than half of patients were only alcohol dependent with no other problems apparent, and this was from their admissions data. Most of these patients demonstrated physical consequences of alcohol dependency. For one additional patient who was alcohol dependent there were suspicions of an additional substance misuse problem. Only one patient who had lots of repeated admissions with alcohol intoxication did not then go onto have a dependency diagnosis in this predominant health code.

A third of patients were drug dependent in addition to being alcohol dependent. A few patients had physical complications of drug dependency too. One of the patients with alcohol dependency had treatment episodes recorded on the SDMD for opiate dependency but had no admissions related to problem drug use.

A typical patient's profile who was alcohol and drug dependent but for whom alcohol related harm was his patient script is described below:

41 year old male with 25 admissions. He had recurrent seizures, hepatomegaly, ascites, chronic hepatitis C, thrombocytopenia, self harm and was alcohol and drug dependent. He DNA'd 1/4 outpatient appointments. He was removed 5 times from GP lists.

Around half of patients had evidence of self harm. One patient who was wheelchair bound had a diagnosis of personality disorder, two patients had sporadic psychiatric diagnoses (both depression), one patient had a diagnosis of paranoid schizophrenia but this was made on early hospital admissions only, and a half of patients had referral or contact with psychiatry without diagnosis. Only four patients had no evidence of any psychological issues.

Six patients with this "patient script" died; the patient's profile below being a typical one:

64 year old female patient with around 60 admissions who was alcohol dependent and who had alcohol related brain injury, seizures and alcoholic liver disease. She DNA'd 2/13 outpatient appointments. She was removed 4 times from GP lists.

6.3.8 Psychiatric illness

These were the patients whose predominant problem was psychiatric illness; usually repeated hospital admissions with psychiatric problems and limited evidence of any physical health or substance misuse problems.

More than half of patients had a shifting psychiatric diagnosis, just under a half of patients had a definite personality disorder diagnosis and just under a half had evidence of self harm. Four patients had sporadic diagnoses and six patients had severe and enduring ones.

One 94 year old patient in this group eventually had a dementia diagnosis made after one with hypochondriasis, one with “conduct disorder” and a couple of mentions of “problems relating to life management difficulty”.

A more typical patient in this “patient script” is described below:

33 year old male with 65 admissions. He had several admissions with a severe and enduring diagnosis of paranoid schizophrenia, various personality disorder diagnoses, admissions following medicines and opiate overdoses, drug dependence and alcohol dependence and some physical consequences of drug use starting to become apparent. He was removed 8 times from GP lists.

No patient with this “patient script” died.

6.3.9 Injuries

For the patients for whom injury was the predominant health problem most were on the drug misuse database but all had evidence of substance misuse when their inpatient and outpatient records were examined too.

A smaller majority of patients had evidence of referral or contact with psychiatric services but no diagnosis; although of these two had evidence of self harm on admission records and one had a diagnosis of non compliance with medical treatment. Two other patients had evidence of self harm and one had a diagnostic code of “irritability and anger” but contact with psychiatric services. A third of patients who were injured did not have any evidence of psychiatric problems documented.

Here is an example of a “revolving door” patient who had injuries as his “patient script”.

34 year old male who had 10 admissions. He had contusions of the thorax, lower back and pelvis, pneumothorax, scalp wound injury, open wounds of abdomen lower back and pelvis, drug dependency, evidence of self harm and asthma. He DNA'd 16/38 outpatient appointments. He was removed 4 times from GP lists.

And here is the profile of the one patient who died in this “patient script” group:

28 year old male who had around 7 admissions. He had a variety of repeated injuries and wounds (appeared to be stab wounds) to the head and trunk including a pleural effusion. He was opiate dependent and had drug treatment episodes. He DNA'd 5/6 OP appointments; the only one attended was psychiatry. He was removed 4 times from GP lists.

6.3.10 Physical Illness

Of the patients with predominantly physical illnesses only one had treatment episodes recorded on the drug misuse database. If her profile had had less missing data, it may have been evident that her 22 admissions were related to consequences of substance misuse but there was insufficient evidence to be sure. Another patient had evidence suggesting alcohol dependency-one code for “harmful use of alcohol” and a number of physical injuries- but again not sufficient to consider the patient to be definitely alcohol dependent with physical health issues. For the remainder there was no evidence from their hospital admissions or OP attendances that they had alcohol or problem drug use problems.

Half of the patients had no evidence of any psychological problems; they had no hospital admissions with any psychiatric codes and they had no outpatient appointments with psychiatry.

Therefore there were seven patients with profiles that contained no evidence of psychiatric health or substance misuse problems. Upon review, four of the patients had clinical diagnoses that could lead to impairment of their cognitive function and possible psychiatric health problems. Two had had a stroke, one had Klinefelters syndrome and one had multiple sclerosis.

The three remaining had limited information available in their profiles, either because they had a low number of admissions or they had a lot of missing clinical data.

Two “revolving door” patients with the patient script of only physical health problems died; accounts of their profiles are below:

27 year old female patient who had around 5 admissions. She had nausea and vomiting, electrolyte imbalance and a coagulation defect. The underlying diagnosis was unclear. She DNA'd 5/6 outpatient appointments including psychiatry appointments. She was removed 5 times from GP lists.

77 year old female patient who had around 20 admissions. She had one admission for psychiatric assessment with no diagnosis and then diabetes, chronic renal failure, chronic obstructive pulmonary disease, heart failure and fluid overload. She DNA'd 15/82 OP appointments. She was removed 6 times from GP lists.

Hence there is no clear evidence that patients with physical illness as their predominant health code do not have substance misuse or psychiatric problems as part of their profiles.

6.3.11 No clinical code possible

Before turning to consider the other themes that emerged from the qualitative analysis; it is important to give careful consideration to the patients for whom it was not possible to build a predominant picture; a shape of the patient, a “patient script”.

Nearly half of these patients had no hospital admissions, and the remainder had a few admissions; often for a range of reasons; such that it was not possible to apply a predominant health profile. Only two patients had no outpatient appointments. Two thirds of patients had high DNA rates (that is missed more than a third of outpatient appointments). Nearly three quarters of patients who had no clinical profile possible, had treatment episodes

recorded on the drug misuse database (SDMD). Of those who were not one patient had admissions with alcohol intoxication and one patient with drug intoxication.

A third of these patients had no evidence of psychiatric problems. When these were combined around one in nine had no evidence of either psychiatric health or substance misuse contained in their profiles.

Here are two examples of patient profiles from this group, a patient with no hospital admissions and one with admissions.

65 year old female patient who had no hospital admissions. She had no drug misuse treatment episodes recorded. She had 31 outpatient appointments in a range of specialities; rheumatology, gynaecology, general surgery, orthopaedics, oral surgery and cardiology. She had 8/31 DNA's. She was removed 4 times from GP lists.

31 year old male patient who had around 10 admissions. He had an open wound to his forearm and no other recorded information on the other admissions. He had 5 outpatient appointments in oral surgery, orthopaedics and ENT with 1/5 DNA's. He was removed 5 times from GP lists.

None of the patients in the “no clinical profile possible” code died.

This group of patients is characterised by insufficient information being available such that no definite conclusions can be drawn about their “patient script” about the shape of the patient. Hence there remains no firm evidence from this group too that there are “revolving door” patients who do not have psychiatric health or substance misuse problems.

6.3.12 Additional code categories

Did not attend (DNA) rates

A striking observation from the outpatient attendance data was the DNA rates. Two thirds of patients did not attend more than a third of their outpatient appointments.

Victim of violence

Another theme which I did not expect to find was the role that violence played in the patient's hospital admissions, bearing in mind that A&E attendance data were not available. A quarter of patients had at least one admission where the injury was assessed to be a result of violence directed against the patient.

Prison, court or forensic psychiatry assessment

One of the unexplored questions about “revolving door” patients was their contact with other services including prison services. One of the problems encountered during trying to calculate an appropriate definition was the possible role that time in prison might have on a patient's propensity to revolve. Initial decisions about the scope of the study discarded attempts to look at linked activity data outwith the NHS. A surprise data finding was that one of the “source of referral” codes included referral from prison, and referral from court. Forensic psychiatry outpatient contacts were also evident (patients are only referred to forensic psychiatry if they have significant contact with the criminal justice system). A fifth of patients had evidence of these codes in their patient profiles.

Deaths

7% of the patients who were included in the qualitative analysis died and a further analysis were carried out from their profiles that looked at their

cause of death and characteristics beyond just what “patient script” they evoked.

Fourteen (53%) of patients had an alcohol related death; as defined by the Office of National Statistics in 2006, and applied to the admission at death data. The definition has been applied to all deaths from 2000 to 2007 and includes ICD 10 diagnoses that have a direct causal link with alcohol dependency, those conditions that are exacerbated by alcohol dependency, (and where this is noted on the death certificate)(General Register Office for Scotland, 2008). The deaths were from alcoholic liver disease (7), pneumonia (3), gastro-intestinal haemorrhage (1), peritonitis (1), ischaemic heart disease (1), heart failure (1).

No patients died from drug related deaths in this cohort. This definition differs in that only deaths directly attributable to drug intoxication are currently included (General Register Office for Scotland, 2009a). The one patient in the cohort who died from HIV related illness possibly related to opiate problem drug use was therefore excluded from this category.

Four additional patients had a substance misuse history recorded during other admissions and died from a chest wound (1), epilepsy (1), pneumonia (1), and heart failure (1).

Seven patients without a substance misuse history remained and they died from heart failure (1), gastro-intestinal haemorrhage, (1), pneumonia (2), chronic renal failure (1), unspecified cancer (lung secondaries)(1) and septicaemia (1).

Removal from GP lists and other health service interaction

Based on the qualitative analysis of the patient profiles I could determine no pattern between the number of times a “revolving door” patient was removed and their pattern of other health service interaction, like hospital admissions or out patient appointments.

6.4 Summary

Drawing on results from the key informant interviews there were three characteristics that “revolving door” patients had in common; unreasonable expectations, inappropriate behaviour and unmet health needs. Patients had unreasonable expectations of what the NHS could offer, displayed inappropriate behaviour towards practice staff that often included verbal aggression but underpinning this, and the reason that patients stayed in the health system, was that they all had unmet health needs. For some this was substance misuse, and for others it was some kind of psychiatric health problem. The GP respondents conceptualised the latter as patients having a personality disorder diagnosis. Depending on how the respondents viewed the patient’s underlying difficulties determined how much or otherwise they thought patients’ could take responsibility for their behaviour and how much they were able to change. “Revolving door” patients were usually socially isolated and had difficulty maintaining functional relationships with family and a range of professionals. Children were sometimes removed as part of a family when a caregiver became “revolving door”.

The quantitative analysis of the “revolving door” patient cohort provided an overview of the “revolving door” patient cohort and the findings broadly agreed with the informant interviews data and added some information about patients’ interaction with secondary care. It proved too complex to successfully analysis the clinical diagnostic codes from discrete hospital admissions per patient. One important difference, which was also detected in the qualitative analysis of the cohort, was the more prominent role that problem alcohol use and dependency played.

Results from the quantitative analysis confirmed that substance misuse was a large feature of the health problems “revolving door” patients had along with physical health problems and psychiatric problems. There was some evidence too that patients struggled in their interaction with secondary care services; due to the prevalence of patients who had ever taken an irregular

discharge from hospital, DNA'd outpatient appointments and the small number of patients who had negative behaviour coded.

More of the “revolving door” patients were male than the typical general practice population and were younger. A striking number of patients had never been married when compared to the general population, supporting the perception that patients are socially isolated and struggle with relationships, and most “revolving door” patients lived in deprived areas in the central belt of Scotland.

The qualitative analysis of the “revolving door” cohort added depth to the broad summary of data from the quantitative analysis, and was used to inform further interrogation of the quantitative data too. The results from the quantitative and qualitative were similar.

In addition to the majority of patients having a substance misuse problem, many patients had evidence of psychiatric problems with admissions for self harm a prominent feature. The prevalence of personality disorder was also high compared to the general population, along with being a violence victim, and for a minority of patients contact with the prison or court system (but this may be under-recorded). That some of these patients are referred for medical assessment by the courts or prisons also implies that they think they have medical problems too.

Statistical inference could not be made about the patients who died. It was difficult to find a comparable denominator to conduct a survival analysis. There was a difference between the number of patients who died in the second and third cohort but this could not be explored further due to resource constraints. However alcohol related deaths accounted for more than half of the deaths in the qualitative analysis.

Overall these patient characteristics could be summarised as being representative of patients with complex, difficult life circumstances, and with tangible evidence of the health consequences of those complexities.

By using the quantitative analysis of the removal episodes, it was possible to match the children with the families they belonged too. The adults who demographically were their parents exhibited the same patient scripts as the rest of the cohort. All the children who had siblings had siblings for whom there may have been background concerns about their family's level of deprivation or stability. This analysis confirmed the results from the key informant interviews that the children's removals were linked to their families.

6.5 Discussion

6.5.1 The role of alcohol

The main difference in the results between the key informant interviews and both the quantitative and qualitative analysis of the “revolving door” patient cohort is in the role that alcohol had. The key informants consistently felt alcohol dependent patients were not usually “revolving door” patients but this was contradicted by the hospital admissions data. Possible explanations for this are that the cohort had somehow been biased towards including more alcohol dependent patients, but the way this could have happened is not apparent. Another plausible explanation is that for the patients the key informants were able to recall, alcohol dependence was not the dominating presenting problem for most of them, not their predominant “patient script.” It may have been that co-dependency or psychiatric issues they may have attributed to personality difficulties were the aspects of the interactions that they recalled in relation to patients’ “revolving door” status. Bound up with that is also the perception demonstrated in the interviews that alcohol dependent patients exhibit less problematic “drug seeking behaviour” as their source of dependency is available legally and easily, compared with drug dependent patients. Alcohol related harm and dependence is known to be a major and growing health problem in Scotland. That alcohol was a causal factor in more than

half of the deaths reflects this, bearing in mind the association between alcohol related death and high deprivation (Information Services Division NHS National Services Scotland, 2007a).

6.5.2 Personality disorder diagnosis and self harm

Another difference in the results was the mismatch between the perception by the key informants that the majority of “revolving door” patients had a personality disorder and the finding from the “revolving door” cohort that about one in six patients had a diagnosis. Again this may be because of selection bias for inclusion in the cohort, but again a more plausible explanation is to do with the context for making a diagnosis of personality disorder. This will be revisited in chapter 8 when I review current theories about personality disorder. Suffice to say that because personality disorder still tends to fit within a moral schema both in the medical and social worlds we inhabit, many patients that may fit the criteria for diagnosis do not have or take the opportunity to have a formal assessment. The patients diagnosed from hospital admissions do so because they have been formally assessed, and the many additional patients the GP respondents described are so because the GPs feel they do have a personality disorder.

6.5.3 Sociological perspectives

It is apparent from the professional key informant accounts in this chapter that they firmly located the reasons as to why “revolving door” patients existed with the patient, as characteristics belonging to them, to do with their unreasonable expectations, inappropriate behaviour and unmet health needs.

Furthermore, as I explored in the previous chapter and this one, even GPs who aspired to maintain the core values of general practice and the NHS, by attending to each patients biomedical needs and a positive doctor-patient relationship with all did not always manage to hold onto “revolving door” patients who were allocated to their practice.

Throughout subsequent chapters I am going to use a number of lenses with which to examine this special circumstance in more detail; knowing what I know from the results so far, to help explain why “revolving door” patients presented such a challenge to Practitioner Services, GPs and the practices they interacted with.

As this chapter has provided me with a medical world view of the characteristics of these patients, from the key informants, from the “revolving door” cohort data which is generated from routine data available in the NHS and from a clinically orientated quantitative and qualitative analysis of it; we will begin with a sociological lens to consider the medical world all these participants are involved in. This builds on the theories introduced in the paper by Shaw on “revolving door” patients in psychiatry (Shaw, 2004).

6.5.4 “Good and bad” patients

May and Kelly (1982) undertook an extensive review of “good and bad patients” in the nursing literature and in key sociology texts. Their critique highlighted some fundamental points about the nature of the data in the papers they reviewed, which is important to consider particularly when generating theories from the key informant interviews in this study. They began by describing the illnesses, symptoms, behaviours, perceived patient attitudes and judgements of staff; which are strikingly similar to the themes and categories identified in these interviews when asked to describe “revolving door” patients in general practice. They went onto describe the discrepancies and contradictions between the “good and bad patient” studies and conclude that the topic lacked external validity. They surmised this could in part be explained by the range of research tools used; but most importantly because they assessed that the concepts that were used are not rigorously defined. The studies explored staff’s opinions about patients, and made assumptions about the meaning of “aggressive”, “inappropriate” for example. Unquestioningly the studies considered the characteristics of “good and bad patients” to be located in the patients; rather than in the

professionals' opinions about the patients and these opinions are treated as objective facts. Causality and consequence were also assumed, considered in a linear simplistic fashion and the links between these not made explicit (Kelly & May, 1982). This is an important reminder for the context of this study; the labels applied should not be viewed by the researcher in the same structuralist manner in which a clinical diagnosis may be applied. For this study "appropriate" too would be a good example (it is not the territory of this thesis to start delving into the structuralist assumptions made about clinical diagnoses). But this study was conducted from a subtle realist perspective; so the respondent's views about "revolving door" patients were valid, as are my interpretations of these, and they are analysed in order to set out a version of the social reality we live in. The failure in this would be if the analysis were to stop there and not seek to get underneath what all the assumptions and labels meant.

Another important aspect of May and Kelly's paper was that they thought carefully about the value based assumption that they felt permeated through all the literature they reviewed; that "good and bad patients" are a problem to be fixed and the fault of poor professionalism. May and Kelly argued that the literature failed to consider that professionals may have understandable reasons for so labelling patients; such patients make their work difficult. They postulated that, with few notable exceptions, an intensely individualistic view of the issue was also dominant; the social setting was not considered and a rigid structuralist approach to theorising too, was also applied across the literature. May and Kelly sought to revise this and used an interactionist approach building on the background of Parson's work on the sick role. Their central, important conclusion was to propose that in the "good and bad patient literature":

"it is in the process of providing or withholding legitimation that patients come to be defined as good and bad" (Kelly & May, 1982).

They expanded on this conclusion in a follow up paper; patients are good patients if they uphold the role of the health professional; they are bad if

they negate it (May & Kelly, 1982). Where do “revolving door” patients and general practice fit into this?

6.5.5 “Dirty work” designations and legitimacy

First described by Everett Hughes in a series of studies from the 1950's and 1960s, and built on by Emerson and Pollner in their study of a community mental health team in the USA; they described “dirty work designations” as seeming to have significance at several levels:

“On one level the designation of a task as dirty work may be understood as a more or less faithful portrayal of its odious and onerous qualities...on an analytical level dirty work designations implicate the perspective of the worker as much as they do the quality of the work...one occupation's dirty work can be another's sought and fought for prerogative... while dirty work designations are the product of a particular perspective they are the means through which the perspective is enacted and perpetuated...dirty work reaffirms the legitimacy of the occupational moral order that has been blemished”(Emerson & Pollner, 1976).

They contextualised this for the psychiatric work setting as being

“...dealt with from an occupational perspective which honours therapeutic skills as the distinctive competence of the worker. The clash between work circumstances presupposed by such an orientation and the actual features of the work yield disparities which are often designated dirty work...”

This emphasised that dirty work, similarly to the interactionist interpretation of “good and bad patients” embodies a mismatch between what the doctor sees as his/her legitimate work and the problem the patient presents with (Emerson & Pollner, 1976). In the previous chapter the legitimate work of general practice was described as having two dimensions; the technical biomedical aspect; and the centrality of the relationship GPs have with their patients. These shall be considered in turn.

A necessary characteristic of “revolving door” patients was that they have unreasonable expectations from the NHS; for some related to difficulty distinguishing between a major and minor illness, for some making requests

to be seen soon after the GP or other staff member thought they had dealt with the patient's problem, for others making requests for treatment that the GP thought was not medical but "drug seeking" and for others simply not doing what the doctor asked of them. All of these negate the technical biomedical work of the GP.

Another necessary characteristic was the inappropriate boundaries of behaviour that "revolving door" patients displayed; either aggression, or breaching the boundaries of what was considered normal patient GP interaction. These undermined the centrality of a positive doctor-patient relationship and negatively reinforced the first. All this leads to the conclusion that "revolving door" patients challenge the legitimacy of the GP's role in a whole range of ways.

Phillip Strong in his Scottish study of dirty work, GPs and alcoholic patients in the 1980's, added further weight to this. In his view dirty work was a function of the patient's ability to negate the professional's self perceived core roles:

"This fundamental disjunction with the role-relationship seems a more plausible account of why alcoholics should be dirty work than that of traditional morality or faulty education"(Strong, 1980).

Strong added an important further dimension to this by drawing on the work of Chalfant and Kurtz who studied social workers and alcoholics in the 1960s. He introduced the idea of schemas of thinking as being important when deciding what is and isn't dirty work:

"we are currently in the middle of a long term shift from a moral to a medical theory of alcoholism and that social workers- and possibly other professionals too- apply elements from both schema. Thus, although they are morally hostile in some ways to alcoholics, they are not entirely so and in the long run these irrational elements will fade" (Strong, 1980).

6.5.6 Medical and moral schemas

Schemas were defined in a cognitive psychology setting in chapter 4 when introducing script theory. Here they are used in a similar way to describe ideas and opinions about topics that are common to groups of people, rather than individuals; societies, professions, cultural group that share group knowledge and understanding.

Schemas of understanding about health and illness are locked into the ways that GP's understand to be the technical biomedical sphere of their legitimate work. There have been some efforts to typologise the range of ways in which GPs might do this using a range of methods and across the decades (Bucks et al., 1990; Calnan, 1988).

A theme that stands out in this study is how the characteristics of the “revolving door” patients that are described in a clinically orientated manner represent the areas of medicine where a moral element to the schemas of understanding firmly remain; areas where the ground is still contested about whether they are firmly the medical work of doctors or whether they represent the “medical social control” of deviancy (Conrad, 1979). Those found in this study are drug dependency, alcohol dependency and psychiatric illness.

There is a large literature on drug dependency that exists in many fields including medicine, psychology and sociology. In fact, addictions is now considered a field in its own right and encompasses all of those and more. It is outwith the scope of this thesis to delve deep into it and discuss all the current ideas that abound about drug dependency. However to compare two models that are divergent in their concepts will illustrate the breadth of ways of conceptualising drug dependency that are current. One model that clinicians tend to work within is a neuro-physiological model that directly links addictive behaviour to enhancement and suppression of certain neuro-chemicals in the brain. The pharmacological treatments that have been developed to treat opiate dependency have their basis in these theories.

However proponents of these treatments do stray out with the biomedical sphere even with this; as many of the given reasons (that have been researched too) for the success of treatments based on this model are to do with reducing crime and wider harm to society (Seivewright, 2000). The other model for illustration is from a sociology perspective that views drug dependency as being created by the prevailing conditions in a society; it is the “addiction system” that causes the harm; legal sanctions, media representation and how people who use substances choose to explain their behaviour (Davies, 2000). A facet in these models (and all the many others) is the degree to which responsibility for the patient’s addiction and expressed behaviour is located either with the addiction or with the patient and underlies much of the moralising on the topic. This relates back to the respondents’ views about patients’ ability to change too.

During the professional key informant interviews I encountered a range of degrees of moral censure from the respondents about patients with drug dependency problems. Each respondent had their own way of talking, some had a style of talk that was more evocative and interpretable as morally censorious about many of the patients they talked about. But I attempted to take this into account and get beyond style when considering attitudes to drug dependent patients.

There were respondents who reported the censure of others such as in this quote

“one of the things that they [drug dependent patients] used to say to us was we [Practitioner Services staff] treat them differently. Its not as though, they walk in, yes, we may know they are a drug abuser but we don’t treat them any different from Joe Bloggs walking in off the street. It’s a case of they are a patient and that’s it. I think they felt that because of who they were, that they were a drug abuser that they got treated differently from somebody else that went in to the practice.”
PS2.

But it was difficult to translate into quotes and put onto paper what I discerned from some of the interviews. There was an aspect too, that it was

not necessarily the language that was used; it was the sense in which it was spoken. Here are two quotes from GP respondents about providing methadone clinics; these respondents differed in their use of language but a sense of moral censure came across in both to me. Do they come across in the text?

“Most of them are completely manageable, we -and that’s one thing we say to them- we take the methadone clinic, we are not going to get our body armour on we are not going to get cursed and swore at. Friday morning was a bad example [referring to an argument with a patient already described]- what happens if you don’t- but it is undoubtedly more manageable. You can argue the goods and the bads for that so, it can be more managed in primary care, there is more support, they are more manageable for their own symptoms but they are- rarely have fights with them. The big fights we have now with them; they all want their benzos [benzodiazepines]. And the way round that; is you have a blanket policy, you know; even if your granny has died for the 4th time you’re still not getting sleeping tablets!” GP5.

“I(interviewer): And what route do you go down for people who are drug dependent?

R (respondent): We have a methadone clinic in the community, (service location) and we are quite happy having patients on the list but we don’t provide...

“I: You don’t do any addiction clinics yourself?

R: No we just link one in with (addiction clinic location) which is just a few hundred yards away from here, so it’s okay from that point of view.

I: Okay and is it pretty easy, you know, is it good access to services?

R: Its good actually, the services are good in fact one of the doctors who works with us, her husband is one of the doctors there so..

I: Uh huh.

R: So we kind of know the service relatively well.

I: Uh huh.

R: Only I think about one of the practices in the health centre actively does a methadone clinic but we just never really got involved in that. We have too many other things to do.“ GP6.

The respondents varied in how they conceptualised drug dependency, some were pretty firmly in a medical schema with tones of moral censure whereas others were more firmly within a moral schema with some aspects of a medical one.

Patients who were alcohol dependent were much less the focus of discussion in the interviews because respondents felt that alcohol dependent patients were not “revolving door” patients and this must be taken into account. However they were quite matter of fact about the patients they did describe, although there were hints of moral censure from some respondents; see for example the quote by GP5 in section 6.1.4.

One possible additional explanation to those already described is that alcohol has successfully undergone a shift from a moral to a medical schema and is so firmly in the technical biomedical sphere that it does not challenge the legitimacy of the doctor’s role.

There is evidence from the GP respondent interviews about psychiatric illness in general practice that they considered them to be in two distinct schemas. This is distinct from more general societal schemas-represented by the Practitioner Services respondents discussions about mental illness discussed earlier. There were those patients who have serious mental health problems, represented (using the commonly used clinical phrase) as “severe and enduring mental illness” in the qualitative analysis of the “revolving door” cohort and there are patients with “personality disorder”.

All of the GPs represented patients with personality disorder as mentally ill but there was moral censure, tied up with ideas about how much responsibility patients were able to take for their own actions. As the

following respondent describes, general practice mirrors the way in which patients with a personality disorder are often treated by psychiatry services too:

“there's a clear pathway there's much more support services now, I mean someone with major psychotic illness; mental health have got a lot of support services for that, intervention stuff but behaviour acceptable, paradoxically they may have little insight but you see that's their, you can identify this person as mentally ill; and so you treat it accordingly. Someone with personality disorder with very complex diagnoses that often take ages; you are thinking 'you are just at it; you are just out to deliberately frustrate our efforts' as it were. And I think, someone who has got a psychotic illness will be frustrating their efforts perhaps but done through their illness. There's a perception of personality disorder, frustrating all your efforts and so on, they possibly out of badness sometimes crosses- and you will get frustrated with them.” GP5.

This is connected with inclusion or otherwise into the technical biomedical sphere too, there are clear diagnostic criteria for schizophrenia (for example), and medication that can be prescribed that will treat the condition. “Personality disorder” status as a clinical diagnosis will be covered in more depth in chapter 8.

6.6 Conclusions

The characteristics of “revolving door” patients were described using the results from the professional key informant interviews, the quantitative analysis of the CHI data-linked data and the qualitating of the “revolving door” cohort. “Revolving door” patients had three necessary characteristics; they had unreasonable expectations of what the NHS had to offer, they exhibited inappropriate behaviour and they had unmet health needs. Problem substance use and psychiatric health problems were important but there was a mismatch between the importance of alcohol dependency from the key informant interviews and both analyses of the “revolving door” patient cohort. This may be because problem alcohol use was not the dominant presenting problems that were recalled about “revolving door”

patients, because patients exhibit less problematic behaviour relating to alcohol dependence, or because understanding of alcohol dependence is located within a medical schema nowadays. A diagnosis of personality disorder was an important psychiatric diagnostic focus for the GP professional key informants, only partially backed up by the “revolving door” patient cohort data in that the incidence was higher than the usual population. Making a formal diagnosis of personality disorder involves clinicians and patients engaging with conceptual areas of psychiatry that remain in a moral schema for many. Children occasionally were repeatedly removed from GP lists and this was due to one or both of their care givers being “revolving door” patients.

Following a review of the literature on “good and bad” patients and doctors and “dirty work,” (Emerson & Pollner, 1976; Kelly & May, 1982; May & Kelly, 1982; Strong, 1980), I concluded that “revolving door” patients challenge the legitimacy of the GP’s work by having clinical diagnoses that are still conceptualised within a moral schema, and by threatening the normal doctor-patient relationship. This brings GP moral censure into the picture and allows GPs to suspend their core values and break a doctor-patient relationship.

On reaching the end of this chapter, I wish to reiterate the sentiment of May and Kelly (1982) when they point out that there may be good reasons why doctors label their patients so negatively and that it might not be simply due to poor professionalism (Kelly & May, 1982). We move in chapter 7 to consider the impact that “revolving door” patients have on the NHS.

7. Results: the impact of “revolving door” patients on the NHS

This chapter aims to present the results and discuss a portion of what is the meaning in the research question, what is the impact of “revolving door” patients on the NHS? The question is further examined when all the chapter results are considered together in the final concluding chapter of the thesis. In this chapter the impact of “revolving door” patients is examined in two areas. The first and the main focus, is the impact on the professionals “revolving door” patients came into contact with including GP practices, and the second on the wider NHS.

7.1 The impact on professionals

7.1.1 Relationship

The majority of the reported impacts “revolving door” patients had on professionals they came into contact with in the NHS, were negative. However, there were two positive areas that the respondents described. The first was the relationship that Practitioner Services staff established with some “revolving door” patients. All the staff interviewed, who dealt directly with allocations described some patients, current and “ex-revolving door,” they felt, unusually, that they got to know them and were encouraged by feeling they had a role in supporting these patients to access NHS services. The GP respondents had a sense of pride about the “revolving door” patients that they managed to stop “revolving” and build a positive relationship with. This is illustrated by this GP who rated this ex “revolving door” patient as his best success:

“R: “Revolving door” patients that stayed I can think of my last one, I would say had been on every practice list in the area I think; and substance misuse, drug seeking behaviour, very bright, face like a melted welly, and very dysfunctional or very peculiar family background; criminality, full of sort of deprivation type stuff and very challenging behaviour to begin with.

I: What sort of stuff?

R: Their shouting that “I need help and you are not doing anything for me and what am I supposed to do” to the receptionist who couldn’t give and immediate appointment to see a doctor within 15 minutes of them joining the surgery.... so he came and after a few difficult consultations of “no that’s not going to help you in my opinion” agreed reluctantly; agreed that the “help” in inverted commas, that I was giving; the service that I was prepared to offer him; were supervised daily dispensing of methadone at the chemist and that was unacceptable. And “no I don’t want that,” to begin with; but after a while of lots of noise, I was able to negotiate starting on that. And then a fair bit of argy bargy at the chemist to begin with, he is now 35 so probably at the age of just about ready, ripe for picking after having been round [“revolving” round practices] for most of his 20’s... and now, he’s one of my best buddies. I mean; I get letters from the jail about how things are he’s dealt with, a load of stuff, he’s got children with significant health issues who are not actually patients in my practice but I know all about them. Because he is very bright, when he was in the jail once he got an A in his higher English and wrote to me to tell me. I get a Christmas card that’s the size of a small house from him and family. And the consultations are very business- like; full of chat; cheery. He is well liked generally by the receptionists because he comes in, and he always asks a wind up question with a smile on his face, and the receptionists have a laugh with him. And so its, again I think for me, for him the reason he stays is because the doctor-patient relationship was hard to begin with but is now...

I: Rewarding?

R: Absolutely rewarding...” GP3.

However the negative sides of attempting to establish a relationship with “revolving door” patients was the dominant description from both Practitioner Services and GP respondents. The prominent feature for the GPs was not simply about managing unreasonable demands and inappropriate behaviour; it went deeper than that to the difficulty they had of establishing any rapport at all with “revolving door” patients:

“I: And you mentioned something about the quality of the relationship and the rapport with her, can you sort of elaborate on that?

R: It's an odd thing; it's when you are talking to somebody and you know you have no mutual points of reference, if I can put it like that. You just don't click at any sort of level. It's like they are half a pace apart from my reality, if you like- which I assume is everybody else's- and they just don't see other peoples' point of view. "GP4.

The Practitioner Services staff described the difficult phone conversations they had with “revolving door” patients where they displayed evidence of their unreasonable demands and inappropriate behaviour to the point where specific strategies for coping with these were applied. Here is a description of the interaction and way of dealing with it from one respondent:

"This one chap just calls me C....it's not a very nice C he calls me; but its not; (my name C) that's how he addresses me; "Hello; (whispers expletive)." I don't want to say that very loudly; and you know I just, this; I'm not going to bother my head. I kid on that I don't even hear him anymore. But some of the staff get upset by it; and its usually the older ones in the team. I know; you might think she's not a young thing, but some of them just- God love them they have led quite a sheltered life- and they think; how can you let somebody speak to you like that? Well they are patients and we have to deal with it. They don't have to deal with it; I have to deal with it. And they just pass it over to me and I get on with it. That's it."PS4.

7.1.2 Workload

All respondents described “revolving door” patients as being high workload patients depending on their respective professional roles. For the Practitioner Services respondents this meant the frequent administrative process of removal and reinstatement taking up a lot of time and its significant cost to the NHS:

"Proportionately we spend a lot of time on those ["revolving door" patients] compared with all the other patients. Obviously because we have to go through a process; we have to take them off the system; we have to move the medical records...and very often you have just got the medical records moved, and they have moved somewhere else. So you have to keep; -changing the system takes two minutes- it's moving the records; getting them

from one practice to another; getting the paper round; that takes the time." PP1.

A large amount of written correspondence was generated about "revolving door" patients. This was due to complaints and hospital letters that were addressed to the patients' previous GPs that were re-routed to Practitioner Services and had to be filed. There were phone calls from patients and practices to deal with. This quote describes one patient's frequent telephone contact with Practitioner Services:

"She will phone three or four different times; but she will be different people. But of course you get to know the voice and that as well; and you see the number coming up on the phone. And the timing; she only phones every Wednesday night to see if she's been allocated the next day; and she will phone the next day to find out what time to phone back, to find out which doctor she's on. So it does sound like it's just more for company and contact at the end of the phone; but obviously she does have medical problems as well." PP2.

For the GPs, "revolving door" patients often took up time because of the need to respond to their demands, behaviour or unmet health needs. This GP respondent describes the consultations with one "revolving door" patient:

"And he frequently gets fixed ideas about things and persistently asks for them...so he keeps going on about that so its quite difficult to keep the consultation to a reasonable length of time...I can see that it would be very frustrating to deal with because you would be running later and later and wanting him to go; he frequently comes back in as well. You know, you think he has gone and then he will come back and asks more..." GP1.

This Practitioner Services respondent describes the disrupting effect "revolving door" patients had on practices:

"The practices get very exasperated; obviously because they can't spend all day on the phone to the one patient, and they can't go and visit at the drop of a hat; you know they have set times to go visiting. And if they are visiting that patient everyday, then they are not visiting somebody else. That's basically where they are coming from; they can only stand the pressure, if you like, every so often." PS1.

7.1.3 Frustrating efforts

Practitioner Services staff saw it as their job to get all patients, including “revolving door” patients, registered with a GP, and to advise patients and practices about registration issues. However they got frustrated with the system that produced “revolving door” patients not the GPs. They felt they have not delivered when a patient who had started “revolving” did not comply with the arrangements staff had made for them and the situation continued.

Practices on the other hand often did not receive the patients' full medical records, or have the time to go through their thick files properly in the short time the patients were registered. This impacted on their ability to feel they were providing the required care for patients. This was linked with the respondents' perceptions about their skills to work with “revolving door” patients.

7.1.4 Unequipped to deal with unmet need

Practitioner Services staff described “revolving door” patients phoning seeking medical advice, advice that staff were not able to give. They often worried that the general advice they did give about accessing appropriate health services might be wrong or make the patient's problem worse.

"I'm not a care worker and I don't know what to say to you. I mean I can listen, yeah, and I can sympathize, and I can make suggestions, but it's just a case of who to phone rather than anything else. I mean, I'm not medical; so you wouldn't want to say anything that would affect her as well. So you're trying to be neutral and even that itself can be quite difficult; trying to get off the phone without sounding as though you just can't be bothered with her." PS2.

Mirroring this feeling of not having the skills to work effectively with “revolving door” patients were the GP respondents as illustrated by this quote. A respondent explained that sometimes it is about services not

engaging with patients and sometimes about patients not engaging with services:

"So the psychiatrists, the psychologists, community psychiatric nurses really don't want to know and that feeling of abandonment is quite difficult to deal with. And so you think, "oh no, what am I going to do with this person?" They clearly need help and I don't actually feel that qualified to be able to deal with it but nobody else is willing to engage with them either. And sometimes there are people who are willing to try but then the patient won't engage with them either. You think "oh please do something that I am advising" but they won't." GP1.

7.1.5 Emotional toll

Practitioner Services respondents got "frustrated", "fed up", "annoyed", and sometimes "angry" with "revolving door" patients. This was partly because they found them difficult to deal with but also because they felt they prevented them getting on with other work:

"..some people will sit and listen, but after a while you just get fed up and think; "no, I have other work that needs to be done as well; its not my job to be sitting here listening to you; you should actually be speaking to a health care worker or somebody else that can give you help: where as I can't." Yeah I can be on the other end of the phone; but that's not what I am here for; so its quite difficult, at times." PS2.

Also over time some of the Practitioner Services respondents came to the conclusion that part of the toll was that no matter what amount of time they spent on the phone, the issues and perspectives of the patient's were unchanging:

"But maybe its just that I have been stupid in the past; and I have listened to them; (laughs) and maybe that's our problem here. But when you get them on the phone to start off with; I think because you don't know what like they are; you tend to listen to them. Until you realize so many months down the line; I wish I hadn't done that because they do keep coming back." PS2.

Similarly the GP respondents described the effort required to try and work with “revolving door” patients and the toll it took on them, as illustrated by this quote from GP4:

“R: I have another guy who is an “ex revolving door”... I find him very difficult, he's been with us now for a long time having been excluded from pretty well everybody else's other surgery in the area, a lot of its to do with seeking to get benzodiazepines for an alcohol problem and turning up drunk and stuff like that. And he's been with us for a long time... something like 8, 9 years...and what I find interesting about this guy is my own reaction to him which I'll tell you about. Are you a Harry Potter fan?

I: Mm-hmm.

R: Do you know what a Dementor is?

I: Yes I do.

R: That's what he is; that is what he is. I can feel the joy leaching out of myself when I see his name on the list and I have to prepare myself for this guy coming in. Now, he's a difficult patient in that he has been yellow carded twice, I've had to write him letters to say don't do that again but he hasn't been yellow carded twice in 12 months at which point I could say you are off you have to go...Why do I put up with him? Because, well one answer would be I haven't found a reason yet; he hasn't stepped over the line yet. But, you can't pick your patients to some extent; you've got a spectrum between the folk that you, you actually look pleased to see them coming in; great I'm going to get a joke from them; they are going to make me feel happy kind of thing. He's at the other end of the spectrum; so if I accept that; the ones that make me feel better; I have to accept the ones that make me feel a bit gloomy! But its great when he leaves I have to tell you.” GP4.

Practitioner Services staff also described practices having significant memories of “revolving door” patients and their experiences with them; to the point where they expressed anger when “revolving door” patients were assigned to the practice again:

“...they claim to know the patient and have had them before; that's usually when it happens and they are quite angry that the

patient has been assigned to them again. And they might be quoting something that happened six years ago or whatever, but they know the patient; he/she was trouble at the time, and they don't want them. "Give them to somebody else". "Well he's been to everybody else; its now your turn; he's been round everybody else in that area." "Oh has he?" But they don't want to know. It does happen." PS3.

One GP respondent felt that all the information that Practitioner Services received about "revolving door" patients from practices was a form of exorcism to attempt to deal with the strong emotions they usually provoked:

"Occasionally the GPs would write to Practitioner Services explaining all their reasons; and that's a bit of a breach of confidentiality actually; because this was an administrative function. But that was the way of it. They were so exercised by this patient that they wrote in and gave them chapter and verse as to how they were putting them off; but there wasn't a kind of safe haven or some area for discussion about how these patients were handled."GP2.

7.1.6 Strategies for working with "revolving door" patients

Boundary strategies

Practitioner Services staff and GP practices used a range of boundary strategies tailored to each patient's needs that gave the patient a clear signal about what was expected of them. These strategies were instigated if the patient struggled to change their behaviour following the communication techniques that would apply to all patients. For example if a patient was swearing on the phone in an aggressive directed manner and continued to do so despite polite verbal requests to stop. A boundary strategy at that point would be to require written communication with Practitioner Services only.

Individual Practitioner Services staff coped by using a range of their own personal boundary strategies like treating each phone contact as a new contact, and by purposively not thinking about work when they left each day, along with those that managers helped them with that have been already described:

"...when I leave through the door it stays at my desk; I don't take it home with me. And I know a lot of people think that's- how can you not take it home with you- when some people are threatening suicide on the phone, and everything; but I don't go home and worry about that. Maybe that's me a bad person or something, but I have a daughter at home; I don't have time to think about what happened in the office." PS4.

Some practices used a written contract with patients with whom there had been issues; setting out what good quality care to expect from the practice and what behaviour boundaries to expect from patients. Some GP practices used a football analogy to sanction behaviour by using yellow cards (warnings) and red cards (removal). There was a clear time scale for this and similarly as in football; after a time had elapsed yellow cards were revoked.

Specialist general practice service

A service already existed in Scotland that worked specifically with patients that general practice struggled to work with. Their focus was to provide general practice care to patients in the Health Board area while focussing on behaviour change such that they could be reintegrated back into mainstream. The GP had more time in each consultation, set clear boundaries of behaviour and focused on establishing a positive relationship with the patient (there was only one GP, which helped focus). A component of this was about positively challenging the patient to consider the impact their negative behaviour had on others and to change it. The patients were then reintroduced back to a mainstream practice; following a discussion of issues and progress with the new GP, and this had been a success for many patients and practices. Some patients had stayed with the service in the long term though because they were very challenging to work with. The disadvantages were that patients had to travel long distances to be seen and this precluded the option of home visits.

Suggested future changes to services

Respondents were asked to consider what they felt would be effective ways to work in the future that might stop patients “revolving”. They suggested the boundary strategies set out above, and discussed whether the model of the general practice specialist service might be a useful one in other Health Board areas. This was felt to be appropriate in places where there would be sufficient numbers and where distance of travel to a centre would not be unrealistic.

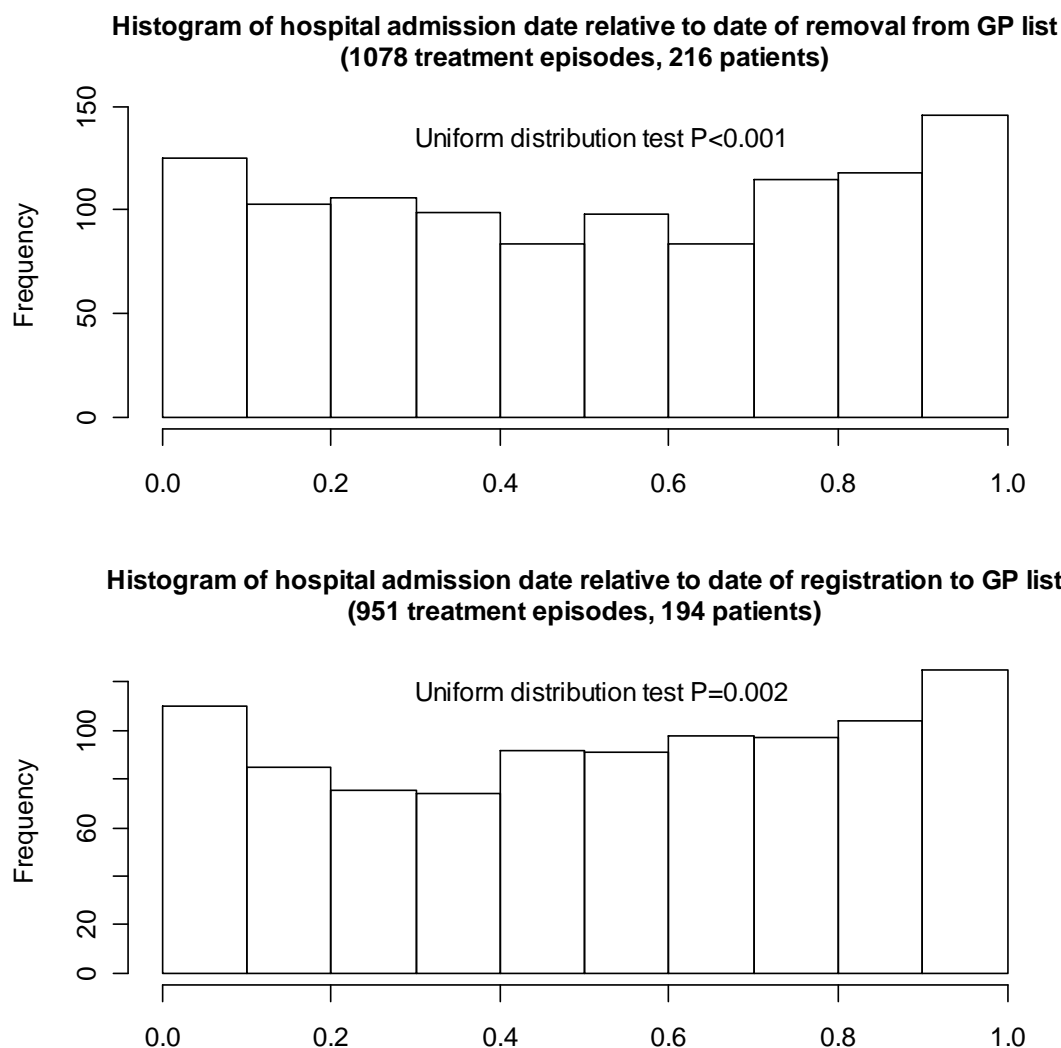
Some respondents also described the role that payment incentives might have. If a patient were identified from an agreed number of removals then a practice could be allocated an additional payment to support the patient. This would include targeted mental health support to address identified problems with the practice and the patient, which might be a combination of a mental health professional, social work and voluntary agency support.

7.2 Impact on the wider NHS

7.2.1 Quantitative analysis of the third “revolving door” patient cohort

When investigating the relationship between the status of being a “revolving door” patient and its effect on the wider health service it was not possible to investigate whether it was this status that led to the pattern of health interaction described. For example whether high hospital admission rates or having a treatment episode recorded on the SDMD was a feature of the patient’s health needs rather than intrinsically related to their “revolving door” status. However analyses of the relationships between being registered with a new practice or removed from a practice, and health service utilization is reported next.

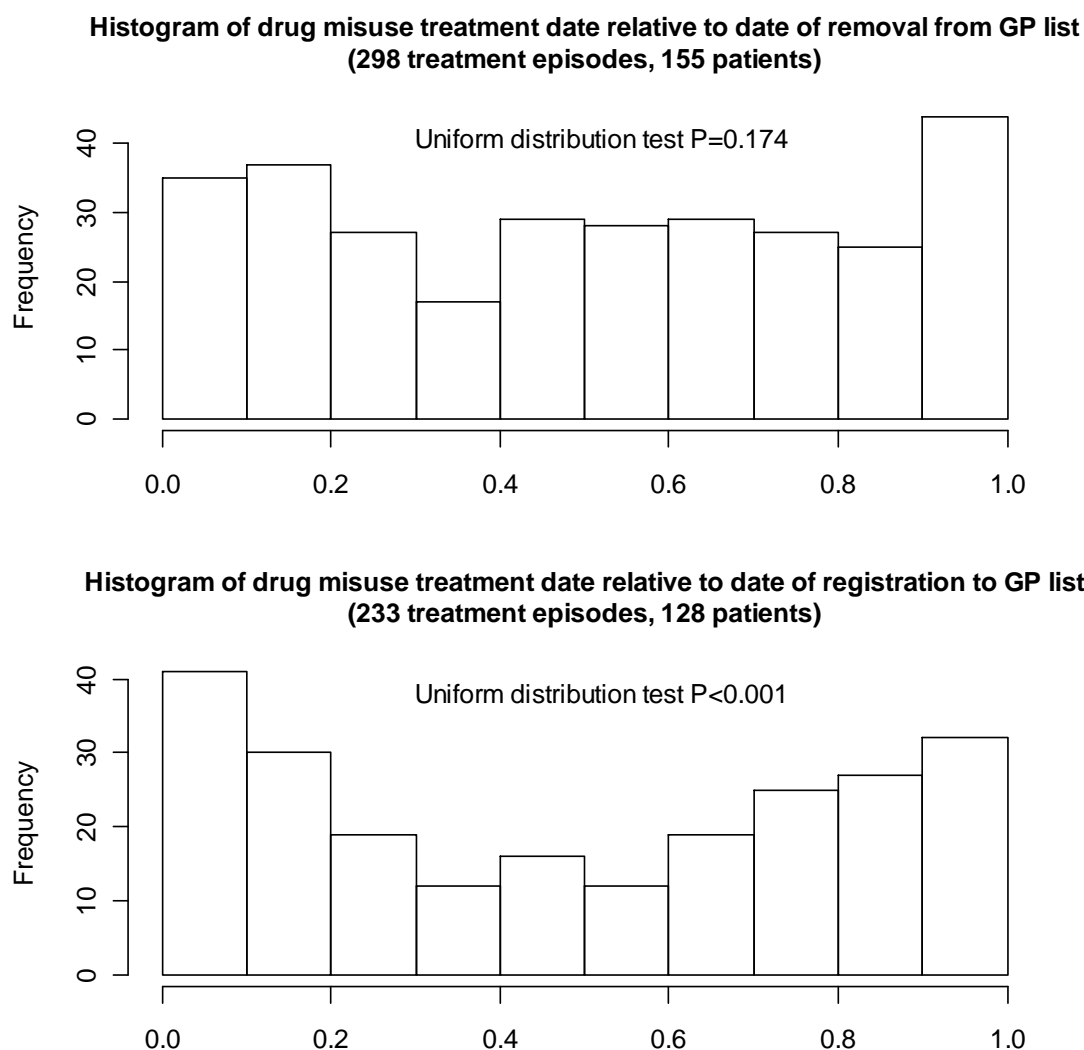
The x axis is the admission dates “expressed as a fraction of the time from the previous removal to the next removal. So $X=0$ means admitted on the same day as the preceding removal, $X=1$ means admitted on the same day as the next removal, and $X=0.5$ means admitted halfway between the two removal dates.” The y axis is “the number of these “fractional” admission dates falling between 0-0.1, 0.1-0.2, etc.” The histograms investigate whether the admission dates are “randomly spread between neighbouring removal dates. If the spread really is random then the chances of falling in the interval 0-0.1 is 10%, and 0.1-0.2 is also 10%, etc, i.e. every value is equally likely so the probability distribution is uniform from 0 to 1” (Johnson, 2011d).



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 16 Histograms of hospital admission dates⁹ relative to removal (top) and registration (bottom) for the third cohort “revolving door” patients who had records linked to SMR01

⁹ Admission dates are expressed as time from the preceding practice date as a proportion of the time between the preceding and the subsequent practice date. P-values for tests of goodness-of-fit to a uniform distribution were estimated from 10,000 simulations. Dates falling on weekends (< 3% of dates) and imputed dates were treated as missing.



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 17 Histograms of problem drug use treatment date¹⁰, relative to removal (top) and registration (bottom) for the third cohort of “revolving door” patients who had records linked to SDMD

There was a statistically significant relationship between a “revolving door” patient being removed from a practice list and this triggering a hospital admission. This may be because the patient had an illness episode for which they sought care from their GP. This interaction may have triggered removal. The patient may then seek care in secondary services. There was also a statistically significant relationship between being registered with a

¹⁰ Problem drug use treatment dates are expressed as time from the preceding practice date as a proportion of the time between the preceding and the subsequent practice date. P-values for tests of goodness-of-fit to a uniform distribution were estimated from 10,000 simulations. Dates falling on weekends (< 3% of dates) and imputed dates were treated as missing.

GP and having a new treatment episode recorded on the SDMD. This may have been because the new GP identified addiction needs when the patient registered and referred them for a new addiction treatment episode or completed the database notification form. There was no correlation between this for other possible combinations of activity including outpatient attendances.

Moreover twenty “revolving door” patients had an ICD code recorded during an admission which commented directly on patient’s expression of negative behaviour during the admission as described in the previous chapter.

7.2.2 Qualitative analysis of the “revolving door” patient cohort

There are similar limitations in reporting aspects of this analysis, as with the quantitative one, that can be attributed to the patients “revolving door” patient status. It was from the qualitative analysis that the theme of expressed negative behaviour being recorded in the ICD 10 codes was identified, evidence that “revolving door” patients had difficulty with interaction or relationships in secondary care too.

A striking observation from the outpatient attendance data was the DNA rates too. Two thirds of patients “did not attend” more than a third of their outpatient appointments. The quantitative data on did not attend rates is included in section 6.7.6 with the other limited outpatient data that was reported to avoid segregating small portions. From that 92% of the cohort missed at least one appointment, the average ever missed was eleven (range 0 to 146) the average missed per year was 0.8 per year (range 0 to 14).

7.3 Summary

From the professional key informant interviews the professionals who came into contact with “revolving door” patients in the NHS found it a difficult

experience. They usually found the relationship challenging. “Revolving door” patients generated a lot of work, they frustrated professionals’ efforts, made the professional feel insufficiently skilled to help them, and found that interacting with “revolving door” patients took a significant emotional toll.

There were strategies already used at different levels in the health service which sought to address difficulties in a range of ways, including using boundary strategies, or a specialist general practice setting for challenging patients (a boundary strategy in itself). The specialist service focussed on improving the doctor-patient relationship and behaviour change, and other suggested future changes incorporated these aims.

There was a statistical link between being removed from a practice list and having a subsequent hospital admission; and being registered with a practice and having a new treatment episode for substance misuse recorded on the SDMD. There was evidence of negative behaviour being expressed by “revolving door” patients during admissions too and most patients missed a number of outpatient appointments.

7.4 Discussion

The toll that working with “revolving door” patients had on professionals working in Practitioner Services and general practice was clearly expressed and also the range of ways that individuals and services have attempted to reduce that toll and make the interaction more appropriate. There was evidence that these difficult interactions continued into secondary care too.

7.4.1 Health service utilisation

What is less robust is the meaning that the existence of “revolving door” patients has on the health service from a wider perspective still; that of health service utilisation. I attempted to concentrate results that can be attributed to patient characteristics in chapter 6 but there is overlap

between this and health service utilisation, for example number of admissions to hospital. I have attempted to restrict health care utilisation to those areas that may be directly related to patients' "revolving door" status. There was evidence from the key informant interviews that their status generated a lot of work for Practitioner Services and general practices. There was limited evidence too that patients were more likely to be admitted to hospital after they have been removed, and more likely to be referred for addiction care after they were re-registered. It was not possible to discern whether this was appropriate use of services or not.

"Revolving door" patients may also have high levels of did not attend rates for outpatient appointments. It was not possible to compare this with the typical general practice population to investigate this further because data are available as appointments missed rates (Information Services Division NHS National Services Scotland, 2011) rather than at individual patient level. This analysis was not conducted for the "revolving door" patient cohort. A&E attendances and out of hours contacts were also not included in this study because the former were not available at the individual patient level nationally, and it was not feasible to pursue the latter in this study once it was identified as an issue. Considered together these results suggest that being a "revolving door" patient did confer some additional cost to the health service. These costs were administrative, interpersonal and possibly clinical. They add weight to the perspective that the apparent demise of "revolving door" patients is a positive development and that future influences that might lead to a resurgence in their numbers are to be resisted. However, have the "revolving door" patients who have now settled into a general practice managed to achieve a positive doctor-patient relationship? It is to the doctor-patient relationship that I now turn.

7.4.2 Problem doctor-patient relationships

With the doctor-patient relationship being so important for the professionals involved and because the previous two chapters focussed on broader social perspectives, I am going to explore now, the interpersonal territory of the

research on the doctor-patient relationship in general practice. Rather than considering the whole field, which unsurprisingly, given the centrality of the doctor-patient relationship to general practice, is big; I am going to give a brief descriptive overview of the topic and then focus down on the problem doctor-patient relationship literature.

Bower et al (2001), a team of primary care researchers whose focus has been on the doctor-patient relationship, attempted to conceptualise the scope of work that has been carried out in this area and this provides a useful means of describing the research field of the doctor-patient relationship.

They described 4 approaches or domains. The first is the psychodynamic domain (Bower et al., 2001) of which the seminal and still influential work of Balint is the obvious example (Balint et al., 1993). Research, theory and commentary in this domain explore the doctor-patient relationship as a psychodynamic process, viewing the relationship as the treatment modality and paying close attention to the emotions of both the doctor and the patient.

The second is the clinical-observational domain, which emerged from attempts from clinicians to understand how the doctor-patient consultation worked and how to improve it. This relies on an understanding of the doctor-patient relationship as being focussed on the expert clinician's behaviours, usually in terms of the communication skills he/she employs. From my review of the problem doctor-patient relationship literature I would add three categories to this domain. The first is understanding the patient in the consultation, based on a biomedical conceptualisation of illness and suffering (distinct from the psychoanalytical which focuses on emotions and lived experience). The second is the health service structural context of the doctor-patient relationship. Research on relation continuity; which is the ability of, and the impact of, general practice's ability to allow patients to form a longitudinal relationship with a GP (or other health professional) over time, is a current example (Haggerty et al., 2003). The

third is research on the patients' perspective, although this tends to include the topics already described in this domain, but from patients' perspectives (Ridd et al., 2009).

The third domain is the social-psychological one which is concerned with the health beliefs, behaviour and ability to change of the patient within the doctor-patient consultation and is mostly located in the health promotion literature.

The fourth domain is the sociological domain. Bower et al present this in two categories, the first as being about discourse and conversation analysis approaches to the consultation and the second as being the study of social process; for example the role of power and knowledge in the doctor-patient relationship (Maseide, 1991).

I will use these four domains as a backdrop to describe the problem doctor-patient relationship literature in general practice (defined to include work from the USA, as office based doctor-patient relationships). This is not an exhaustive review; there were some papers from the 1960s and 1970s which subsequent papers built on and there were also studies of poor quality. Both of these sets of papers are not presented because they do not add anything substantive to what is described below.

Research, theorising and commentary is evident in the first two domains, but not explicitly in the social-psychological or sociological domains. This may be because theories of health promotion and sociology tend to be located across settings, so there may be problem doctor-patient relationships in general practice used as examples, but this was not retrieved by key word search engine literature searches. More plausibly it is because located in both their theoretical discourses is an active avoidance of any level of moral censure (use of the word "problem"). I will critically appraise the papers in the remaining domains and then consider what relevance they have for this study.

Psychodynamic

Two papers both from the USA have proposed theoretical models based on psychodynamic theory. In Groves' (1978) influential paper on the "hateful patient" he proposed 4 "stereotypes" of patients to describe those patients who "kindle aversion, fear, despair or even downright malice in their doctors". He emphasised that these were patients who most doctors would find difficult to work with so would not be better cared for by transferring them to another doctor. Groves (a liaison psychiatrist) accepted that with some patients, negative emotions will be experienced by their doctor, and that they should be understood and used as a basis to begin thinking about forming a more functional relationship. The categories were evocatively described as "dependent clingers", "entitled demanders", "manipulative help rejectors", and "self destructive deniers".

"Dependent clingers" had a "self perception of bottomless need" and eventually exhausted the doctor in their overt expression of this.

"Entitled demanders" are best described directly:

"Demanders resemble clingers in the profundity of their neediness but they differ in that -rather than flattery and unconscious seduction- they use intimidation, devaluation and guilt induction to place the doctor in the role of the inexhaustible supply depot... unaware of the deep dependency that underlies these attacks on the doctors. The physician in turn does not recognise that the hostility is born of terror of abandonment. Moreover such patients often exude a repulsive sense of innate deservedness"

"Manipulative help-rejecters" expressed the same neediness but did so by denying that any advice or intervention the doctor provides can help them. They want simultaneously to be in a relationship with their doctor so have many, many problems they bring, but at the same time are fearful of getting too close.

“Self destructive deniers,” “stir up malice” in their doctors. They too are “profoundly dependent and have given up hope of ever having their needs met.” Groves views these patients as “chronically suicidal” and recommends that they be viewed as terminally ill. In his experience they are the most difficult patients to care for empathically.

Groves sets out ways to manage these patients, by acknowledging the feelings as “useful clinical data” and seeking to behave positively towards them; setting limits on the dependency for the “dependent clingers”, re-channelling entitlement into expectations of realistically good medical care for the “entitled demanders”, “shar[ing] pessimism” with the “help rejecters” and for the “self destructive deniers” beginning to accept that the patient might want to die (Groves J, 1978).

Groves’ paper drew on case studies of patients to illustrate his points. In each of the descriptive stereotypes he described, I heard echoes of examples of “revolving door” patients that were described in this study, they included all 4 stereotypes but particularly the “entitled demanders”. What stood out was the pragmatism with which he stated it was normal for some patients to provoke negative responses in their doctors; and that this should be used as clinical data, and used to reformulate an effective response. All these responses required unusual effort on the part of the doctor.

The second US paper focuses on the strategies that may be used to work more effectively for “patients it is not easy to like”. A central theme similar to Groves’ is that the patient’s interaction is a replication of all the relationships he/she has. Nesheim (1982) explicates the patient and doctors perspectives thus:

“These patients use time-tested, finely tuned, often unconscious mechanisms of offense and defense developed over years of experimentation with family, friends and public. A lifetime of personal pains and needs has equipped the difficult patient with a variety of tools and techniques to extract from the world the

necessary measure of support and succour...The logic of such patients is bound only by utility and the acquired effective politics of interpersonal successes, whereas the physician's logic is enmeshed in the restrictions of professional demeanour, theoretical rigour and the scientifically useful (but interpersonally lethal) notion that the world is moved by cause and effect."

He describes the attributes of the patients in five areas; "dependency", "contention", "suffering", "drama" and "psychiatric disorder"; the last being to consider that some patients exhibiting the former ones may have a treatable disorder. They overlap with the characteristics described by Groves and the strategies he describes are similar too; to recognise when patients evoke negative feelings and to then use them to make a "second diagnosis" of what it is about the patient that evokes these feelings. He goes into more detail about the continuing care of patients. This includes follow up with the appropriate specialist in tandem with scheduled appointments with the primary care physician, discussing patients with colleagues, setting limits on the doctor-patient interaction if necessary, and accepting when there are symptoms the primary care physician (or anyone) cannot treat (Nesheim, 1982).

Clinical Observational

I included work by one team from the USA in this domain that looked at expert clinician's behaviour. Schwenk had carried out a previous study to determine the prevalence of difficult doctor-patient relationships (Schwenk et al., 1989). His follow up paper in 1992 focussed on the management strategies that a doctor should employ to improve the doctor-patient relationship. This replicated much of what was recommended in the psychodynamic approach; except with more of a focus on specific communication skills (Schwenk & Romano, 1992).

The majority of the research focus in this domain has been in the biomedical conceptualisation of illness and suffering. Two papers attempted to synthesise the emotional responses by which doctors identify problem doctor-patient relationships and fit them into clinical diagnostic categories

by using questionnaire studies. One unsuccessfully tried to fit them with a historical personality disorder model (Malcolm, Foster, & Smith, 1997) and another grouped them into medical and social groups. The medical ones were “conditions for which no cure exists”, “conditions with low probability of cures”, “conditions challenging physician’s competence or diagnostic skill” and “conditions for which patients or others are perceived culpable.” The social ones were “characteristics that threaten or impede therapy”, “characteristics threatening physician’s authority or prestige” and “characteristics impeding physician patient communication.” This paper locates the reasons why these prompt difficulty as being because doctors prescribe to the “protestant work ethic” which all of these categories subvert (Klein et al., 1982).

The influential work of O’Dowd brought the term “heartsink” patients into the literature in the UK (O’Dowd, 1988). In he and McDonald’s research study he determined there to be two categories of “heartsink” patients; those who were high users of care with a lot of poorly defined conditions that GPs felt they could no longer usefully help, and lower users of care who had had a fairly recent trigger event in their lives which prompted them to present with psychological problems; their personalities and behaviours presenting particular problems. Interestingly O’Dowd notes that the GPs taking part in the research did not suggest removal from the list as a solution to managing these patients (McDonald & O’Dowd, 1991).

Hahn et al (1994) attempted to devise a validated tool to identify problem patients in the primary care and general medical clinic setting in the USA. Doctors completed a questionnaire tool (heavily influenced by the work of Groves), a sub set of matched patients completed brief self assessment tools for mental illness, and a subset of patient’s notes were scrutinised by the research team. They concluded that difficult patients had a combination of somatisation, personality disorder and mood or anxiety disorders and advocated a shift away from cure to management directed treatment goals (Hahn et al., 1994).

The other research conducted in the UK was by Mathers et al (1995) who shifted focus onto the characteristics of GPs in an attempt to explain the reasons why GPs report a range in the number of “heartsink” patients. In this study these were defined as patients with whom the GP felt helpless and with particular types of patients (patients with multiple symptoms, with psychiatric problems, difficulty communicating with, who were hypochondriacs, and frequent attenders). Their study found four “explanatory variables” that were linked with the number of “heartsink” patients that GPs experienced. Higher perceived workload and job dissatisfaction, no prior communication skills training, and no relevant postgraduate qualifications were associated with reporting higher numbers of “heartsink” patients (Mathers, Jones, & Hannay, 1995). A follow up paper by Mather’s (1995) described the outcome of a workshop utilising these results and strategies for working more effectively with “heartsink” patients. It set out a model of seeking to work with patients in much the same way as set out in the psychoanalytical approach but expressed in language more familiar to general practice; communication skills based. “Sharing”, “boundaries”, “challenging”, “confronting” and “accepting” were key words in this (Mathers & Gask, 1995).

A discussion paper by the Welsh Philosophy and General Practice Discussion Group (1999) re-examined the research on “heart sink” patients and were uncomfortable with the focus of the problem lying with patients. They argued that it is more to do with the way that doctors perceive their work and what is in and out of the biomedical model that is a key influence. They recommended that the underpinning philosophy of general practice should be expanded to include suffering in a broader sense beyond the focus on the biomedical that included soteriological (being about salvation) dimensions (Butler, Evans, & and the Welsh Philosophy and General Practice Discussion Group, 1999).

There is a substantive literature on problem doctor-patient relationships in a health service structural context, about so called “frequent attenders” in general practice. In the most recent review of the literature by Smits et al

(2008), frequent attending patients are characterised by; having only physical illness (28%); clear psychiatric illness (21%); being patients in temporary crisis (10%); being chronically somatising patients (21%); or those with multiple problems (20%). The evidence suggests that patients with the first three (only physical illness, clear psychiatric illness, being in temporary crisis) will attend frequently for a short time, usually for about a year and then settle down into a more average attendance pattern once their respective problems are treated or settle down. This is viewed as acceptable patient behaviour. The remainder of the patients (and there are suggestions that these are patients with complex needs and often undiagnosed psychiatric health problems) become “persistent frequent attenders.” These patients are thought to have unnecessary consultations that lead to ineffective health care (Smits et al., 2008). The dominant identity of these patients is to do with their propensity to seek frequent consultations with their GP. I could find no consideration of removal activity in any of the “frequent attenders” literature.

Likewise no paper could be found that focused on the patients’ perspective although similarly some studies in the patient removal literature did so and this study attempted to.

Crossing domains

A paper by a UK GP reviewed the “difficult patient” literature from the 70’s and 80’s from general practice and other fields. In it Smith (1995) considered sociological, clinical observational and psychodynamic perspectives. He reviewed the role of the patient; considering abnormal illness behaviour, somatisation and personality disorder. He discussed the evidence about the characteristics of doctors; how much they adhered to a medical model or a psychosocial one, how much they were able or not to tolerate uncertainty and risk taking. He then considered the doctor-patient interaction in terms of the literature on “patient satisfaction” at the time. He then moved on to consider the “public domain” which touched on some health promotion and sociological constructs and then the “personal

domain” which took a psychodynamic approach to the doctor-patient relationship (Smith, 1995). He then moved into territory which has received more attention in the general practice literature this decade; a return to the biopsychosocial model (Borrell-Carrio, Suchman, & Epstein, 2004) and a systems based approach to considering general practice issues, articulated and extended by “chaos theory” even more recently (Innes, Campion, & Griffiths, 2005). The strength of this paper was its ability to integrate cross disciplinary thinking on the topic although its discussion of strategies for working with patients added nothing new to me when I read it when compared to the existing literature.

7.4.3 Patients with medically unexplained symptoms

“Somatisers” or patients with “medically unexplained symptoms” merit brief consideration here as this area of research does not quite fit into the problem doctor-patient relationship literature domains in itself; but does come up in the previously mentioned papers. A focus of current research and theory has been on establishing the conceptual and diagnostic boundaries of what constitutes a somatising condition along with possible treatment options; these are focussed on psychological therapies, pharmacological treatments and to some extent the doctor-patient relationship and collaborative working with other professionals (Fink & Rosendal, 2008; Kirmayer et al., 2004). There was evidence from a small number of the patient profiles in the qualitative analysis of the “revolving door” patient cohort that patients with somatoform disorder or medically unexplained symptoms were evident, but this was not explicitly described as an issue by the professional key informants. Again whether a patient was identified as a “revolving door” patient was dependent too on the patient’s perceived expectations and behaviours.

7.5 Conclusions

The professionals who came into contact with “revolving door” patients in the NHS found it a difficult experience; they found the relationship

challenging, they generated a lot of work, they frustrated professionals' efforts, they made the professional feel insufficiently skilled to help them, and they found that interacting with "revolving door" patients took a significant emotional toll.

Strategies were already used at different levels in the health service which sought to address these difficulties including using boundary strategies and a specialist general practice setting for challenging patients who focussed on improving the doctor-patient relationship and behaviour change.

There was a statistical link between being removed from a practice list and having a subsequent hospital admission; and being registered with a practice and having a new treatment episode for substance misuse recorded on the SDMD. This was additional evidence that the status of being a "revolving door" patient brought additional costs to the NHS beyond the interpersonal difficulties and administrative burden described and that any future developments that may lead to a resurgence in the number of "revolving door" patients should be resisted.

There is much resonance with what is described in the problem doctor-patient relationship literature and the "revolving door" patients described in this study. There were few "revolving door" patients, but they stood out for negative reasons; and these were all patients who took a high emotional toll on the professionals who worked with them. They did not allow GPs to carry out their legitimate work, because the GPs could not fit their problems into a biomedical disease model or there was something about their interpersonal interaction that meant the doctor-patient relationship was difficult. Frequent attenders and patients with medically unexplained symptoms were described in this literature and some were "revolving door" patients. A synthesis of practical suggestions from the literature including some from the results is described in appendix 18.

In the next chapter 8 I turn to the impact that being a "revolving door" patient might have on the patients themselves.

8. Results: impact of being a “revolving door” patient

8.1 Professional key informant interviews

This chapter sets out to answer the research question which is, what is the impact of being a “revolving door” patient? This is from the perspective of the professionals who worked with “revolving door” patients. The perspective from the patient who is an “ex-revolving door” patient is described in the next chapter 9.

All the respondents covered two main areas, the impact that being a “revolving door” patient had on those patients’ health care, and the emotional impact of being repeatedly removed from practices. The impact on “revolving door” patients’ health will be reviewed at the end.

8.1.1 Quality of health care

Although a lot of effort was put into doing so, it was often difficult to keep medical records up to date with the patient’s frequent moves round practices. Hence the practices did not receive all the information about the patients’ medical history. An example of this is described below:

"He’s got a box of medical records... They don’t go out. The summaries we try and pass those around; but that’s when you tend to think, well, if they are not getting the full medical records then, they don’t know what’s happened in the past, and they can’t really make judgments and stuff like that. I mean there is no way you could put them out; it’s a huge box. And its not as if a GP is going to spend time and sit and go through it; as long as they have got the summary of the treatment that was being given in the last practice, and hopefully continue it. To know what medication they are on, that’s the main thing." PS2.

Some respondents felt that “revolving door” patients found it difficult to get to know how to use the successive practices services they revolved through:

"I would imagine that it makes it very confusing for them; and many of these patients are of limited intelligence and limited coping abilities, really. I think they often become quite confused about what is going on. It takes a while to get to know a practice, in my experience as a professional. It takes a while to work out who does what, what you are entitled to when you phone up; and this kind of stuff. For somebody who has a much more chaotic life it must be very hard. So I think from that point of view it alienates the service from them." GP1.

They felt that "revolving door" patients often fell through the net of screening programmes too, especially cervical screening. One GP respondent talked about his experience of "revolving door" patients often accessing unscheduled secondary care to seek help with problems and this often led to inappropriate (and expensive) responses by the health service. This reinforced the patients' help seeking in a similar way during the next experienced health problem:

"they just don't get their illnesses looked after in terms of chronic diseases and so on. So you may find they are accessing hi-tech care, emergencies; or even accessing low-tech care, in terms of emergencies in general practice; but everything is an emergency; their life is an emergency, life is chaotic." GP6.

Respondents were concerned that the effort put in by one clinician to treat a condition or refer to a specialist might not be followed up subsequently. Moreover, that "revolving door" patients may not have their chronic disease medicines reviewed, with each successive GP believing that the previous doctor had done so. "Revolving door" patients may have even run the risk of having medicines started without previous ones being removed; accumulating problems of unnecessary poly-pharmacy:

"Again you would think you know; if they are on repeat prescriptions; does anybody really look at that? Do they just join the next practice, and require a lot more? Should somebody be looking at whether that really is still necessary?" PS3

District nursing services could be accessed only through being registered with a GP, so removal from GP lists might affect delivery of this service. It

was thought that “revolving door” patients might not be referred or it may have taken longer for patients to be appropriately referred to secondary care and other services too. Moreover, if a “revolving door” patient was successfully linked in with secondary care, clinicians may not have been able to discuss their case with a GP who knows the patient as this Practitioner Services respondent pointed out:

"And again, even if someone is doing it very well, say a patient is attending secondary care; if they have repeatedly changed their GP, then it is difficult for secondary care to keep up with them. So you are not getting the relationship, of say, my GP being able to freely discuss me with a clinician in secondary care because they know me; and you are not getting that. There is no continuity." PS5.

There was a big focus on the doctor-patient relationship. The respondents felt that because patients move practices frequently, they are not able to build a doctor-patient relationship with GPs. Some of the GP respondents evidenced this by the nature of previous clinical entries in the GP notes. Linked to this was a concern that this lack of relationship would mean GPs would not take an interest in their care:

"Continuity of care isn't it? You are not going to get some[GPs] taking the overview; often it's just patching people up; giving them something of what they want; and getting rid of them. A quick summary! That is being unfair; some people will try to deal with them." GP2.

Additionally, the GP respondents had experience of having to put in a lot of effort to work through the issues that the patient's unrealistic demands and inappropriate behaviour brought into the consultations, to actually get to the point where they were able to deal with the patients' health needs:

"R: ...trying to get them to stick, to try and get a depth of relationship, such that the noise disappears and we can actually start to deal with some stuff.

I: What do you mean by that?

R: By the noise? As dysfunctional interactions with the wider team and the less than helpful expectations of the service that we are able to provide, yeah that's probably it.

I: How do you do that?

R: That takes time, that's again building up a relationship, and setting boundaries that are realistic, or trying to find ways that the patient thinks would be more helpful for them to access the service..." GP3.

8.1.2 Emotional impact

There was a strong sense of the professional respondents trying to make sense of consequences for a group of patients whom they struggled to understand. They could all see how it would affect them personally if they were repeatedly removed, but they varied in their views about how much this translated to "revolving door" patients:

"I think perhaps they have a preconceived idea that they are not really going to get the help that they are asking for. (pause) And that people are being quite obstructive and don't really understand them. They are probably right actually; (laughs) that people don't really understand where they are coming from. It is difficult for us to understand; we haven't really been there... So yes, they come in, in desperation; but at the same time probably thinking it is not going to help." GP1.

Respondents felt that "revolving door" patients fell into two groups. The first were patients for whom the experience of being repeatedly removed from GP lists would add to other negative life experiences and would further reduce their poor self esteem. The second which they thought were the majority, they felt, would be angry and have a strong sense of entitlement. This view is illustrated by this quote:

"A lot of them have an attitude that it's their right; and they are going to get it. I don't know whether they would really be affected by that, and think it was some stigma against them. A lot of them I think, it goes over their head, and they don't think of it that way. But I am sure some of them would feel that, that

wouldn't be necessary, and shouldn't have happened, and what's wrong with me; why can't I get a Doctor ? "PS3.

The impact they felt it had on the patients was to reduce trust, self esteem and add to already experienced stigma.

8.1.3 Effect on health

Respondents were reluctant to link the "revolving door" status of these patients with poor health. All felt that "revolving door" patients had poor health, else they would not be wishing to have their ongoing health needs met, but they felt that their status of being repeatedly removed from practice lists was only one small part of a constellation of problems. They felt more that that being repeatedly removed was more a symptom than a cause of complex underlying health and social difficulties.

8.2 Quantitative and qualitative analysis of the third and second "revolving door" patient cohorts

When investigating the relationship between the status of being a "revolving door" patient and its effect on the patients themselves it was not plausible to infer a causal link between being a "revolving door" patient, the characteristics described and the effect they may have on the patient. Data were also of insufficient number to make statistical inference, and it was difficult to find a comparable general practice group to consider carrying out a survival analysis.

8.3 Summary

The professional key informants' perspectives were that being a "revolving door" patient had impacts on the quality of care that patients received in general practice; due to information not being passed on, and issues to do with chronic disease, screening and medicines reviews. The perceived lack of doctor-patient relationship "revolving door" patients had with successive

GPs was important in this. It had an emotional impact too; for some adding to stigma, lack of trust and the other problems they already had and for others, to their anger and sense of entitlement. There was no perception that being a “revolving door” patient had a direct effect on patients’ health or health outcomes but the results presented in this chapter add further weight to the idea that the apparent demise of “revolving door” patients is to be welcomed.

8.4 Discussion

In the respondents’ discussion of the impact that being a “revolving door” patient had on the patient, they returned again to the core values of general practice, so often articulated throughout their accounts. Both the Practitioner Services and GP respondents had clear ideas of what the health service should offer patients and what the same service did not offer “revolving door” patients. “Continuity” was mentioned often and I am going to bring in a theoretical perspective on continuity to attempt to provide a framework for considering what the respondents described.

8.4.1 *Continuity*

In the previous chapter when I reviewed the literature on problem doctor-patient relationships relational (or personal) continuity of care fitted into the health care structural aspect of the clinical observational domain. Aspects of relational continuity were a key part of the discussion; simply defined as “an ongoing therapeutic relationship” (Haggerty, Reid, Freeman, Starfield, Adair, & McKendry, 2003). The lack of this relationship has come to be a central theme of this thesis and requires no further discussion at this point.

There are two other types that together describe the whole of the current conceptualisation of continuity.

Informational continuity is “the common thread linking care from one provider to the other and from one health care event to the other” and involves both aspects of the formal record of clinical information that is contained in patient records and the informal knowledge that clinicians hold about patients they know (Haggerty, Reid, Freeman, Starfield, Adair, & McKendry, 2003). A number of examples of breaches in this type of continuity were described by respondents; clinical notes not being available, chronic diseases not being reviewed, or medicines amended and appropriate links with secondary care delayed or unproductive. On the other hand Practitioner Services staff described occasionally that district nurses would phone Practitioner Services staff to ensure a patient was re-registered, discover where, and then discuss ongoing care with the patient’s new district nurse team.

Management continuity describes the integrated working that members of the health team do to look after the patient effectively, and over time. This is thought to provide consistency, and offer flexibility for the patient (Haggerty, Reid, Freeman, Starfield, Adair, & McKendry, 2003). Because so much relational and informational continuity were lacking for these patients this had a big impact on management continuity to the point where at times Practitioner Services staff coordinating the patient’s registration episodes, were the only positive evidence of this and the key NHS member of staff coordinating their care.

8.4.2 Psychological perspectives

There was much less certainty on the part of the respondents when they were considering the emotional impact that being a “revolving door” patient might have on the patients themselves. This may be because it was asking respondents about the inner life world of another person, in contrast with the more tangible description of what effect being a “revolving door” patient might have on their quality of care. However, as I described in chapter 6 I perceived that this was to do with the explanatory models that respondents used to think about “revolving door” patients; how much

“revolving door” patients fitted in with respondents’ biomedical models of understanding their presentations, and the degree of moral censure they attached to their behaviour.

Over the preceding two chapters I have focussed on theories that consider the social world (sociology) and interpersonal (doctor-patient relationships) perspectives or lens on “revolving door” patients. However coming from the general practice disciplinary perspective that I do, and hearing repeated examples of respondents trying too to understand the life world of “revolving door” patients, it is to considering two ways to approach the intra-psychic world of patients that I now turn. I will review “personality disorder” first of all, as this was a diagnostic label applied across all the data collected and one of the common themes from the problem doctor-patient relationship literature. I will then turn to consider adult attachment theory.

8.4.3 Personality disorder

Over the past twenty years the conceptual understanding and the treatment options for patients who might be considered to have a “personality disorder” diagnosis has received a lot of attention in psychology and psychiatry. The generally accepted view is that personality traits which “describe regularities or consistencies of actions, thoughts, feelings [which] are the basic unit of the study of personality” are stable across the life course and can be assessed with consistency. After much debate there is current consensus that all aspects of personality can be ascribed to 5 dimensions; the so-called “five factor model of personality (NEOAC);” “neuroticism versus stability”, “extraversion versus introversion”, “openness to experience versus conventionality”, “agreeableness versus antagonism” and “conscientiousness versus lack of self discipline”. Personality disorder correspondingly is defined as “enduring patterns of cognition, affectivity, interpersonal behaviour and impulse control that are culturally deviant, pervasive and inflexible and lead to distress or social impairment”.

Personality disorders are termed axis II disorders in the international classifications of psychiatric diagnosis; this is to distinguish the assessment of “traits”, which represent the patients’ normal psychological function; as distinct from assessment of “symptoms” (Axis I), which represent a disruption to the person’s normal psychological function. These distinctions are not quite clear cut, as in some clinical disorders (abnormal psychological function) patients take on “enduring characteristics” as a component of their illness.

Ten patterns or categories of disorder have been identified and are grouped into clusters where categories are likely to coexist. To be given a formal diagnosis a patient must meet a predetermined number of criteria within a category, but patients often meet the criteria for more than one category (but usually in one cluster). These are “cluster A: (odd, eccentric) paranoid, schizoid, schizotypal”; “cluster B: (dramatic, erratic) antisocial, borderline, histrionic, narcissistic”; “cluster C: (anxious, fearful) avoidant, dependent, obsessive-compulsive”.

However debate remains about these categories; partly because their empirical basis is not established, partly because there is such overlap between these and axis I disorder diagnoses, and partly because there is no current means of assessing or ascribing severity. Moreover to have a diagnosis of personality disorder label applied to a patient in its current conceptualisation only serves to explain behaviour and predict future patterns; it does not seek to understand why the behaviour is happening (Blackburn, 2006).

There has been a significant body of work too, seeking to understand why patients have a personality disorder. Current thinking is summarised as “the cumulative effect of a number of difficult life events that have reacted with underlying biological predispositions to create a way of interpreting and responding to other people that is self destructive and/or destructive to others” (Alwin, 2006). The important role that the theory of attachment plays in this will be considered later. However the expression of, and others

interpretation of these behaviours is socially bound. What is considered abnormal varies by the person's characteristics; gender, culture, and the context within which they live (Alwin, 2006).

So far what this brief review hopes to have achieved is that personality disorder provides us with a way of beginning to understand why some patients express behaviour that is difficult for others to understand and accept. However the motivation for writing the textbook that much of the content of this review draws on is also indicative of the place that current understanding of personality disorder has in clinical practice. Practitioners and researchers expert in personality disorder felt it necessary to produce a book for community mental health teams to set out current thinking and practice in order to persuade them to change their view of (and services for) patients with a personality disorder diagnosis. This lack of integration is only likely to be more pronounced in general practice and indeed a chapter in this book adds weight to this view, when considering patients with personality disorder in other health settings. They present the evidence that patients with a diagnosis of personality disorder have significant co-morbidity and high mortality. The authors make the link between personality disorder and the literature on frequent attenders and patients with somatisation. Unfortunately I think they fall into one of the pitfalls inherent in thinking about how to better care for patients with personality disorder, which is to recommend serious and in-depth attention to expert diagnosis and formulation as a starting point (Bennet & Kerr, 2006). It would take an enormous realignment of thinking (from a moral to a medical schema of thinking about personality disorder) and resource (to provide the expert psychology input working in general practice) across community health care services to bring that about.

Attempts to assess the role that personality disorder has in "difficult" patients in primary care were made in a very small study in the USA by Schafer and Nowlis (1998). They measured personality disorder diagnosis in twenty-one patients who had been identified as "difficult" by their primary care physicians but who had no previous personality disorder diagnosis. They

made a diagnosis in 7/21, noting this in 1/22 control patients (Schafer & Nowlis, 1998). This study was of insufficient quality to be included in the review of the problem doctor-patient relationship literature but is mentioned here to highlight that the role of personality disorder in this area has been considered in research settings. The status of a diagnosis of personality disorder being made by a subjective non formal assessment by a general practitioner (either knowing the patient for a long time or in the short time “revolving door” patients were known to practices) is un-researched and the consequences for targeting management or treatment interventions based on this is unknown.

However hope does lie in the recent development of treatments for personality disorder. There is accumulating evidence, although not sufficient as yet to compile a NICE guideline (UK wide clinical guideline on the topic) on management of personality disorder. Four current psychological theories underpin the psychological approach to treatment of personality disorder.

The first is a developmental framework concerned with the development of the sense of self and using conversational psychotherapy approaches. These encourage the patient to become sufficiently self reflective to be able to integrate traumatic memories and recreate their sense of self more positively and function better. This is seen as a long term therapy. The primary role of the therapist is while understanding (not enacting) the role relationship the patient brings to the therapy, they facilitate this change (Moorey et al., 2006a; Moorey et al., 2006b). Mentalisation Behaviour Therapy (MBT) is an example of a specific approach to treatment of patients with borderline personality disorder (Fonagy & Bateman, 2007).

The second is using cognitive therapy, usually over the long term to “address maladaptive patterns of thinking and behaviour” using the cognitive model of personality disorder. The therapist focuses on core beliefs (or schemas) that the patient holds about themselves and how this translates into behaviours and problems. While working through changing

these, issues of understanding what the patient's beliefs bring to the relationship, along with clear, consistent boundary setting is very important.

The third model is Cognitive Analytical Therapy (developed by Ryle (2002)) which uses both psychodynamic and personal construct models to co-produce a reformulation of the patients' problems in written form. This is a relatively short lived intervention.

The fourth, and one most commonly discussed in its specific role for borderline personality disorder is Dialectic Behaviour Therapy (DBT) developed by Linehan (1993). It uses cognitive models but focuses on the impact that emotional dys-regulation, learned in early childhood, has on cognitive processes and seeks to identify stimuli that trigger these. DBT takes a biopsychosocial approach to trigger identification and change. Research is ongoing on its use in different clinical settings (Moorey, Davidson, Evans, & Feigenbaum, 2006a; Moorey, Davidson, Evans, & Feigenbaum, 2006b).

There is also limited but accumulating evidence of a productive role that medication has to play in treating symptom clusters. Anti-depressants (especially serotonin specific re-uptake inhibitors (SSRIs) can help to regulate mood and reduce impulsivity, and anti-psychotics can help to reduce perceptual abnormalities and sometimes be used as an adjunct during mood regulation crises (Newton-Howes, 2006).

It may be that as evidence about effective treatments accumulates then a personality disorder diagnosis will move more firmly into the biomedical sphere. This may lead more patients and clinicians into having a better understanding of personality disorder, promote the skill set required to achieve a functional doctor-patient relationship with such patients, and eventually prompt more services and patients to seek treatment options. There was evidence of some awareness of these skills in the accounts of some of the GP respondents in the interviews as they made a link between complex difficult backgrounds and interpersonal difficulties. They also

explicitly worked within boundaries patients could cope with psychologically. A challenge for general practice in the future is to synthesise what is known and emerging in the personality disorder field, and take for its own, the relevant skills needed to work with these complex challenging patients.

8.4.4 Adult attachment

The literature is large and continues to expand as many different disciplines and fields integrate research and theory on adult attachment theory, for example in psychiatry (Fossati et al., 2003), and in psychotherapy (Lopez & Brennan, 2000). For the purposes of this thesis I will restrict my review to a brief description of adult attachment theory and then turn to the research and theoretical attention that has been paid to it in primary care.

Building on evolutionary theory and work on primates, John Bowlby in the 1960s identified the human behavioural tendencies for infants to seek safety and survival through their relationship with a primary care giver. Mary Ainsworth carried out empirical work with human infants and their mothers in the 1970s delineating the “Strange Situation” procedure which allowed a reliable rapid assessment of three attachment types. This was then further developed by Mary Main in the 1980s who added a fourth type, “disorganised” (Main, 1996). Research groups have then gone onto develop a number of attachment assessment tools for adults that are based on the four childhood categories (Ka, 2006), along with research that confirmed attachment style to be mostly stable into adulthood (Davila, Burge, & Hammen, 1997).

Attachment styles were sets of behaviours, formed in infancy, which were responses to interaction with their primary care giver. These sets of behaviours were maintained over the life course as a cognitive schema that “predicts the likely behaviour of others and self at the time of threat and then designates an appropriate behavioural action” and were considered as a trait characteristic (Hunter & Maunder, 2001). Most attachment styles

were thought to be adaptive, promoting psychological safety for the infant in response to the behaviour of their primary care giver, but often problematic if they persisted into adult relationships. There are a number of different ways to conceptualise attachment styles and a detailed discussion of the differences between the models is not required here, although it does give an indication that conceptual coherence is distant yet. Each seems to have their advantages and disadvantages. They do all agree that attachment style can be considered in two groups, secure and insecure (Hunter & Maunder, 2001). The groups are considered here with reference to the responses expected in the Adult Attachment Interview which to date has accumulated the most data as a robust form of assessment (Ka, 2006).

The first, and the secure category which described the majority of adults, (in low risk, i.e. non specific clinical or social settings) was “secure-autonomous” which corresponded to secure in infants (the majority too). A secure adult was able to give a coherent account of their attachment experiences, valued them, and was able to describe with some distance their positive and negative aspect. A secure adult tended to be autonomous and be comfortable with intimacy in his relationships.

The second category and the first of the insecure, was “dismissing”. A “dismissing” adult’s positive descriptions of his/her attachment relationships were unsupported by specific memories. Negative memories were described as having no effect on the adult. This corresponds with the “avoidant” category in infants whose early attachment experiences have required them to take themselves away from the harmful effects of their primary care giver’s behaviours. A dismissing adult was dismissive of attachment and was “counter- dependent”

The third category which was also insecure is “preoccupied”, adults remained preoccupied with their attachment experiences and exhibited strong negative emotions about it. This corresponded to “resistant-ambivalent” in infants. “Preoccupied” adults were preoccupied with relationships and exhibited high emotional reactivity.

The fourth category which was also insecure was “unresolved-disorientated” which corresponds to “disorganised-disorientated” in infants. Unresolved adults struggled to articulate what they thought about their attachment relationships and this may come across as bizarre behaviour. Moreover this attachment style was thought to represent an even more disordered attachment style than the first three described, the response was not adaptive and is usually triggered by unresolved trauma or loss (Ka, 2006).

Evidence is still accumulating about the relative contribution that the different attachment styles make to predictions about an adult developing some form of psychopathology, but there is firm evidence they do play a role. There has also been a small amount of research examining if the attachment style of the care provider is important; and it seems to be too (Dozier, Cue, & Barnett, 1994).

Attachment theory has been used in some disciplinary responses to developing treatments for psychiatric illness, for example in treatment of borderline personality disorder (Fonagy & Bateman, 2007), and for patients with medically unexplained symptoms (Taylor et al., 2000; Waller, Scheidt, & Hartmann, 2004).

Attachment in the doctor-patient relationship

People may activate their attachment style in significant relationships when they are under pressure (stress), whether that be through worry, or illness. Two papers have given attention to the role of attachment theory in the context of the doctor-patient relationship and they each describe different attachment models to the one I have just described.

Hunter and Maunder (2001) examined the role of attachment style on patients admitted to hospital for medical reasons. The model they chose represented attachment style along a continuum, which they found useful. Anxious was at one end and avoidant at the other, with secure in the middle. Disorganised (unresolved) could move rapidly between the two

poles. They emphasised the importance of “reflective functioning”, which they ascribe to Fonagy (Hunter & Maunder, 2001). This is another term of description for mentalisation (self-reflection) mentioned earlier when describing one of the evidence based therapies for borderline personality disorder (Fonagy & Bateman, 2007).

The second paper by Thompson and Ciechanowski (2003) reviewed the role of adult attachment style in doctor-patient relationships in the US primary care setting. They used the classification developed by Bartholomew and Horowitz (Thompson & Ciechanowski, 2003).

Both papers came to similar conclusions about how patients would present if the range of attachment styles were activated, I have opted to present the Hunter and Maunder paper predominantly with additions from the other if they add to the discussion.

Hunter and Maunder (2001) described a securely attached patient as giving an account of their illness in a coherent manner, able to describe their negative emotions in a way that did not threaten staff and able to seek help in a way that they would get it, the majority of patients.

They described an insecure avoidant attached patient as the “compulsively self reliant patient” who health teams found easy to care for because they seem self reliant, but this could become extreme, accounts of their illness could be incoherent (Hunter & Maunder, 2001) and they may reject what was seen as appropriate care angrily. Carers required to accept the level of independence the patient may need while paying attention that they would indeed receive the treatment they needed; being encouraged to turn up for appointments, possibly employing some flexibility with their scheduling, and encouraging concordance with medicines (Thompson & Ciechanowski, 2003).

“Insecure anxious” was the third category of patient in the paper by Hunter and Maunder; from their model by Hazan and Shaver. Insecure-preoccupied

may be similar but it was not clear from the literature how much overlap had been agreed. These patients were described as “compulsive care seekers,” “whose inner sense of inability drove them to depend on others but who invariably found the other’s help insufficient, leaving them with near constant anxiety and an unquenchable thirst for soothing.” Grove’s “dependent clingers” were invoked by the authors here too. These patients required clear and consistent boundaries, set in empathic interactions and care provided in such a way that the patient comes to understand they will receive care no matter what symptoms they present with. An example given was scheduling regular appointments that are not contingent on symptoms. Attention was required, and in such a way that the dependence was accepted, with an attempt to reframe the patient’s anxieties as manageable. The clinician was acting as the patient’s “regulator” of their emotions (Hunter & Maunder, 2001). Thompson and Ciechanowski added that these patients may also seek to inappropriately look after their doctor too (Thompson & Ciechanowski, 2003).

Hunter and Maunder postulated that it was possible with the appropriate staff input to provide a secure attachment base for patients who have these attachment patterns, such that they might be able to form a secure attachment relationship.

Finally patients with disorganised attachment styles are presented as often being experienced as very difficult to care for; they exhibited “help seeking behaviour often in an exaggerated or hypochondriacal manner but accompanied by an angry, dismissive attitude”. Seeking to understand the behaviour by understanding that the patient “though lonely and desperate for contact can’t bring himself or herself to trust it” was one strategy along with explicitly providing the same level of care that the team would do with any patient (Hunter & Maunder, 2001).

8.4.5 Personality disorder, attachment style and “revolving door” patients

Having a personality disorder diagnosis means that a patient has a pattern of thinking, relating, and behaving based on abnormal personality traits that interfere with his or her function in life. Having an insecure attachment style means that variably, and in response to a stressor, a patient will exhibit difficulty in thinking, relating and behaving with respect to a significant other. There is evidence of an increased incidence of insecure and disorganised attachment styles in patients with personality disorder and they share many aetiological factors (Alwin, 2006; Fonagy et al., 1996). There also remains enough categorical uncertainty in both fields to make distilling down the key messages and distinguishing between categories quite difficult and it would not be rigorous to consider applying diagnostic labels from either field to “revolving door” patients.

However there are two reasons why personality disorder and attachment theory are important for this study. Firstly, they provide two useful (and overlapping) means of understanding the inner worlds of some patients for whom if they have a personality disorder or unstable attachment pattern, the usual rules of the doctor-patient relationship do not apply. These patients have a different set of rules that govern their world view either due to their character traits (personality disorder) or their relationship style under stress (attachment disorder). They have minimal volition about these. Coming to an understanding about this in general practice may help to reduce moral censure, and help practices and GPs both manage and predict future behaviour. Furthermore evidence is continuing to accumulate about the interventions that will reduce symptoms and harm; although not yet in general practice settings (Moorey, Davidson, Evans, & Feigenbaum, 2006b).

8.5 Conclusions

Being a “revolving door” patient impacted on the quality of care that patients received in general practice in terms of relational, informational

and managerial continuity of care. It was noted that at times Practitioner Services administrative staff provided the sole management continuity for some “revolving door” patients. This status had an emotional impact too; for some adding to stigma, lack of trust and other problems they had, and for others, to their anger and sense of entitlement. There was no evidence that being a “revolving door” patient had a direct effect on patients’ health or health outcomes but the results presented in this chapter add further weight to the idea that the apparent demise of “revolving door” patients is to be welcomed.

Current thinking on personality disorder diagnoses and adult attachment theory are two useful ways to begin to understand the inner world of “revolving door” patients. Both of these provide robust explanations that help us to understand why for “revolving door” patients the usual rules of the doctor-patient relationship do not apply.

Understanding these theories better in general practice might also help GPs to promote more functional doctor-patient relationships and consider treatment interventions for patients.

The final results chapter 9 follows with the account of an interview with an “ex-revolving door” patient.

9. Results: an “ex-revolving door” patient’s account

This is my account of the one interview conducted with an “ex-revolving door” patient. Denis talked about his experiences of being removed from GP lists and his experience of health care. He talked about his life and his relationships with his son, his wife and his family.

9.1 “Revolving”

Denis described going around a lot of doctors and going “through hell with the lot of them”. He described going into “health centres that were supposed to help you” and not getting help, and without explanation. It was unclear when Denis started “revolving” but it seems not to have been with the family doctor he started with. He reports often being prescribed one week’s medication and then the next time told, “no”, that this could not be prescribed again. It was Denis’s perception that it was a GP who started him, and the blame lies with him, on dihydrocodeine (an opiate painkiller) and diazepam. Denis describes going in and telling the GP that he had back pain. Denis described a queue outside the surgery door as this GP was well known for prescribing whatever patients asked for. Denis described going round each doctor he was allocated to at least twice and there seems to have been a great number of them. He could name quite a few. There was a sense of rejection in what he said:

“I would see a doctor maybe the first time in the seven days, and not again until maybe the second time round again years later” (“revolving door” patient (RDP)1).

Denis felt the doctors were not honest with him;

“they would get me to go an’ see them at the practice; and then when I get there; they would suddenly have to go out on a house call- which was a lot of rubbish- I sat in practices and watched

them shouting patients, I sat and watched that; more that one time.” RDP1.

Denis felt he should have been treated with respect and like any other patient. At one point he even saw his lawyer to get advice about legal action.

Denis believed that the different doctors somehow passed on information about him that was incorrect. They thought he was a violent patient, but he was clear in his own mind that he was not. He remembers one verbal argument with a female GP during a house call but she did give him the prescription. Denis does not perceive himself as having a violent criminal record.

Denis described stopping “revolving” when he was allocated to his current GP about 15 years ago. Denis views his current GP as a bit more flexible, like sometimes when he is late, leaving his prescription with reception for him to pick up. His current GP prescribes methadone for him. Denis sees this as help, rather than just feeding his habit like what other doctors used to do. Denis feels you know where you are with his current GP, he thinks that is important, and he likes that. However he is not without criticism too. Denis is keen to come off methadone, he is ready too; and although his GP says he can come off it any time; he doesn't reduce his dose even though he asks him too.

9.2 Illness

Denis saw himself as being in poor health, having been in hospital fourteen times. He described having eczema, having had three heart attacks and pulmonary tuberculosis. He had taken overdoses of medicines and tried to kill himself twice by hanging. The second time was just after Denis's Dad died. His current health was poor and he had serious symptoms around the time of our interview.

Denis described himself as being naive about drugs, first seeing cocaine being used by his wife and one of her friends and not knowing what it was. At the time he was working and described distancing himself from this. He also described using heroin first at the age of 42, only when he was unable to get a prescription; his wife's sister introduced him to it. She and his wife knew he had five thousand pounds at the time and after 3-4 weeks it was all gone, spent between them on drugs.

It was difficult to work out the chronology of Denis's account, both during the interview when I probed to try and work out relationships between a range of events, and later when trying to analyse the interview. I got a sense that the happenings and consequences Denis described were frequently told stories, accounts that the patient held as the story of his life so far. When I tried to probe about details, not just timeframes and connections, but also the role he might play in what happened, Denis responded with another part of his life story. What he told, I did not always manage to see as having relevance to what I asked and the meaning of what he was saying often became apparent much later in the interview. This was different from the accounts of the professional key informants. They too of course told frequently told stories but they were able to reflect in the here and now, responding to requests to elaborate on the story they were telling, in a way that I understood at the time, and later during analysis.

9.3 Family

Here is one example when Denis moved from the account of his father's death to what later emerged to be an account of his mother's death.

"I: That must have been a really difficult thing to see, and be so involved in, and then suddenly for him to be gone.

R: I was really close to my dad since a wee baby right through. I have another four brothers and sisters; I was the wee boy because I was the youngest one. When that happened to my dad, I tried to kill; get rid of myself. Then, my mum worked, and he had a heart attack; round about my age as well; he had a

(incomprehensible); it wasn't that that killed him; it was cancer; but my mother; I was away working (incomprehensible) when that happened (pause). "RDP1

Here is an example of when I tried to get more information to help me make sense of time frames:

"I: What age were you when you started taking DF's? [dihydrocodeine] I am just trying to pin it all together; as doctors do!

R: I actually started getting people to... (incomprehensible) (stumbling words and then silence)

I: Don't worry...

R: GP practice and then I got scored off and went private, no he went private; staying away in (urban location).

I: Yea I don't know the (urban location) GP's that well really.

R: Everybody knew this doctor.

I: So he was well known?

R: Aye, for giving prescriptions out!" RDP1.

The account contained elements that could be seen as contradictory too, such as in the above description of the GP who started Denis on dihydrocodeine; Denis blames him for starting him on dihydrocodeine but at the same time describes purposively going to see this GP because he knew he would prescribe him what he asked for.

The other aspects of Denis's account that stood out were the circumstances when he did, and did not claim responsibility for what happened to him. Denis claimed responsibility in three areas; in the current success of bringing up his son, in his current abstinence from street drugs, and in the care he provided for his father before he died. For example he described the good care he provided to his son; he was neat and tidy, he played football and went swimming and how impressed social workers and other

people that he managed to be a good and caring father. However in every other area of his life he described, in his experience as a patient, in his previous experiences as an addict, in his relationship with his wife, and his relationship with his wider family, responsibility for what happened always lay with others. Denis described in detail the difficulties his wife caused and still causes for him and his son; neglect, drug taking (including in the presence of their son), being unfaithful repeatedly (including with someone she is related too), always being interested in using his money, stealing from him, lying about him to the authorities and even making complaints to the council about him in an effort to get him evicted from his current tenancy (where he was happy). Denis described lots of other difficulties with his family including not being told that his mother had died and not being invited to the funeral. He described one sister in particular who caused a lot of problems for him and who was also a “revolving door” patient.

9.4 Responsibility

Missing from Denis’s account was any negative role he may have played in these relationships. A quote which illustrates this describes a time when his brother had moved in with him, had come off alcohol and then one Saturday night went out drinking. He never came back, having carried out some robberies and then been seriously injured. He ended up in full time care. Denis found out about this some months later. He kept his brother’s benefits for about a year.

“..this is the first time I gave him the key of the door, because I wasn’t, want to, I would lock him in, so as he wouldn’t take a drink. So the first day he got the key of the door, then he was coming up the road, stayed to, all night, at a proper thing [night out]. Sunday morning he was coming up the road to get money- I was giving him his giro [benefits] money- and that, ma [my] you know, off my money. And then he chucked it right up the road[threw all caution to the winds]. And he got caught with another boy that done it, his nephew I think it was; they stole everything. And then they did a home in (urban town), a home he worked in too; because he worked for (home support) people. But he ended up deaf and dumb and all that. So I didn’t know until 2

month later where he was; I thought he had went back to his wife. So I left it at that. I wasn't; he was in a home; he never made it up to get his money or nothing. And I still kept it there; I still kept it; his giro, for over a year." RDP1.

Denis could not find explanations for why he was previously repeatedly removed from practices despite me asking quite openly on a couple of occasions as illustrated here:

I: And what were the doctors like with you generally?

R: I think their attitude was terrible.

I: Can you expand on that a wee bit and tell me what was terrible about that?

R: "Oh not you again; em, you need to go and get yourself a new doctor; you are scored off this practice as from today" then "look; away you go" that kind of talk. I think it is ridiculous.

I: How did that make you feel?

I: Terrible! I would say "I should be getting treated like anybody else that is a patient in this practice; the same as I am worth"; say; "I am just like any other patient in here and should be treated the same and a bit of respect like I am doing with you" He said "don't talk to me like that" and I said "aye that is the way I talk and if you don't like it there is nothing I can do about that; I just don't like your attitude". I can not help the way I talk.

R: What do you think would give them trouble though with the way you talk?

I: I don't know

R: I am not finding any trouble with the way you are talking today

I: I don't know, I just don't know, I would like to know that; my face did not fit.

I: So what changed for you? What stopped, what changed all that hell as you described?

R: I don't, I don't know, obviously found a doctor to take me the way that they finally accepted- Dr Name, 15 years I have been way him-that is a long time me having a doctor! It is it is a long time; I have not messed him about; I have been late a couple of times; but surely you are allowed that? That is not messing about because you have good reason for that." RDP1.

But there does seem to be a type of admission at the end that Denis sees his successful relationship with his GP as different from the previous ones.

9.5 Trouble

Denis described numerous serious and negative happenings, in addition to his "revolving door" patient experiences and his complex and difficult family relationships; including suicide attempts, being recurrently robbed, being homeless, and being held hostage and physically tortured. Many of these in some way were connected in Denis's account to his wife's behaviour. This quote described one such incident:

"She [his wife] even set me up for a robbery and got me robbed and all that. And the wean got a knife to his throat; in front of his own mother [his wife] and she even left the ones that done it[did not retaliate]. I seen a solicitor about it; I didn't even get the police. I should have, after doing that to her own wean, and doing it to me; I got tortured and burnt under ma ouksters [armpits] with lighters and everything." RDP1.

9.6 Stigma

Denis repeatedly said that his face doesn't fit. Finally when I asked him what he thought needed to be done differently to stop patients being "revolving door" he said this:

"Take them as a person; treat them like a human being. Don't treat them as a druggie, or a junkie, or what ever they call us. You know even people on methadone are being treated; I mean me and all, personally; I feel as if I am treated like a second class to everybody else sitting in that chemist [when waiting for his methadone]." RDP1.

9.7 Chaos narrative

A quote from the sociologist Arthur W Frank began this thesis. It is to his work on narrative that I turn to, to help make sense of Denis's account. Frank claims that there are three types of narratives that patients tell of their illnesses and lives; "restitution narrative" (things will work out), "quest narrative" (illness is a journey and this journey in itself brings gains) and "chaos narrative" (the person is so disrupted by illness that nothing makes sense).

Chaos narratives are "stories that cannot be told", so once a person is able to start telling it they have gained some distance from the chaos, a space has been created in which they are able to make sense of their lives and what is going on. But this often means that to the listener, stories are disjointed and do not make sense. The teller is managing to make sense of portions of what happened and get them out but not create a coherent whole; they may never be able to.

Frank started this work when he developed cancer, and after having been a professional who had tried and failed to gather illness narratives, it was when he became ill himself and started writing about it, that his work gathered pace. Others wrote to him and he started to examine writings on illness. Much of the foundation of his work is about the experience of pain and suffering but later these move onto to consider people who may have complex lives and complex difficulties, often including the experience of poverty. Frank argues that post modern medicine does not cope with chaos narratives; medicine likes to be able to make sense and explain all things. It deals with people for whom lots of terrible things happen to, by making sense of them in a biomedical framework. Patients have labels like "depression" given to them, for example, so that the clinician can cope with what they are witnessing. Frank states that we have to learn to listen. We have to learn that some patients will never move on from a chaos narrative; we have to accept that, and listen (Frank, 1995). Had I listened to Denis's

account? I returned again to the interview and read carefully again what I said and when. I realised I had tried to pick up on the positive, the coherent in Denis's narrative-even though this was a research interview and not a clinical encounter-and rewarded this with praise as illustrated by this quote:

"R: I am glad I am away from it; [his marriage]don't get me wrong it did take me a while; I mean I was with her for thirteen years, just over that. We did have a good life; then she asked me to get back with her a couple of month ago there- no way man!

I: Sounds like setting your health aside you know you live in a quiet place; your son is at school and....

R: She visited a couple of month ago; or she was up for money. She didn't want to see the wean [their son] because when she came in, she sat and blethered [chatted] for a minute, then she lay down there. And I said; 'don't tell me- you haven't changed a bit- I can see you haven't changed a bit; lying down; shutting your eyes; and talking about money as usual!" RDP1.

9.8 Discussion

So Denis's GP when he recruited him on my behalf recognised that he would tell his story, and he did. This is a chaos narrative that Denis is beginning to be able to tell. Where does his account fit in with the other stories? This thesis is my story; my attempt to pull together data which are stories with a particular language and lots of small pieces of other people's stories of theories and their data. Can I construct some coherence from this chaos narrative?

Contained in Denis's account was evidence that he felt stigmatised by being repeatedly removed from practices, and intertwined for him, by being drug dependent. This was an experience that continued for him, as he attended his chemist for supervised methadone treatment.

Denis fitted one of the patient scripts that were activated in the "revolving door" patient cohort, substance misuse combined psychiatric illness. The

ethics of conducting a research study prevented me from finding out if he was actually contained in the cohort.

What I concluded from the interview was that Denis was male, in his 40's and had a history of drug dependency, self harm and rather undefined (in a biomedical model sense) current physical health problems. He came from a deprived background and struggled in his relationships. He had also been to prison. In his account was the evidence that he sought medication from successive GPs who thought this unreasonable. It was the offer of, and the stability of treatment, that enabled him to establish a positive doctor-patient relationship with his current GP. He knew this GP well and he felt secure, although was not entirely uncritical of the care he provided.

9.9 Conclusions

This single account from an “ex-revolving door” patient adds further vivid depth to the results presented in previous chapter. I was unable to find evidence that contradicted or detracted that already presented.

The concluding chapter reviews the main findings of the thesis, the conduct of the study and makes recommendations for the future.

10. Conclusions

10.1 Discussion

10.1.1 Reaching a definition of “revolving door” patients

A door that neither closes nor opens but moves round and round is an apt metaphor for the contexts described in the “revolving door” literature across many fields. There was an implicit sense that its use was intentionally pejorative; being about undesired states that are not

successfully resolved. “Revolving door” patients were not examined in the single episode patient removal research conducted in the late 1990’s and mid 2000’s, however scrutiny of the research revealed evidence of their existence in the form of deviant cases that have been excluded from the statistical analysis (O’Reilly, Steele, Merriman, Gilliland, & Brown, 1998b), in a recommendation in a research report to the UK government, (Munro, Sampson, Pickin, & Nicholl, 2002); and in a description in a qualitative study of patient perspectives on removal from GP lists (Stokes, Dixon-Woods, Windridge, & McKinley, 2003).

After exploring three numerical definitions when attempting to answer the first research question, what is the definition of a “revolving door” patient in Scotland, the final definition was a patient who was removed 4 or more times from GP lists in 6 years. This definition acknowledged that it was the status of being repeatedly removed from GP lists that set these patients apart from the usual general practice population.

The data from the professional key informant interviews suggests that there were external influences in the production of “revolving door” patients too. These were the geography of the area that practices were located in, the history of regulations governing removals, the amounts that Health Boards were willing to intervene to support patients who were being repeatedly removed, and the GP appointment system.

10.1.2 The apparent disappearance of “revolving door” patients

The CHI data on repeat removals from GP lists and the accounts of the professional key informants suggests that there was a dramatic decline in the number of “revolving door” patients in Scotland during the time frame of the study. According to the informants an early important factor was the development of treatments, and improvements in the delivery of services

for problem drug users along with pressure from a number of professional bodies for GPs to change removal behaviour. What they felt finally brought about their almost complete decline as the study concluded, was the positive, ethical, regulatory, and financial climate of the 2004 nGMS GP contract. Trends in the data on all patient removals would support this view.

I chose this topic of research from the perspective of a clinician who thought that the presence of “revolving door” patients in general practice was undesirable. That they have reduced so dramatically in number is therefore a welcome development. However I remain cautious in my optimism about this. This study described numerous influences that had effects on the NHS and general practice, and future influences may arise to undermine this definite progress. This study was undertaken in the Scottish NHS when at the time of writing sweeping changes to the NHS in England are being debated. Of particular concern are the proposed removal of geographical boundaries to GP practices in England (Department of Health, 2010). The effect this might have on cream-skimming patient populations to exclude complex patients like “revolving door” patients is unknown.

This reduction in numbers reflects the findings in the paper by Geller (1992) that was a historical analysis of “revolving door” patients in psychiatric hospitals. It demonstrated that the difference in prevalence over time was about the ways in which psychiatric services were configured and not something intrinsic to the characteristics of the patients (Geller, 1992).

However there remained parts of the story which were unexplained. What was it about the case of “revolving door” patients that allowed successive GPs to suspend the core values of general practice and remove them from their lists?

The rest of the study explored this by answering the remaining three research questions; what are the characteristics of “revolving door” patients in Scotland, what does their existence mean for the NHS, and what is the

impact of being a “revolving door” patient from the perspectives of patients themselves?

10.1.3 Characteristics of “revolving door” patients

According to the professional key informants “revolving door” patients had three necessary characteristics; they had unreasonable expectations of what the NHS had to offer, they exhibited inappropriate behaviour, and they had unmet health needs.

Problem substance use and psychiatric health problems were important but there was a mismatch between the importance of alcohol dependency in the key informant interviews and the prominence of alcohol in both the quantitative and qualitative analyses of the “revolving door” patient cohorts. This may be because problem alcohol use was not the dominant presenting problem that was recalled about “revolving door” patients because patients exhibited less problematic behaviour relating to alcohol dependence. It may also have been because understanding of alcohol dependence was located more within a medical schema of understanding compared to problem drug use.

From the quantitative analysis of the third cohort, “revolving door” patients were more likely to be male, they were younger, mostly unmarried, and were from predominantly deprived areas in the central belt of Scotland. The majority of patients had evidence of contact with secondary care. In this and the qualitative analysis of the second cohort substance misuse and psychiatric illness including self harm was a predominant component of that contact, along with physical illnesses. Injury and violence were apparent too, and for some patients there was evidence of prison or court contact.

10.1.4 Relationship career of the “revolving door” patient

An important distinguishing feature of a patient who became “revolving door” is that they had a succession of doctor-patient relationships. Stokes (2004) coined the phrase of the doctor-patient relationship “career”

(Stokes, Dixon-Woods, & McKinley, 2004). I shall use that concept to describe the relationship career of “revolving door” patients. This synthesises in a narrative form some key results from all the data in the study. The narrative describes the influences that led to “revolving door” patients being produced, the impact “revolving door” patients had on the NHS, and the impact that being a “revolving door” patient had on “revolving door” patients themselves.

From the professional key informant interviews data I understood that patients may have started off having an established relationship with their GP either directly, or via the GP knowing their family. When for a range of possible reasons-physical, mental, addiction or bureaucratic- the patient had health needs to be met, they begin interacting with the practice and the problems began. The degree of tolerance that the GP or practice had towards the patient, influenced the significance of a trigger episode, that would lead to their removal. GPs who were tuned into more complex patients and who had skills to work with them had higher tolerance; but stress and time pressure had a negative effect. If the patient spread their difficult interactions across health professionals this might help too. There was an important theoretical insight that I felt underpinned this narrative. It drew on the literature about “good and bad patients” and “doctors and dirty work” (May & Kelly, 1982) (Kelly & May, 1982) (Emerson & Pollner, 1976) (Strong, 1980) and will be discussed further shortly. This was the role that GPs beliefs about what constituted the legitimate work of general practice had, and how those beliefs fitted with the patient’s health needs and behaviour.

The respondents described when the tipping point was reached; either with a number of small episodes of discord over expectations or behaviour, or one large episode about these, the patient would be removed and invariably would need to be allocated. This brought its own enacted stigma status which caused the next practice to be wary. The next practice would not know the patient and the GP’s tolerance level would be influenced as before;, but start off reduced.

It was perceived as a difficult experience for the successive GPs and practices the patient revolved through too. The relationship was difficult, the patient generated a lot of work, they frustrated their efforts, they made the professional feel insufficiently skilled to help them, and interacting with them took a significant emotional toll. Drawing on the literature on continuity of care (Haggerty, Reid, Freeman, Starfield, Adair, & McKendry, 2003), all of this meant the “revolving door” patients’ lacked relationship continuity and there were a number of ways in which they experienced informational discontinuity too. For some “revolving door” patients Practitioner Services staff who administered their frequent allocations were their only management continuity at times. In conclusion “revolving door” patients may have an established doctor-patient relationship before they start to “revolve” and they may re-establish one when they stop, but they do not have for much of their relationship career.

There was some evidence that the status of being a “revolving door” patient are associated with additional costs to the NHS in addition to the interpersonal difficulties and administrative burden described in the professional key informant interviews. There was a statistical association between being removed from a practice list and the patient having a subsequent hospital admission; and one between being registered with a new practice and the patient having a new treatment episode for substance misuse recorded on the SDMD.

The professional key informants felt that this relationship career had an emotional impact on “revolving door” patients too. For some they felt this added to stigma, lack of trust and other problems they had, and for others, to their anger and sense of entitlement.

It was not possible in this study to determine whether the status of being a “revolving door” patient had a direct effect on patients’ health or health outcomes.

Denis's account, that of the single "ex-revolving door" patient resonates with the findings described in this narrative of the "revolving door" patient's doctor-patient relationship career. The rest of the discussion that follows hopes to illuminate further what was at work during the years he was "revolving door".

10.1.5 The central role of legitimacy

Following a review of the literature on "good and bad" patients and doctors and "dirty work" (Emerson & Pollner, 1976; Kelly & May, 1982; May & Kelly, 1982; Strong, 1980) I concluded that "revolving door" patients challenge the legitimacy of the GPs work. This is because these patients commonly had clinical problems that attracted moral censure to varying degrees. This depended on where the GPs' beliefs about drug dependency, alcohol dependency and psychiatric illness lay. These were clinical conditions that varied in their transition from a moral to a medical schema of understanding. By having unreasonable expectations of care, or exhibiting inappropriate behaviour, patients also threatened the normal doctor-patient relationship. This brought GP moral censure into the picture and allowed GPs to suspend their core values and break the doctor-patient relationship by removing the patient from their list.

10.1.6 Problem doctor-patient relationships

There were two reasons to focus on the doctor-patient relationship in the thesis. The first was because it formed a lot of the focus of the professional key informants' narrative about "revolving door" patients. The second was being mindful of the warning given by Kelly and May (1982) following their review of the "good and bad patient" literature (Kelly & May, 1982). They cautioned against focussing solely on the expressed negative attributes of patients in the discourse as this was a narrow structuralist perspective. I bore this in mind during my review of the problem doctor-patient relationship literature. Some papers sought only to categorise patients

(Klein, Njaman, Kohrman, & Munro, 1982; McDonald & O'Dowd, 1991) but many recognised that the doctor's response to the patient was just as important (Mathers, Jones, & Hannay, 1995; Schwenk & Romano, 1992; Steinmetz & Tabenkin, 2001). This determined not only how the health service responded but also influenced how patients behaved. A seminal paper by Groves (1978) used a psycho-analytical perspective focussing on patients which influenced a number of subsequent papers in this field and a later paper on adult attachment styles in health care setting (Hunter & Maunder, 2001).

There were similarities between the patients described in the problem doctor-patient literature and the "revolving door" patients described in this study. Patients were small in number but stood out for negative reasons and had a high emotional toll on the professionals who encountered them. My conclusion from the analysis of this literature was what all the patients or patients in the doctor-patient relationships had in common was that they challenged the legitimacy of the doctor's role. This was for the same two reasons as for the "revolving door" patients, because their problems could not be fitted into a biomedical disease model (eg patients with medically unexplained symptoms) or there was something about their interpersonal interaction that meant the doctor-patient relationship was difficult (eg persistent frequent attenders). There was much overlap between the suggestions made for how to manage problem doctor-patient relationships in this literature. Some of the strategies were reported in this study by the professional key informants. These included the use of boundary strategies (see appendix 18) and the function of the specialist general practice for challenging patients.

The patients who were included in this study are either no longer "revolving" or are doing so at a much slower rate. However the analysis of data presented here, drawing on the literature on problem doctor patient relationships presented above, allows a rare window with useful insights into what is at work in all problem doctor patient relationships in general practice

10.1.7 Personality disorder, attachment style and the unwritten rules of the doctor-patient relationship

The GP respondents held the view that the majority of “revolving door” patients had a personality disorder. However this was not reflected in the proportion of patients who had a definite personality disorder diagnosis in the analysis of “revolving door” patient cohorts. There were three plausible explanations for this. The first was that the cohort captured many of the patients with problem drug use who later stopped “revolving” due to changes in drug treatment services. The second was that patients had not had the opportunity to have, or had avoided formal assessment for personality disorder. This may have been because, assessment services were not available, or because patients and clinicians (in primary and secondary care) may have been reluctant to broach the issue. A third possible factor was that GPs may have used the diagnostic label as an explanatory model for describing why they viewed patient’s interaction as difficult and over estimated the role that personality disorder may have in the case of “revolving door” patients. However taking these factors into account, the prevalence of definite personality disorder diagnoses reported in the quantitative analysis of the second cohort and the qualitative analysis of the third cohort of “revolving door” patients is higher than the usual general population prevalence (Bennet & Kerr, 2006).

From the literature on the topic, having a personality disorder diagnosis means that a patient has a pattern of thinking, relating, and behaving based on abnormal personality traits that interfere with his or her function in life (Blackburn, 2006). Having an insecure attachment style means that in response to a stressor a patient will exhibit difficulty in thinking, relating and behaving with respect to significant relationships (Hunter & Maunder, 2001).

One of the assumptions reported in the literature on single episode patient removals was that removal from a GP list was an educational strategy that taught patients to change their behaviour, thereby learning about the

unwritten rules of the doctor-patient relationship. The data from the professional key informant interviews suggest the “revolving door” patients they were discussing did not learn to change their behaviour (because they were successively removed) and the same sets of patients expectations and behaviours were replicated with each practice. There was also no evidence in the key informant interviews that the reason for the dramatic reduction in the number of “revolving door” patients over the course of the study was that patients had changed, and this was reinforced by the descriptions of the patients who had stopped “revolving”.

Another assumption from the single patient removal literature was that patients understood the unwritten rules of the doctor-patient relationship. I have suggested that current theories about personality disorder and adult attachment are important in how we might think about “revolving door” patients; using this insight, we know that patients with these diagnoses function differently in their thinking, relationships and behaviour. Even more importantly they have minimal volitional control over their thoughts, relationships and behaviours (Blackburn, 2006). Hence I theorise that patients who persist in having unreasonable expectations of what the NHS had to offer, persist in exhibiting inappropriate behaviour, and continue to seek NHS care for their unmet health needs are not going to change the way they conduct their relationship with their GP. Patients with these diagnoses simply do not have the same understanding about how relationships function and so cannot adhere to the unwritten rules of the doctor-patient relationship.

However, for the “ex-revolving door” patients, those who still revolve slowly the challenge remains. This is the difficult work of utilising productive strategies to promote a positive doctor-patient relationship such that the “background noise” (GP3) of difficult interactions can go away and patients can be the recipients of good quality general practice care that all patients deserve. There is potential for the current thinking on working with patients with personality disorder and insecure attachment style (Moorey,

Davidson, Evans, & Feigenbaum, 2006a; Newton-Howes, 2006) to inform how professionals might manage in difficult doctor patient relationships.

10.2 Strengths of the study

10.2.1 Using mixed methods

The main strength of this study was that it used mixed methods to answer the research questions, bringing different types of knowledge about the topic into the frame for analysis and dialectical comparison. This helped to contextualise data, direct data collection and highlight strengths and weaknesses. For example when seeking to make sense of the complex data available about hospital admissions for the “revolving door” patient cohort quantitatively, the qualitative analysis highlighted the difficulty of identifying data on physical consequences of problem drug use from single ICD diagnostic codes. This may have led to the under-reporting of prevalence of admissions due to problem drug use problems. It took the construction of the patient profiles and the integration of the information about each admission to be qualitatively analysed for this important pattern to emerge. The apparent disappearance of “revolving door” patients and what this might add to the theoretical understanding of the issue might also have been missed if this study had relied on single quantitative methods (not seeking patient perspectives), or qualitative ones (not examining routine data). Careful attention had to be paid at each step of the research to ensure that the process of data collection and analysis kept to the epistemological boundaries of each method used.

This study sought to cross some of the usual boundaries of health care research by defining the patient group by a complex activity within the health service rather than by a single clinical diagnosis or other attribute of the patient. It also attempted to draw on theoretical perspectives that crossed disciplines using several lenses with different focuses. By using this multidisciplinary approach the study sought to represent the complexity of the social reality that was sampled and enrich the findings of the study.

10.2.2 Reflexivity across the methods

Because this was a mixed methods study with the dominant methodology being interpretivist and qualitative I applied the same level of reflexivity to each method used. This meant that I scrutinised the meaning attached to each portion of data and my interaction with it. The particular stance I employed with the linked removal data was highlighted in the quantitative work carried out in collaboration with the expert statistician. I had a particular operational knowledge of the data because firstly it is a representation of the data I use in my professional clinical work and secondly because I had undertaken the qualitative analysis of the data. Because I, and then the working relationship I had with the statistician made this explicit, it allowed me to more rigorously consider what it was acceptable to analyse, investigate and report in the data. I also accept that a different clinician and statistician might analyse, investigate and report different aspects of the data. This is rarely acknowledged in the reporting of quantitative data.

Undertaking the qualitative analysis of the data was a special case. I attempted to use explicitly, almost in an embodied sense, two components of my identity. One was my GP one, as a type of respondent in the study and the second my researcher one, as the arbiter of reflexivity in it. I criticised my biomedical clinical knowledge, my general practice expertise of working with complex patients, and my own schema of understanding between what is medical and moral.

By invoking “patient scripts” to describe the characteristics of a sample of the “revolving door” patients, this technique explicitly drew on my schematic knowledge as a general practitioner to characterise the patients. This necessarily was a subjective assessment but it had some internal validity as what it sought to do was provide a description of general practice patients. It drew on years of experience of working with complex patients in general practice using the deductive skills that doctors use to synthesise and integrate clinical knowledge about patients. But no doubt, and I kept an

awareness of this at the front of my mind, that I too was using the complex interaction of moral and medical schemata that imbue physical, mental and addiction problems in clinical practice. Bearing that in mind, I make no claims that they are categories of patients, only an attempt to get underneath the data in an explicit way that investigates broad themes and issues.

10.3 Limitations of the study

10.3.1 Poor quality of the CHI data

A limitation of the study was the poor quality of the patient removal data. All the options for imputing the data had some drawbacks, so none of the cohorts could claim to be the whole cohort of patients removed from 1999 to 2005. The implications of choosing a discrete time frame of 1999 to 2005, which was the best available data at the time the study was conducted, was that patients who were just beginning to revolve prior to or after the cut-off dates would have been excluded.

10.3.2 Using routine NHS data to describe complex patients

The limitations of using routine NHS data to attempt to describe patients overall health morbidity became apparent as this study progressed. Expert statistical input helped to interrogate the data but I concluded that much more resource in terms of focus, expertise and time would have been required to provide sufficient quantitative interrogation of the data for these complex patients.

10.3.3 Patient recruitment

There were several factors that I thought were important when reviewing the difficulties encountered in recruiting current and “ex-revolving door” patients. Most obviously current “revolving door” patients who were previously small in number during the study recruitment interval, did not come into the registration system. Because I had put effort into establishing a positive research relationship with Practitioner Services staff in the three

registration offices and involved them at all stages of planning, I was confident they had made stringent attempts to recruit patients. This was the first time they had been involved in a research study and it was exploring an issue that they saw as important to them and the nature of the correspondence with them indicated this to me.

I targeted recruitment of “ex-revolving door” patients by selecting geographical areas where they were previously more prevalent. Where possible I approached GPs with whom I had a professional relationship. I anticipated this might mean they would be more likely to recruit patients on my behalf. In practice the GPs who were able to identify patients, were all in practices that were involved in undergraduate medical education. However they were also GPs who were interested in the research topic and who expressed an interest in the challenges of establishing effective relationships with “revolving door” patients. They also seemed to be sensitised to the registration status of some of their patients and viewed trying to stop patients moving around practices as part of the challenge of their work.

Those GPs who tried to recruit patients on my behalf and who made contact with me to let me know they had not identified patients, had all had to rely on practice meeting discussions or reviewing notes. Some reported they did not have any “ex-revolving door” patients and some stated it was too time consuming to look back through thick sets of case notes and identify patients. It may be that these practices did not have any “ex-revolving door” patients on their lists or it may be previous registration status was not a part of the “patient scripts” they used when thinking about patients’ issues and needs. This may be because they had rarely encountered them.

However from the experience of the recruitment attempts that were carried out there were other recruitment issues that arose from the study design. Caldicott guardian permission meant that I was only able to recruit “revolving door” patients prospectively as they came back in to Practitioner Services to be allocated a new practice. If Practitioner Services staff had

been able to recruit “ex-revolving door” patients on my behalf then recruitment may have improved.

An important aspect of the recruitment process for the one patient that was recruited was trust. He had been approached by a professional that he had a positive relationship with and agreed to take part in the study with the assurance that I was trustworthy. Practitioner Services staff reported having this trust relationship with some “ex-revolving door” patients and also the quickly dependent nature of contacts with some others that they thought would be replicated in the research setting.

A conclusion of this study is that patients who have been repeatedly removed from GP lists tend to struggle in their relationships generally and that considering this from a personality disorder and attachment theory perspective therefore lets us understand the particular ways this might lead patients to be in relationships, the research relationship being no different from this. For me this adds a new dimension to the phrase that is often stated when discussing patient groups in health service (and other discipline) research; “difficult-to-recruit patient groups”. The parameters of recruitment process for this study were shaped by considerations of protecting patient confidentiality. Assumptions were made that patient information sheets, polite letters and audio recordings were sufficient information to let a patient decide whether they wish to take part or not. But based on this research study experience, for patients who may struggle in their relationships, trusting the researcher was of even more importance.

Trust of course is important in any research study where participants are involved. I put forward the idea though, that in research settings where aspects of low health service engagement are being explored (whether that be with services, or treatments) then distinct attention should be paid to these theoretical areas to shape study design. This might include explicitly identifying a trusted person and involving them in recruitment by allowing them to give information and promote trust in the research.

This study also highlighted that for some patients their circumstances and level of stability changed frequently too, so a study design that took this into account would be desirable.

10.4 Generalisability

This study which draws on qualitative and quantitative data which inform each other and integrates the results in a dialectical manner seeks to achieve analytical generalisability (Morse, 2010). That is by drawing on literature from relevant topics the results from this study can be compared with these, and inferences made about the general topic of “revolving door” patients in general practice and problem doctor-patient relationships.

10.5 Recommendations for professional practice

By drawing together the research conducted and theoretical areas explored in this thesis I make the following recommendations for general practice and service planners:

1. The analysis of the professional key informant interviews and the routine data on patient removals suggests that defining a “revolving door” patient as one who is removed 4 or more times from GP lists in 6 years would be a good starting point from which to conceptualise the problem when considering future NHS responses to patients who may be repeatedly removed from GP lists. This sufficiently distinguishes between “revolving door” patients and the usual general practice population taking the influences described in this study into account.
2. Based on the analysis of data in the study and drawing on the literature on personality disorder and adult attachment (Blackburn, 2006) (Hunter & Maunder, 2001) I suggest that , GPs and NHS planners may find it useful to conceptualise “revolving door” patients and patients who are

at risk of becoming so as having difficulty forming and maintaining relationships. .

3. That the strategies for promoting better doctor-patient relationships contained in the problem doctor-patient relationship literature (Balint, Courtenay, Elder, Hull, & Julian, 1993; Groves J, 1978; Mathers & Gask, 1995; McDonald & O'Dowd, 1991) and reported by some respondents in this study should be revisited by clinicians trying to enhance their advanced consultation skills, as these strategies are relevant for use with all patients who challenge the legitimacy of the doctors' role.
4. As a result of drawing together literature from a number of fields I found that the implications of the current theoretical understanding of personality disorder and adult attachment theory adds weight to strategies used in the problem doctor-patient relationship literature. Attempts should be made to integrate these knowledge areas into general practice specialty training and continuing professional development for GPs so that GPs will be better equipped to work with such patients.

10.6 Recommendations for further research

The following areas should be considered for further research:

1. Having utilised the sensitising concept of "patient scripts" in this grounded theory, mixed methods, study this novel way of utilising how doctors conceptualise their patients should be further explored in a research setting. This may be of particular use in research with complex patients.
2. The experience of conducting this study was that using routine NHS data to attempt to describe or measure morbidity in patients with

complex health problems proved difficult. How better to do so should form further work in this area.

3. Another experience of conducting this study was the central importance of fostering trust with potential research participants who might be considered to be “hard to reach”. Further research paying attention to this might help research in primary care with complex patients better flourish.
4. An important theoretical conclusion from this study was a unifying explanation for all problem doctor patient relationships. In it patients challenge the legitimacy of the doctor’s role. This should be a focus for future research in the field of problem doctor-patient relationships.
5. A further important theoretical conclusion was the relevance of current theories about personality disorder and adult attachment to understanding problem doctor-patient relationships. The utility of these theoretical perspectives should be investigated in the general practice research setting.
6. Moreover the role that having a personality disorder diagnosis or insecure attachment pattern for the quality of general practice care that a patient might receive is a novel area for future research too.

10.7 Conclusions

This study focused on the definition and characteristics of “revolving door” patients in general practice in Scotland. It explored the impact these patients had on the NHS and the impact being a “revolving door” patient had on themselves. During the conduct of the study the numbers of “revolving door” patients reduced dramatically because NHS responses to “revolving door” patients changed. This was initially due to changes in approaches to treating problem drug use and pressure on removal activity

from professional bodies and then finally the 2004 nGMS contract. “Revolving door” patients themselves did not change

GPs were able to suspend their core values and remove patients because “revolving door” patients may be seen to challenge the legitimate work of general practice. This was because the dominant health needs that “revolving door” patients had were generally contained in a moral schema of understanding. This meant their needs were not viewed as biomedical or their expectations of behaviour threatened the doctor-patient relationship. This window into one area of problem doctor patient relationships, and synthesis with other literature fields, produced the important conclusion that this challenge to the legitimacy of the doctor’s role may be common to all problem doctor-patient relationships.

Personality disorder and adult attachment theories led to the conclusion that “revolving door” patients do not understand the unwritten rules of the doctor-patient relationship; so removing them from GP lists did not change their behaviour. Awareness of these theories and future research in these areas might help GPs work more effectively with these patients. The aspiration remains that patients who have been “revolving door” patients should receive good quality general practice care.

Appendices

Appendix 1: Reaching a definition of a “revolving door” patient

The following sets out the background to the 3 numerical versions of the definition of a “revolving door” patient that became the final definition. This was that a “revolving door” patient was removed 4 or more times from GP lists in 6 years.

First definition

I considered the length of time a patient stayed with a practice to be a key variable; as this may influence the care they received from the practice, and their ability to build relationships with health professionals. Therefore the removal date was subtracted from the reinstatement date for each registration episode, to calculate the number of days each patient stayed on a practice list.

High degrees of skew were observed in the distribution of number of days on lists for individual patients: some patients may for example have moved away temporarily or been in prison for lengthy periods. The median number of days on list was therefore chosen as the best summary of duration of registration with practices, to try and take account of this complexity.

For the patients who had a median “days on list” of less than 100 days, they had a mean value of 33 days on a list, around one month, this was considered a reasonable representation of the “fast revolving door” patients. A median “days on list” of less than 366 days was initially used as the definition of a “slow revolving door” patient. The problems of the missing dates and dates out of chronological order were investigated, but I and the health board statistician could find no robust way of imputing the

data to improve the data quality. The anonymised details of the 673 patients from this first definition were then data linked with the routine NHS data sets as previously described.

Second definition

When reviewing the health board statistician's calculations of the means of the "median days on list" for the first definition it became apparent that the mean calculated for the "slow revolving door" patients was the mean for the whole cohort. The first definition was then reviewed and a second definition was constructed.

The definition for the "fast revolvers" remained the same, "median days on list" of less than 100 days. A range of intervals that might better capture the definition of "slow revolving door" patients was explored graphically and patients who had a median "days on list" of less than 180 days with a mean value of 135 days on a list (around four months) was felt to be the best representation of this. It was hoped that this definition would be specific enough to distinguish between "fast" and "slow" revolvers yet have sufficient range to take the complexities involved in the removal episodes into account. There was an arbitrary element to setting these intervals but they made sense.

Third definition

Once the Robertson Centre statistician was involved in the study he carried out an initial data reduction on the patient removal records, successfully imputed the data and applied the second definition to the remaining patient records as he described below:

- The initial full removals database consisted of all patients with at least 1 record, where a record is defined as any trio of variables (registration ["on"] or removal ["off"] date, postcode and practice code) where the date is present. This database has a total of 52375 records on 33602 patients.
- Records from 1998 or earlier were deleted, leaving 33560 patients with 52298 records.
- Duplicate records were deleted, assuming that multiple removals or registrations of the same patient at the same practice on the same day are duplicate records, leaving 52251 records on 33560 patients.
- The records were ordered by date within each patient the missing on/off events imputed (e.g. "off-on-off-on-on-off-on" would have become "off-on-off-on-off-on-off-on").
- Missing event dates were imputed. The pattern of gaps between events was used to impute missing dates. E.g. if "off" dates tended to fall shortly before "on" dates but a long time after the preceding off date (i.e. a tendency for rapid re-registration and relatively long periods on a list), then this information was used in imputing missing dates. More precisely, the median fractional location of a date between its two neighbours was used to impute missing dates. If this median was not available (because there were no sequences of three complete dates), then the most common off-on gap across the whole data set, which was zero, was used to impute the remaining missing dates. These two procedures imputed all missing dates.
- Patients were excluded if they had been removed fewer than 4 times *and* were not among the 673 patients for whom record linkage was requested. Removals were counted as the number of 'off' records (including imputed records). These last two steps leave 8879 records on 823 patients. Children and patients with record linkage but with fewer than 4 removals were retained only to allow included and excluded populations to be compared in *the diagram at the end of appendix 1.* (italic text changed for clarity)

(Johnson, 2011e)

Figure 18 Method of data reduction, imputation and definition for the "revolving door" patients

Each option for imputing the data had consequences, during which some patients were in and some were out of the cohort. The option we decided on had three consequences; firstly some patients (seven in total) who had been included in the initial cohort were out, because the process of reordering the dates meant they no longer had sufficient removal episodes to be considered (a missed date was taken up by the date that would allow them to have ≥ 4 removals). Secondly some more patients were included because more dates were available to calculate median days on list, these patients had fewer negative values so were in, and thirdly for some their

median days on list was now so long they no longer fitted the inclusion criteria and became “non core patients”.

The following shows how the patients moved category depending on whether the median days on list was calculated using the imputed or non imputed dates.

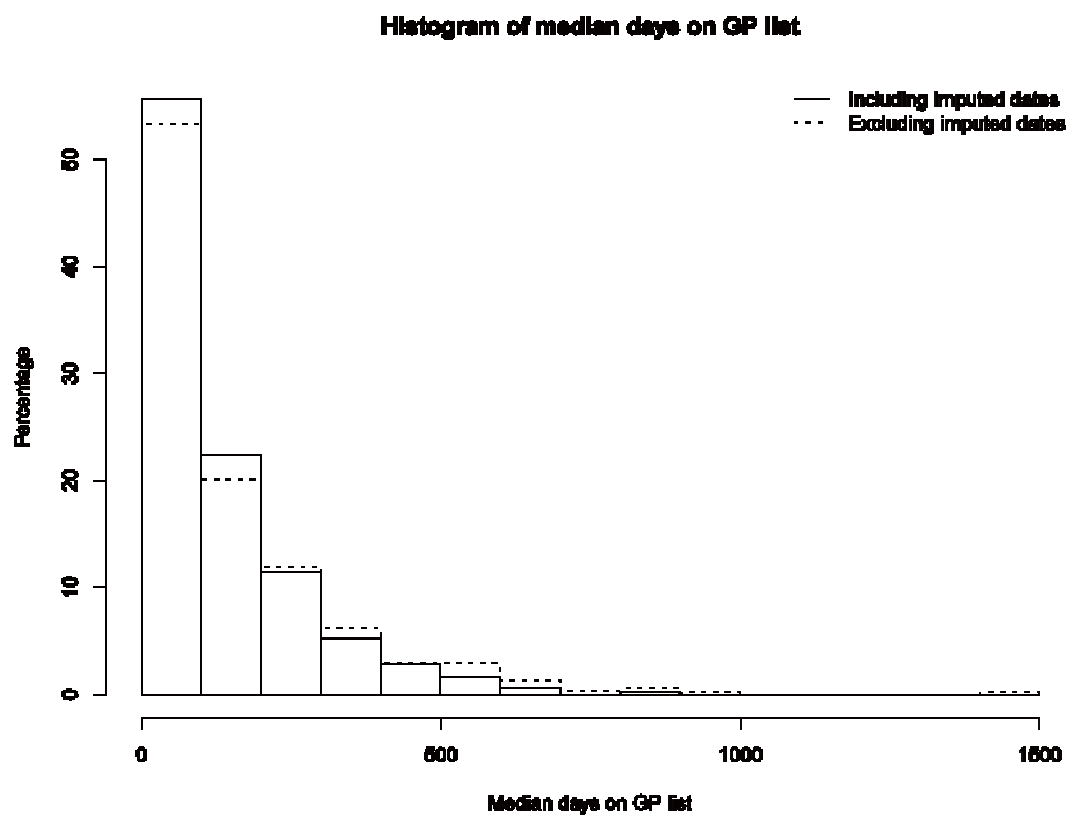
Table 22 Comparison of number of patients and their median times on a practice list using both the imputed and non imputed dates for calculation of the “revolving door” patient cohort

		Total	Median days on GP list (imputed)			p ¹¹ Nc vs rest	p Fast vs slow
			Fast (0-100)	Slow (101-180)	Non-core (181+)		
Median days on GP list (excluding imputed dates)	N _{OBS} (N _{MISSING})	544 (11)	306 (3)	108 (5)	130 (3)	<0.001	<0.001
	Fast (0-100)	290 (53.3%)	297 (91.2%)	9 (8.3%)	2 (1.5%)		
	Slow (101-180)	94 (17.3%)	16 (5.2%)	73 (67.7%)	5 (3.8%)		
	Non-core (181+)	160 (29.4%)	11 (3.6%)	26 (24.1%)	123 (94.6%)		

Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

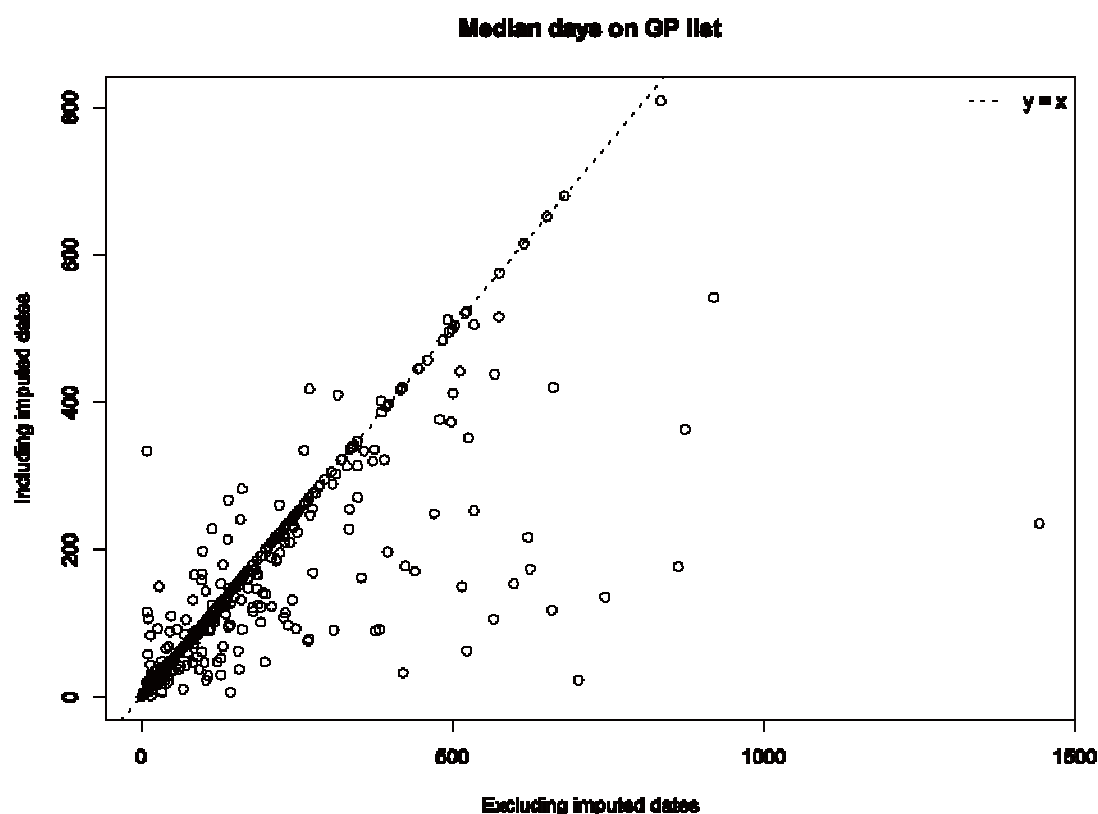
Most of the patients who were included in the cohort after imputed dates were used to calculate the median days on list were included in the “non core” group. Only three patients came into the “fast revolving door” patient group and five into the “slow”. The biggest movement between categories was for the “slow revolving door” patients; with 8% moving up into the “fast” category and 24% becoming “non core”. The following illustrates graphically the level of agreement between the original and imputed data sets:

¹¹ P-values are from Wilcoxon Rank sum tests of equal medians (continuous variables) and Fisher exact tests of equal proportions (categorical variables). For categorical variables with more than two categories, P-values were approximated from 10,000 simulations.



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 19 Histograms of median days spent on a practice list calculated from data including and excluding imputed dates for the “revolving door” patients



Statistical analysis conducted by Paul Johnson statistician Robertson Centre for Biostatistics, University of Glasgow

Figure 20 Scatterplot of median days spent on a practice list using imputed dates versus not using imputed dates for the “revolving door” patients

Once the characteristics of the “revolving door” patients had been analysed comparing the three groups of “fast”, “slow” and “non core revolving door” patients it was concluded that there was no difference between them and the definition should include all patients who had been removed more than 4 times from GP lists in 6 years. This meant that there were three cohorts of “revolving door” patients from the 1999 to 2005 data, derived from the three versions of the definition but all included in the final definition.

The following diagram provides an overview of these three cohorts and how they relate to the analysis and the subsequent results. The cohort that was

data linked was based on the first definition, the cohort that was qualited based on the second and the cohort that underwent quantitative analysis based on the third. The groups of patients that are grouped in this way are summarised by their mean age, the proportion that are male, and their mean median “days on list.” One consequence of the inclusion of the imputed data was that the “fast” and “slow revolving door” patients that have been qualited represent those patients who had lower median days on list in the cohort. Patient demographics were comparable across the groups.

Analyses conducted on the three cohorts of 'revolving door' patients and their summary demographic descriptors

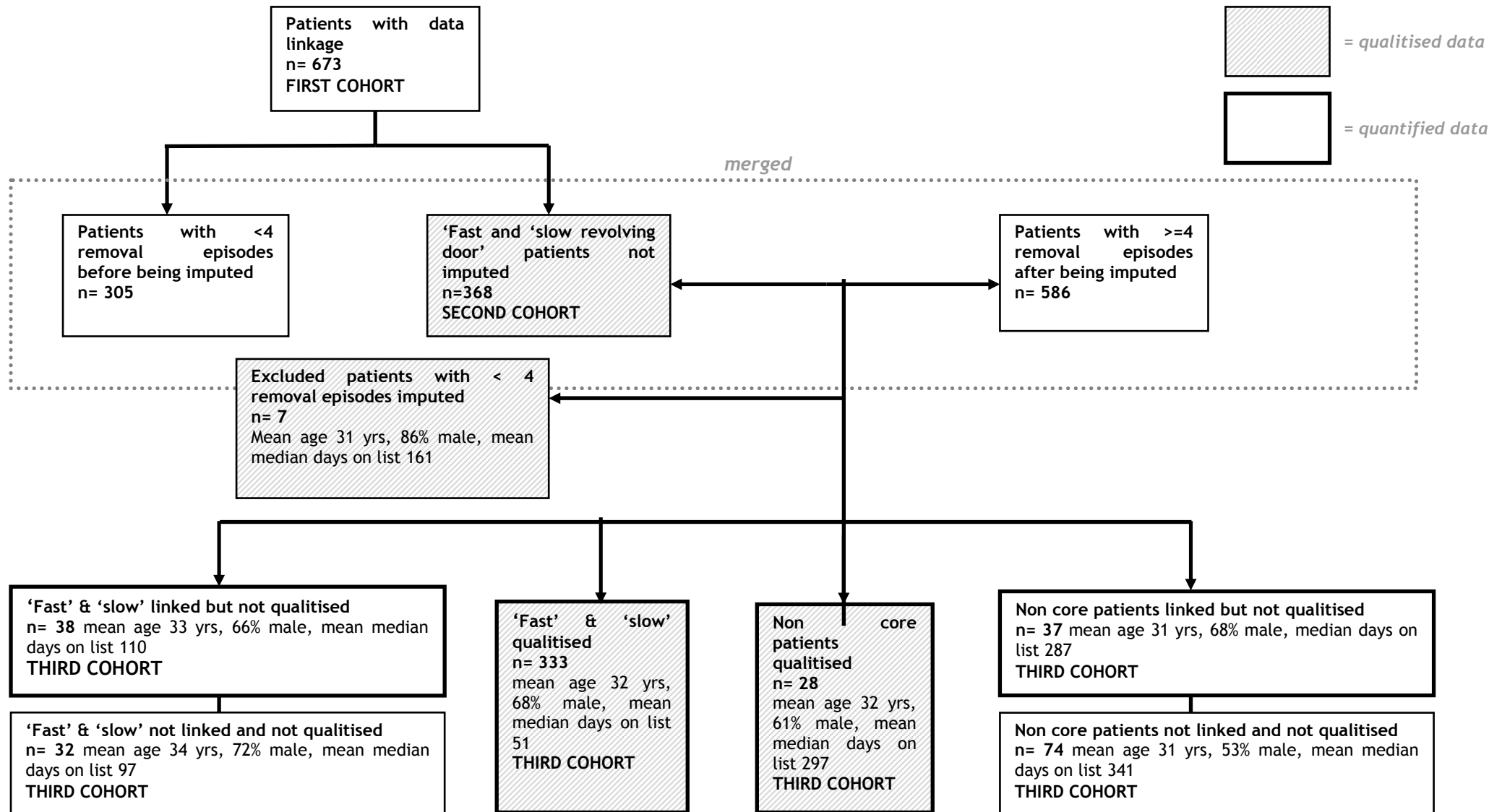


Figure 21 Analyses conducted on the three cohorts of "revolving door" patients and their summary demographic descriptors

Appendix 2 Professional key informant recruitment letter

Dr Andrea E Williamson (headed notepaper)
GP and clinical university teacher
Telephone
E-mail:

00/00/06

Name
Address

Dear

Defining “revolving door” patients: request to take part in a research study

I am undertaking an independent study for my PhD thesis called *'Patients who are repeatedly removed from GP lists: analysing the revolving door'*. I am interested in this topic because of previous clinical experience and research in primary care.

The first phase of the study aims to develop a definition of “revolving door” patients and work out their characteristics. This will involve considering data taken from the CHI to look at possible patterns and also to listen to the perspectives of staff in practitioner services that may have contact with such patients.

In the first instance I would like to interview you as a regional registration manager for GP registration and one member of staff in your region whose main work role is to administer GP registration.

Examples of some of the questions I have are:

- ⊙ What would your definition of a “revolving door” patient be?
- ⊙ What circumstances do you think lead to the production of “revolving door” patients?
- ⊙ What impact do you think being a revolving door patient may have on the patient, on practitioner services, on the health service?

Taking part would involve about one hour set aside out of your normal work day to take part in an interview. The interview would be confidential and for the purposes of the research project only. The study has NHS management and ethics committee approval.

An information sheet sets out the study in more detail and is enclosed along with the proposed consent form.

I would be grateful if you could also distribute the enclosed pack called 'administrator' to administrative staff who may be interested in taking part.

Please get in touch at the contact number or e-mail above if you wish to discuss any aspect of the study. I will be in touch by phone in a fortnight to discuss whether you and one administrative staff member have had an opportunity to consider taking part in the study.

Yours sincerely,

Andrea Williamson

Appendix 3 Participant information sheet



Research on defining “revolving door” patients

You are being invited to take part in this study. Before you agree to take part it is important that you understand why the research is being done and what it will involve. Please read the following information carefully and feel free to ask any questions you are unsure about.

Who is conducting the study?

This independent study has been developed by Andrea Williamson, a PhD student based in General Practice and Primary Care, University of Glasgow and funded by that department. The study is supported by the Primary Care Division of Greater Glasgow Health Board and Andrea is an employee of both organisations.

What is the purpose of the study?

There has been no previous research examining “revolving door” patients (those who are repeatedly removed from GP lists). This is despite permanent registration with a GP being necessary to access most health services in the UK. This study aims to start researching this topic of “revolving door” patients by answering the following research questions:

- © What is the definition and characteristics of a “revolving door” patient in the context of GP registration in Scotland?
- © What is the meaning of the existence of “revolving door” patients from a health service perspective?

Interest in this topic stems from clinical work with disadvantaged patients and a previous study examining how patients achieve GP registration.

Why have you been chosen?

You may come into contact with “revolving door” patients in your day to day work in Practitioner Services and GP registration. I wish to interview each Practitioner Services regional registration manager and one member of staff in each regional office whose main work role is to administer GP registration. This will help me to build up a picture of your perspectives on the issue.

Do you have to take part?

Nobody has to take part in the study. Taking part is entirely voluntary and you are free to withdraw at any point. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

What does the study involve?

Most people are apprehensive about being interviewed even if they are used to it. The purpose of the interview is to discover what your thoughts and experiences are about a group of patients you may come into contact with. I have an idea what I wish to cover in relation to this but you have control over how the interview is shaped and what you wish to say.

Is the research confidential?

Yes. Your involvement in the study will be completely confidential. Your interview will be taped so that I have an exact record of your words, but the tape will be wiped at the end of the study. Everything you say will be made totally anonymous and your views will be grouped together with those of the other participants so that your identity is hidden. Nothing you say will be reported back to any member of staff. Information linking your identity with your interview will only be seen by me.

What are the benefits of taking part?

Your help in this study is very important to provide your perspective on this under researched group of patients.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time. You may decide to allow the data collected up until you withdraw to be used in the study or you may prefer that it is destroyed. Your wishes will be respected.

What if I have concerns or a complaint?

If you have a concern about any aspect of this study, you should in the first instance contact me and I will do my best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting: Phil Hanlon, Professor of Public Health, Public Health and Health Care Policy, University of Glasgow, 1 Lilybank Gardens, Glasgow G12 8RZ. (phone number)

What will happen to the results of the study?

The findings will be reported when the research is completed in three years time and I will send you a copy of the report if you wish one. This final report will be a summary of my PhD thesis. The report will be disseminated to relevant NHS and public bodies and the research will generate publications in peer reviewed health service journals too. No individual will be identified in any reports or publications arising from this research.

What will happen if you agree to be involved?

I will make contact with you at your office and arrange a day and time to visit your place of work. I will ask you to set aside one hour out of your work time and arrange a meeting room away from your ordinary work interruptions. I shall attend promptly at the time we have agreed to carry out the interview.

Who has reviewed the study?

Oxfordshire Research Ethics Committee B reviewed the study.

**If you require further details about the research, please contact:
Dr Andrea Williamson on (mobile number) E-mail:**



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Appendix 4 Consent form for professional key informant interviews

Study Number:

Participant Identification Number for this study:

CONSENT FORM

Title of Project: **Defining “revolving door” patients**

Name of Researcher: **Dr Andrea E Williamson**

initial box Please

1. I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
3. I agree to take part in the above study.	<input type="checkbox"/>
4. I agree that the researcher can record my interview and that the interview can be transcribed afterwards.	<input type="checkbox"/>
5. I understand that my name will not be attached to tapes or transcriptions.	<input type="checkbox"/>
6. I understand that my personal information is strictly confidential. I know that the only person who may see information about my part of the study or listen to the recording of my interview is the researcher and the employed transcriber.	<input type="checkbox"/>
7. I understand that the recordings of my interviews will be destroyed at the end of the research and that should I choose to withdraw from the study, any	

information will be destroyed should I wish it to be.

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed, 1 for participant; 1 for researcher site file.

Appendix 5 Topic guide for professional key informant interviews

Defining “revolving door” patients: Topic guide for semi-structured interviews

Introduction to research: nature and purpose, confidentiality and permission

1. Participant background

- ⊙ Name/sex/ age/professional role of participant
- ⊙ How long have you been in your current post?

2. Definition of “revolving door” patients

- ⊙ Do you think the **concept** of “revolving door” patients is a **valid** one?
- ⊙ Is it a **useful** concept?
- ⊙ Would it be used **by colleagues**?
- ⊙ What would your **definition** of a “revolving door” patient be? (probe meanings). Can you identify how many times they would need to be removed to become one? Over what time scale would this be?
- ⊙ What **circumstances** do you think lead to the production of “revolving door” patients?
- ⊙ What are the **influences** on their production?

3. Characteristics of “revolving door” patients

- ⊙ 'Can you describe (without breaking confidentiality) **the last case** of a “revolving door” patient that you dealt with?
- ⊙ Was that person a **typical** case?
- ⊙ What **other types** of “revolving door” cases do you come across? Can you **describe** (without breaking confidentiality) a **recent case** like that?
- ⊙ Are there **other types** of “revolving door” patients you can think of? Please give an example (without breaking confidentiality)

- ⊙ Are there any “revolving door” patients that **particularly stick in your mind aside from** the cases you have already described?
- ⊙ If so (without breaking confidentiality) can you **describe their case** and say **why they stuck**?
- ⊙ In your opinion are there **circumstances common to all** “revolving door” patients? If so, please describe the range of circumstances.
- ⊙ Do you think there are **behaviours common to all** “revolving door” patients? If so, please describe the range of behaviours.
- ⊙ Do you think there are **attitudes common to all** “revolving door” patients? If so, please describe the range of attitudes.
- ⊙ Can you describe (without breaking confidentiality) any patients that have become “revolving door” and that do not **completely fit the usual pattern**?

4. Meaning for practitioner services

- ⊙ What does the existence of “revolving door” patents mean for **practitioner services**?
- ⊙ How does their existence **impact on staff**?

5. Meaning for GPs

- ⊙ Can you offer any insight into **why GPs may remove** “revolving door” patients from their list?
- ⊙ Are there practices or GPs who are **more likely to remove** patients than others?
- ⊙ If so, why? Can you (without breaking confidentiality) **describe an example** of such a practice?
- ⊙ **If not** can you identify what the **main precipitator** is?
- ⊙ Are there practices or GPs who are **more likely to keep on** “revolving door” patients?
- ⊙ If so, why? Can you (without breaking confidentiality) **describe an example** of such a practice?

6. Meaning for patients

- ⊙ What do you think the impact of being a “revolving door” patient has on that **patient's access to health care**

- ⊙ What do you think the impact of being a “revolving door” patient has on that patient's **quality of health care**
- ⊙ What do you think the impact of being a “revolving door” patient has on those **patients health?**
- ⊙ What do you think the impact of being a “revolving door” patient has on those patients **view of themselves?**
- ⊙ What impact do you think the existence of “revolving door” patients has on **other patients?**

7. Implications for change

- ⊙ Would you consider the **existence** of “revolving door” patients to be **inevitable**, or not?
- ⊙ Are there any **changes that could be made to the GP registration system** or the **way that practitioner services work** that could help reduce the number of “revolving door” patients? If so, please describe your suggestions.
- ⊙ Are there any **changes** that could be **made in GP practices** that could help reduce the number of “revolving door” patients? If so, please describe your suggestions.
- ⊙ Are there any changes that could be made **by working with “revolving door” patients themselves?** If so, please describe your suggestions.
- ⊙ Can you think of **anyone else it would be useful for me to speak to** about revolving door patients?

8. Closure

- ⊙ Summary and points missed

Appendix 6 Twelve codes and summaries for PSD respondents

Summary of PSD interviews

Here is my summary of what I learned in the interviews with six Practitioner Services Division (PSD) staff from the three offices in Scotland. I would like you to read it and decide whether you agree with what I have written. I will be delighted if you can make written notes at the side to discuss when I phone you in the next week or two. There are also some points I am not sure about; either because I am not sure I have picked them up correctly or because different people have responded differently to the same question. I have put asterisks beside these points. Contradictions are to be expected; what I am looking for is any possible explanations for those contradictions. I hope this makes fairly easy reading and I look forward to your responses!

Definition of a revolving door patient

Both the concept and the phrase 'RD' (RD) patient is viewed as valid by Practitioner Services (PSD) staff. The phrase isn't used in practice but a patient would be considered 'RD' when they had had multiple removals from a range of practices. They saw the concept as one that some professionals would recognise but not patients.

The numbers of patients in each health board who revolve is small; however PSD staff know these patients well and the practices they revolve around although they acknowledge there may be further patients in this category who they don't know because they have limited contact with.

Process of removal

The majority of patients are removed because practices let PSD know they wish the patient to be removed; occasionally a patient will persistently remove themselves because they wish to get to another practice. Occasionally a patient is not happy with any practice they are allocated to.

Patients are moved around within geographical areas so revolve between the same practices in the area.

Frequency of removals and assignments

Regulations require that practices have to keep patients for a minimum of seven days before they are moved except when they are removed for reasons of violence. In some areas the previous 'gentleman's' agreement of keeping patients for three months is still adhered to by practices and in others PSD staff understand that patients will be kept on for thirty days before removal.

These perceived timescale rules govern how long RD patients stay with practices before removal as some practices will remove routinely after that time scale. The particular difficulties the patient brings also influences how long they remain with a practice.

A patient may be starting to revolve when they have been removed three or four times over months.

Fast revolvers

Fast revolvers are patients who are regularly, constantly on the move; every seven days in extreme cases.

Slow revolvers

Slow removers are removed less frequently revolving over months possibly every three months. They may settle down for up to a couple of years but then they will be removed and begin to revolve again.

Considering the CHI removal statistics

The chronology of patient removal dates on the CHI record can be out of synch because a patient manages to find a new practice within the seven days before they are recorded as removed; this doesn't happen often. Sometimes PSD will find a new doctor sooner if continuous treatment is required; that would be exceptional.

The role of assignment

A patient is assigned to a practice when they have difficulty registering with the GP practice of their choice and they request to be allocated to a GP practice. They need to be resident in the area for three months to be registered. Practices don't need to take them on. Most patients who are assigned do not become RD. Sometimes patients are assigned a couple of times because they have a problem with their GP; a poor relationship or the wrong gender match.

Patients also have a right not to be registered and there are examples of one or two RD patients who resist being registered despite having health needs. Practitioner services staff have an allocation rota within geographical areas and allocate the patient according to this rota only. No practices are exempt from this rota. The only exception given was one female GP who had previously felt threatened by one RD patient, and also the homeless PMS practice.

Rota skipping

Most of the time PSD can not match the health needs of the patient with the services the practice provides but occasionally in some health board areas they will try and match request for a female or male GP, or a patient who is housebound and therefore needs house visits or a patient whom they know will be seeking methadone treatment. They will allocate the next patient to the practice they have missed. The rota is quite constraining and they are not always able to oblige. This allocation according to need is seen a bit like the housing points system. The patient has to put a good case for this to happen.

Practices can not refuse to take the patients but some practices do request removal of the patient soon after they are allocated. Practices are not told they are getting an RD patient but they may have had them registered two or three times before or they see the assignment letters in the GP records.

Closed lists

An unusual aspect of assignment is when a practice has closed its list usually due to population increases. Hence all new patients in an area are assigned and it is viewed as a fair distribution of patients with no stigma attached to those patients.

Allocation as inferior status

In one PSD office assigned patients cannot remove themselves from a practice list; the practice has to do so. This is because the office was getting too many requests for assignment, often linked to patients not getting methadone treatment. *Do you think this has an impact on the behaviour of assigned patients in this PSD area?

PSD staff feel there is a stigma associated with being assigned. Practices and PSD staff wonder what is wrong with the patient that they could not get themselves a practice.

Practices also see it as a licence for removing 'bad' patients; patients who are abusive or drug misusers * Are you able to elaborate on this more and say why you know this happens? Some practices also remove assigned patients before they see them; either because they don't feel they should have any patients assigned or sometimes because they don't wish that particular patient back with the practice. RD patients' track record is remembered by practices.

However there were also an example given of a practice that did not prejudge an assigned patient the patient felt welcomed and remained with the practice.

Most patients however don't seem to see stigma associated with allocation; those that do have also taken issue with why they have been removed in the first place.

Link with RD patients

Assignment is important because all RD patients are assigned. They cannot find a practice that will register them. When allocating a RD patient PSD staff go round all the practices in the geographical area before going back to the beginning. In the past when there were more RD patients PSD staff had to be careful not to allocate two patients to the same practice at the same time. This would not have been fair to the practices. RD patients are often in the same areas. *Can you consider if this is true of your experience please?

One PSD staff member had no experience of RD patients because she has not worked with allocations at all.

PSD also hope that with a bit of time passing practices will forget what patients are like and let them be allocated without removing them immediately.

PSD perspectives on general practice

Core work of general practice

PSD staff view GPs as there to treat patients.

However PSD staff are not clinicians so don't understand general practice fully but patients do need care that someone should be providing.

Sometimes they can't see why practices don't just keep patients on they do not see the other side of it; the patient being demanding and other negative behaviour. They do however sometimes also wonder why GPs can't just comply more with patients requests around substance misuse medication but this may be normal practice. Drug misuse treatment is also not seen as core general practice by all PSD staff. Some PSD staff felt that the refusal of practices to treat patients is acceptable as patients can access street drugs.

PSD staff wouldn't suggest that GPs remove patients to try and meet targets but target patient groups (such as women, children and those over 65) have more contact with the practices.

PSD hope practices treat all patients equally and treat all patients well but examples were given where this may not be the case. PSD staff felt that GPs were driven by payment incentives.

Challenges of general practice

However PSD staff are also aware that GPs can not spend hours listening to a patients problems as they have other patients to see or visit. They often do not have the time to spend with patients. PSD have a strong sense of fair distribution of resource between patients.

PSD staff also recognise it is a difficult work environment and they would not like to have to deal with the situations practices have to deal with and live in the same area. One PSD staff member considers the physical presence and attitude of the GPs to be important regarding keeping patients with problems under control.

One staff member felt that GPs were always correct in their decision to remove a patient.

Interaction with general practice

Practitioner services role with both practices and patients is to provide guidance about registration. Complaints are handled by the NHS trust. An example is of a practice who were sending all patients who requested registration to a neighbouring practice saying their list was full.

PSD advise patients and practices to get and give refusals for registration in writing.

The majority of the time practices do not provide information about the patient or the removal episode. PSD are the administrators; why should they know what happens in surgeries or if someone is presenting for methadone? That is seen as a medical issue. Sometimes the practice will give an explanation to justify their actions. One example is of the district nurses phoning on the patient's behalf to request a new GP. They wish to remove her because her behaviour has become intolerable but she has serious medical needs that require care.

PSD background knowledge of RD patient

PSD staff do end up knowing a lot about some patients; particularly RD patients and they get to know them well. In some cases PSD staff build up a relationship and are on first name terms with RD patients. They can also make a reasonable guess as to the reason for removal based on the patient's home address (it may be sheltered or supported accommodation).

Patients will also phone up and tell PSD staff the medication they require; this is often methadone treatment. RD patients will phone and give the details of their issues with the practice and often seem like they are lonely and need to talk. They will talk about their health problems too.

PSD staff also get a lot of information about RD patients' behaviour based on the manner in which they interact with themselves.

Some of the PSD staff also sometimes see patients in town and can see a visible improvement in their appearance sometime after they have accessed drug misuse treatment.

However PSD staff do make the point that unless a patient phones PSD they don't know why the patient is being removed; they get a general letter from the practice that gives no information. There may be RD patients out there whom they know nothing about.

PSD attitudes to RD patients

PSD treat RD patients in the same way they treat all patients; equally well.

PSD staff see RD patients as two groups; one for whom being a RD patient adds to the stigma of their other difficult life circumstances and one for whom their main aim is to get 'one over' on the health service.

Legitimacy of health needs

PSD staff seem to be ambiguous about the legitimacy of RD patient's health needs. On the one hand they feel that RD patients have health needs that require to be met; on the other hand they make comments about RD patients believing they have health needs or are housebound or need appointments. One PSD staff member also gave the example of one RD patient who really seemed to have a problem but could not get GPs to take it seriously; she stood out as unusual.

PSD staff also talked about RD patients not turning up for appointments resulting in genuine patients not being able to get appointments.

PSD staff consider RD patients to be demanding and seeing their needs being met as their right and what they are entitled to 'I pay your wages' etc. They feel that they are unable to see the bigger picture; that there are others who have a right to see their GP too and that

they are selfish. They see the care that drug users get and wish that level of care. RD patients also have a tendency to blame others for their problems.

In saying all of this PSD staff also recognise that the aggressive and demanding behaviour that RD patients express is a symptom of an underlying problem. The patients are not difficult; they have difficulty with registration.

However they feel that a lot of the time RD patients are clever and calculated in their behaviour; they know what behaviour will achieve which outcome and they know the system very well; for example they do not revert to violence. PSD staff find it difficult to understand how RD patients get to know the system and use it as well as they do.

Generally PSD staff feel that the difficulties lie with the patient rather than the practices.

PSD staff feel that RD patients can not be changed and that their existence is inevitable.

Characteristics of RD patients

RD patients are produced as a result of breakdown in relationship with the GP or a member of the practice team. There are numerous influences that produce RD patients. The majority of RD patients used to be drug users but this has changed dramatically in recent years. The majority of RD patients are now considered to be patients who exhibit challenging behaviour.

PSD staff consider RD patients to have the following characteristics based on both their interaction with them and the information they receive from practices:

Patients who exhibit demanding behaviour

RD patients don't have boundaries. A common factor in all RD patients is that they abuse time; they may phone the practice continuously or appear and expect to be seen without an appointment. They may not turn up for booked appointments then present late and expect to be seen. They may also make numerous complaints to the practice about their care. PSD staff also experience aspects of this behaviour from RD patients; they may make repeated phone calls to PSD or want a new GP immediately; that just isn't possible. Some PSD staff have stopped asking RD patients to try to find a new GP themselves and this makes the relationship with PSD staff better than previously

RD patients have health needs

All RD patients have health needs or perceive that they do. Why else would they want another doctor; they are not in love with the health service but need it for some reason. If patients don't need to be seen in general practice they don't re-register with another practice.

RD patients are high workload dependent patients

Many RD patients have specific high dependency needs such as being housebound and requiring regular nursing input for their medical needs or having agoraphobia and requiring house calls. Some RD patients request consultations for perceived health needs very frequently and can not distinguish between a minor and major illness and the subsequent response they expect from the practice. Some GPs do put in a lot of work with RD patients but then they are moved on again and the next doctor has to start again. Some RD patients express needs that the GPs find hard to meet; some patients have unrealistic preferences for one GP; some patients phone repeatedly even after they have just been seen and practices feel they cannot satisfy their needs. RD patients health needs may change as they get older; as their families grow up they become more dependent on the health service.

Patients who are abusive or impolite

Patients who are persistently abusive or impolite to reception staff can become RD patients. Some RD patients struggle to control their anger and blow up easily.

One PSD staff member feels it is the older RD patients who are more abusive.

RD patients don't quite fit in

PSD staff conceptualised all RD patients as not fitting in with what is expected of patients interacting with general practice. They described RD patients as not fitting the norm of only going to the GP once in a while or being in a target population. They are challenging, non compliant, quite intelligent; often aware of their rights, have expectations of the care they should receive, and are chaotic.

The role of violence

PSD staff members had very diverse views on whether RD patients were violent or used threats of violence. In some health board areas they clearly were a significant number of RD patients and in others they were a small minority. * Can you explain this contradiction?

Patients with mental health problems

PSD staff give examples of RD patients who they feel have mental health problems. Examples are of patients who behave bizarrely, seem to have conversations with themselves, appear delusional, may display inappropriate sexual behaviour and that personality may have a role. They also view the patients who exhibit very demanding behaviour as having mental health problems.

Patients with drug addiction

In some HB areas the majority of RD patients have drug misuse problems but this varies proportionally with accessibility of drug treatment services. In the areas where accessibility has improved a lot the number of RD patients with drug misuse problems has almost disappeared.

Drug users become RD patients because of their presentation in practices; they can become aggressive and demanding or it can be because they are seeking methadone treatment or they may have stolen prescriptions. The two do not always overlap. Some GPs do not provide treatment and patients in areas where there are long waiting lists for treatment in drug services perceive that this was linked to the practice they were with. Therefore if they behave in such a manner as to get themselves removed from that practice this might mean that they will get onto treatment more quickly at another. This is in the area where assigned patients could not remove themselves. PSD made an effort to educate patients that the waiting list was long no matter which practice they were registered with and these removals have since reduced a lot.

Drug users also become RD patients when their expectations of treatment do not match those of the GPs providing treatment.

There are also examples of RD patients who had stopped revolving when they were on maintenance treatment.

There was also a feeling that a lot of the previous RD patients who were drug users were getting older, physically more unwell and maybe were burnt out; their aggression and drug seeking behaviour has settled down.

Patients with alcohol addiction

Patients with alcohol dependence are a small number of RD patients.

*Can you think of examples?

Older patients

PSD staff in some PSD office areas felt that the majority of RD patients that haven't settled down are older patients; over 60 years of age and they tend to be from the more affluent leafy suburbs. * What is your experience?

Some nursing home patients

A few nursing home patients become RD patients although some health boards have PMS schemes to look after NHS patients. *Can you explain further why this may be the case?

Families

One person; usually the main caregiver; often the mother; has problems with the practice; she is removed along with the whole family. However PSD staff felt this practice of family removals was variable; some practices do keep the children registered when the caregiver moves to another practice.

Patients who default appointments

One PSD staff member felt that RD patients are also those who persistently default appointments. This staff member felt that because these patients don't make a fuss; they simply don't turn up; the health service don't pay them much attention.

Multi agency problems

Some RD patients have problems with every agency they deal with; for example the council; this becomes apparent when the health board look into that patients problems with general practice; sometimes they even have contact with these other agencies.

Unusual RD patients

For some patients who become RD a one off break down in the doctor patient relationship (themselves or another family member) mean they get caught in the system of assignment - removal but don't have major underlying problems. Sometimes PSD staff are surprised by patients who are articulate, give you their side of the story and are surprised they are removed and need to be allocated. They do acknowledge they only get one side of the story. * Do these patients become RD though?

The following are individual examples of patients who are unusual RD patients:

RD patient diversity

PSD staff emphasised that although you can say some patients need anger management, some have drug problems, some alcohol problems every patient and practice is different. The reasons for removal can be very different and difficult to classify.

Influences producing RD patients

Demographics

Rurality

Geography has a big influence on whether RD patients are produced.

Few patients in very rural areas become RD patients because they know they often have no choice of which practice they can go to. Practices are also aware of this and tend to think harder before removing as the patient will simply be allocated back to the practice. PSD staff feel that staff in rural areas are more tolerant; they know they have to try and work with patients with problems as there is no alternative. Patients generally also tend to contact the GP only when they have a serious illness.

In cases where problems do occur arrangements can be made to treat the patient; this may be in a secure place like the local hospital. However in rural settings when removal or the threat of removal does occur after an aggressive episode for example the patient seems to appreciate the implications of this and settle down once they are allocated back to the same practice. Most therefore don't become RD. A drawback of this though is that patients may realise they will be registered with that practice no matter how they behave so will carry on being violent and aggressive. Occasionally in rural areas a patient will become RD as they move back and forwards between two practices in the area.

Hence the vast majority of RD patients are urban patients.

Deprived versus affluent areas

Different practice areas have different problems. In deprived areas GPs are viewed as more tolerant of negative behaviour and also tend to have drug misuse treatment more available. PSD staff felt that generally something had to have gone really quite wrong in these areas for patients to become RD. In affluent areas there are educated patients who try to tell the GP how to do their job. GPs in these areas may still be revered and treated in a certain way so if patients don't conform to their standards of behaviour they are removed.

Patient registration system

Adherence to strict practice boundaries

There are historical and geographical influences that impact on practice boundaries and how strictly practices adhere to them. The establishment of out of hours cooperatives were a big influence as the areas covered had to be clearly agreed. In some localities practices work well together and in others not. Tightening practice areas due to perceived workload pressures can lead to bulk removals despite the need for home visits being very much reduced these days. They are expected to retain the existing patients out with the new boundary area but they often don't.

Closed lists

There are some urban areas where all patients have to be assigned; because practices have closed lists; often there is no space to accommodate new GPs. Closing the list has become more difficult to achieve under nGMS so fewer practices are currently closed. However under the previous contract there were areas of practices who refused to register all new patients and used the assignment system as a means of distributing patients fairly between practices. This meant that they also felt more justifiable in putting 'bad' patients off the list as they had been assigned to them.

Impact of nGMS

Non discriminatory framework and accountability

The nGMS contract sets out a clear non discriminatory framework and PSD staff feel that because of it practices know they should be accepting patients and not putting them off if they live in their practice area; it has made them more tolerant. This tolerance does seem to vary a bit from health board to health board and has taken variable timescales to take hold but especially the city practices have become much more so. Their attitudes have changed from being unhelpful and *'don't tell me what to do'* to trying much harder with patients. Practices are much more likely to take patients on and although they may later remove them they can then find another practice more easily. PSD are getting phone calls from patients about being removed but then a few days later it is apparent from the registration system that they have found a new practice themselves. GPs are also expected

to warn the patient before removing them and then give a reason for removal which is a change from the previous contract. Even now practices will simply state 'breakdown in doctor patient relationship' and consider that good enough information. Practices also expect this information to be audited by the health board although this may not yet be the case.

All these factors have meant a radical positive change regarding assigned and RD patients. Practices are much less likely to remove patients, the numbers have reduced dramatically and the RD patients who are still removed are staying longer with each practice. There are also still patients phoning up to let PSD staff know there is no point assigning them to a particular practice because they have already refused to register there when they went to the practice in person.

PSD working with practices to keep RD patients

Since nGMS some PSD offices have tried to work with GPs more to either hold onto or get help from health board regarding RD patients.

Plurality of first point of primary care contact

The nGMS contract has meant that patients can contact NHS 24 for information, or can see their pharmacist for minor ailments, and practice nurses do a lot of the routine care and see patients for minor ailments. All these professionals seeing patients too in addition to GPs means they are no longer the sole point of contact for patients who are 'difficult'. That GPs no longer provide out of hours care also means they also have more time in the day to deal with patients.

Removal of prevention targets

Before nGMS families were put off because immunisation targets weren't being met. With the new contract that has stopped because practices are no longer paid for immunisation targets.

Delaying tactics for registration

PSD have heard some evidence from patients that practices may try and delay the registration process by asking for ID and proof of address from patients. PSD see this as a delaying tactic and to do with meeting 48hour access targets. Practices are struggling to meet these so if they delay the registration process of some new patients they can make the target.

The quality outcomes framework

A drawback of the new contract is that the new targets for payment are quality measurements for tangible measurable things. RD patients are a group of non compliant patients who will make targets go awry. There is no financial incentive in nGMS to manage such a group of patients by encouraging them to be compliant. *Can you clarify what is meant by complaint?

Attitudes of practices

There are no practices that constantly put patients off but there are practices who are known to remove more patients than others and there are practices who very rarely remove patients. This varies by health board area as some PSD staff are not aware of any variations in practice.

Tolerance

The degree of tolerance of patients by GPs and practices was a very common feature that determined whether a practice would remove a patient or not. GPs are more likely to tolerate negative behaviour by a patient if they have an established doctor-patient relationship. Practices who have a higher number of patients who exhibit challenging behaviour in deprived areas have higher tolerance too and are better at managing problem situations; they know how to handle a patient shouting or arguing. Practices who provide treatment for drug misuse are more likely to be tolerant. Tolerance may also vary with how GPs see themselves; those who put themselves on a pedestal may be less tolerant.

GPs and practices also have differing ideas about what constitutes threatening or violent behaviour. In some practices a patient raising their voice is viewed as violence and would trigger a removal whereas in others it would be seen as challenging and an issue to sort out. When the legislation around removals for reasons of violence came into being these variations in perception were highlighted as practices have to provide some detail about the circumstances for removal. This variation also makes it difficult for patients to know what is acceptable behaviour as they revolve round practices. Conversely some practices are reluctant to make a removal a 'violent' one as they do not wish to get the police involved. This means that the subsequent practice may not be aware of potential risks. PSD staff felt that occasionally practices would reach a tipping point with individual patients. They may have been with the practice for a long time and have been challenging; then one day the practice snaps, the patient is removed and they become RD patients. For some RD patients however it does not matter which practice they are allocated to; PSD staff know that after a few weeks the patient will be removed.

Practice removal activity

For many practices the removal of a patient is viewed as a last resort; practices pride themselves on not removing patients and circumstances have to be extreme before they will do so. nGMS and its non discriminatory framework has reinforced this attitude. These practices view removing a patient as moving their own problem onto to another practice and this is not fair. Some of these GPs therefore feel they should not be allocated patients. GPs exhibit a wide degree of heterogeneity in their own attitudes and behaviour towards patients and removal. Other GPs and practices exhibit a 'zero tolerance' approach to any perceived violence.

Some practices will however remove a patient without seeing them; they may send a fax requesting removal within a few hours of receiving the allocation.

Meeting patients needs

PSD staff highlight the importance of practices providing the services patients are seeking most of the examples being around providing methadone treatment or methadone treatment that is maintained over time. They also note that patients are discharged back to general practice from psychiatry when psychiatric services can no longer offer them support; but there general practice does not have the skills to deal with these patients.

One PSD staff member feels that practices are managing patients who default attendance at appointments more considerably by practice staff visiting patients who don't attend screening appointments, or by screening opportunistically when patients present for other reasons. These practices have effective practice teams who work together.

One PSD staff member also felt that the general practice booking system triggers problems too. Patients with chaotic lives cannot cope with the booking system and when they then turn up to the practice unexpectedly confrontation occurs and they are removed. This generates RD patients.

Intransigency of RD patients

PSD staff feel that practices tend to assume that RD patients do not change over time and they dread having them back if they have previous knowledge of them. This attitude was mirrored by some PSD staff too.

Influence of older versus younger GPs

One PSD staff member feels that maybe older GPs aren't so used to treating drug users as their job has changed so much since they started practising. This means that younger doctors coming along may deal better with drug misuse problems. However this staff member felt that the older GPs can also be more stubborn at times and hence refuse to remove patients. But younger ones GPs may have new ideas and will try different things. On balance this PSD staff member is not sure if older or younger GPs would be better but in her PSD area a lot of new GPs are coming in as older ones are retiring and it will be interesting to see if this has an impact on the creation of RD patients in the future.

Impact on general practice

Process of removal

Practice receptionists mostly contact PSD about removals/assignments; sometimes the practice manager if a particular issue, in certain circumstances it will be the GP. Because patients are not removed lightly; there will have been a team meeting or a discussion in the practice.

Practices has to provide health care for minimum of seven days after they are registered but if the patient or practice have difficulty with this during that period they can contact PSD to make alternative arrangements so that continuous cover can be provided.

RD patients cause practices to feel

Upset

RD patients tend to upset practices

Exasperated

Practices get exasperated by RD patients; they don't have all day to speak on the phone and cannot do home visits at the drop of a hat.

Example of a patient who would hang up her phone and leave it connected on purpose to block the line. She would give all the GPs a hard time.

Under pressure

Practices can only stand the pressure of RD patients every so often and will sometimes pull out of health board agreements to take RD patients on a rotational basis.

Threatened

Practices often do not cope with RD patients because of their aggression and violence or because they make allegations against the practice.

Angry

Practices can get quite angry that a patient has been assigned to them again.

Time available

Practices do not have the time to spend with patients who seek a lot of time both on the phone, by appointments and with home visits. They have many other patients who need their time and home visits too.

Impact is felt by a range of staff in the practice

PSD staff are aware that particularly for housebound patients it often the nursing staff who are exposed to verbal or physical aggression. As district nursing services are determined by practices then they seek removal from the practices.

Full medical notes availability

The GP records of RD patients who move practices frequently often do not keep up with the patient. The practice may only receive summaries and medication.

Other patients attending the practice

Patients may be frightened by RD patient's behaviour in the waiting room.

Why do RD patients contact PSD?

All NHS patients may contact PSD because they think they can see a GP there who can provide prescriptions or sick lines; or they phone to request a new GP. Some patients turn up angry because they have been removed from a practice (hence the PSD offices have a security entrance and Perspex windows).

Most of the RD patients phone PSD staff with any problem they might have; it may be a medical one or to tell their story of difficulties with a practice. PSD staff observe that these explanations always blame some one else for their problems. Some of these calls are angry or abusive ones; although some patients phone the next day to apologise. Some RD or even ex-RD patients simply phone for a sociable chat.

Impact on PSD

PSD staff wish to be supportive of RD patients

PSD staff see it as their job to get all patients a GP; it is part of what they do. Staff try to be neutral and listen to RD patients but it is hard as phone calls keep staff from their other work. However patients are grateful for PSD staff listening to them.

Time available

PSD staff spend proportionally a lot of time on RD patients. The administration resource required for RD patients is high especially compared to the number of RD patients there are compared to the total number of patients.

Administrative process

PSD staff have to go through the process of taking RD patients off the system; checking that their CHI number is correct, they have to move the medical records; take them in and out of storage and to and fro the practices, they have to send the allocation letters out when removal letters come in. There is a timetable to adhere to all at significant cost to the NHS.

PSD staff have to check that the records are where they should be and that the correspondence has gone out. PSD often find that they have just got the medical records of a RD patient to the practice and the patient has moved somewhere else despite making an urgent request to the previous practice for the records. Trying to make sure that hospital letters keep up with the patient is also difficult.

PSD staff have to spend time carefully checking the allocation lists to look at the patients previous allocation history. PSD staff have to make sure they are being rotated fairly round practices. In the past when there were a lot of RD patients and all moving very quickly some of the PSD staff would keep a tally of which patients were where at any one time.

There is also a lot of written correspondence generated about RD patients because of complaints.

Sometimes the practices will contact PSD for advice as they are about to remove a patient too.

Speaking to RD patients on the phone

Some of the RD patients phone PSD staff frequently and they are the patients they have the most contact with RD patients may phone daily for a number of days or several times a day; this takes a lot of staff resource to deal with; then the calls can peter out for a time but at peak times they can go on for some time.

Being involved in HB management of RD patients

In some health board areas PSD staff are involved in health board management of RD patients.

.In one area PSD staff will contact the local challenging behaviour practice to ask to refer a RD patient after they have learned of incidents in practices. The practice has already removed them but PSD staff have concerns about allocating the patient to a further practice. The challenging behaviour practice will assess the patient; they may say they will be fine in mainstream general practice or they may take them. But PSD staff can say to the subsequent practice that they have taken advice.

PSD staff feel

Frustrated

PSD staff do get frustrated with the system that produces RD patients at times; not the GPs. It is frustrating when a patient has started revolving and PSD staff try to come to an arrangement with practices. When the patient doesn't want that there is nothing PSD staff can do; but they feel they have not delivered.

Fed up

Some staff at PSD will listen to RD patients but after a while you get fed up and think you have other work that needs to be done.

Depressed

It is quite depressing listening to RD patient's problems and not knowing what to say. However this has improved a lot since the number of assignments has reduced.

Upset

Patients being abusive (previously in reception now just on the phone) can be a bit upsetting. One PSD staff member treats every phone call from a RD patient as a new contact; if she didn't use this strategy she would not be able to speak to half of the RD patients because they have been so abusive in the past. This staff member feels that particularly older members of the team get upset by being spoken to in such a manner.

Sad

Some PSD staff members feel sad when listening to what the RD patients tell them especially if they do not seem to receive the care they need; although over the years this can start to feel repetitive as they tell the same stories over and over.

Stupid

Some PSD staff feel stupid when they have initially listened to a RD patient but then months down the line they keep phoning back.

Scared

One PSD staff member feels scared by the thought of seeing RD patients out in the town.

Annoyed

In general phone calls from RD patients can be annoying because it keeps PSD staff from their work

Rewarded

At other times taking the time to listen to RD patients can be rewarding because they are grateful PSD staff have taken the time to listen.

Under skilled to cope

PSD staff often feel that they do not have the skills to cope with RD patients and their complex problems; they are not health care workers or care workers. They feel they can listen and offer suggestions of who would be best to phone for help. They also worry that they would say something that would make the situation worse.

PSD staff have developed coping strategies for dealing with upsetting patients

Different PSD staff cope differently with upsetting RD patients; some only allow a designated person to deal with certain patients; usually the manager; some have personal strategies for not taking their work home with them and some do not allow certain RD patients to make telephone contact with PSD at all. All correspondence must be in writing.

Inappropriateness of information given to PSD staff

One of the PSD staff feels uncomfortable sometimes that PSD staff do find out so much about RD patients, their health problems and what occurs in the surgery; after all they are administrators and not health staff. * Do you think similarly?

Impact on RD patients

Lack of continuity of care

RD patients do not build up a doctor patient relationship and do not experience continuity of care. Maybe one GP will try to get an appointment set up for some treatment but then the patient will be moved on, another GP takes over and this is not pursued. Likewise a patient can get one type of treatment with one GP, move to another and the next GP provides a different treatment. PSD staff expressed concerns that RD patients may not have their treatment reviewed; each practice accepts their repeat prescriptions and continues prescribing what has been prescribed before and may even add to the list of medicines.

This lack of continuity contributes to RD patients lack of stability.

They compare them to patients who visit their GP very infrequently and who may experience a lack of continuity because health staff may have changed. However these patients do not have unmet health needs; unlike RD patients who experience a lack of continuity despite frequent interactions with health staff. They did acknowledge that continuity of care for all patients does vary from practice to practice so if a RD patient did stop revolving continuity would still not be guaranteed.

However PSD staff felt that health visitors would keep an eye on elderly RD patients so the lack of continuity would not impact so much on them; a different case than the younger patients whose poor health is put down to deprivation and where they stay rather than lack of treatment.

Medical records keeping up with the patient

Keeping health records up with RD patients can be a problem; and many have very large records so summaries and medication are sent round instead. PSD staff feel that GPs are not likely to spend time going through the notes anyway. Hospital letters do not keep up either. All of this means that RD patients are not fully assessed.

Access to health care

Referrals to hospital may not be done or their access to secondary care may be slowed down; even if a RD patient is in secondary care successfully this can still cause problems as the secondary care clinicians cannot freely discuss their case with a GP who knows them.

How RD patients are dealt with in the short time they are there depends on the practice District nursing services can only be accessed through being registered with a GP.

Drug users treated differently

PSD staff got the clear impression that RD patients who were drug users felt they were treated differently from every one else. They felt discriminated against.

Stress of constantly moving practices

Being on the move around practices impacts on RD patients health with the stress of trying to build up relationships; getting appointments, trying to get referred to services.

Self worth

PSD staff felt there were two ways that being a RD patient could impact on their self worth; one was that for patients who already have low self esteem it adds another negative thing to add to the list; they cannot get a GP to stay with. On the other hand other RD patients did not see it that way; they see having a doctor as their right; they may have instigated the removal themselves and see it as getting one over on the NHS.

HB management of RD patients

Reorganisation the health board now means that the CHP manager now deals with these issues. The patients still revolve around the same areas.

The gatekeepers of health board involvement

It is PSD staff who speak to the health board (HB) about RD patients they are concerned about.

Triggers are PSD running out of practices to send the patient to, a patient revolving around practices very frequently or aspects of the patient's behaviour that PSD hear about from practices, the complaints manager or that they experience themselves. The decision to involve the HB is based on a hunch and these factors not the number of removals a patient has had. Triggers vary depending on the geographical area the patient lives in and means that in some urban centres RD patients do not have health board involvement as it is possible for them to move frequently without running out of practices.

Sometimes the health board will make arrangement for the existing GP to see the patient in a secure setting; by having a facilitator present or seeing the patient in a hospital setting.

A payment can be made to practice for taking a patient on for a limited time. * Can you clarify that such an arrangement exists and is this true of RD patients?

Commonly if the health board have become involved then an allocation rota of practices is set up. A list of practices has the RD patient (and possibly his/her family if relevant) registered with them for a specific time period and then they move onto the next one. The length of agreement varies from health board to health board and from patient to patient. It is usually three months minimum but examples of patients being rotated every two weeks was given; previously she had only lasted 24 hours with each practice and so some practices were getting her back after just a week and beginning to refuse to have her allocated. Some practices remain reluctant to have her on the two week rotation.

Role of enhanced services

Enhanced services for difficult patients have been set up in some city health boards but not in others; and vary in their perceived effectiveness.

They also vary in their target population; some for violent patients (who are not usually RD patients) and some for patients who exhibit challenging behaviour. The role of these services is to assess and work with patients to achieve compliance with general practice care before moving them back to mainstream GP services. RD patients do get seen in the challenging behaviour practice and occasionally in one of the city homeless practices because one of the GPs will help PSD out when they are struggling to find a practice for a RD patient.

These enhanced services are viewed as providing a breathing space for the GPs who see RD patients; sometimes the patients will not ever be seen at the challenging behaviour practice but during that time they will not be seen anywhere. This may also mean that practices forget what the RD patient is like and will keep them registered for a while.

Setting up these enhanced services is facilitated by having committed enthusiastic clinicians being involved. A drawback of these services is that they cover a large geographical area and it may be difficult for patients to travel to the service. However for these patients who don't fit the norm of patients attending general practice these services are often more responsive to need; they may offer flexible appointments or deal more opportunistically with unmet health needs.

Yellow/red card system

One health board has previously tried a yellow/red card system; if a patient is abusive or not behaving or having relationship problems with the GP they get a yellow card as warning; if behaviour persists a red card and they are removed. This was viewed as a kind of contract between the patient and the GP. Patient would be aware of the consequences. This system didn't work because it was tried out in a rural area who had very few problem patients. The health board subsequently decided to deal with patients on an individual basis as problems arose.

Patient's right not to be registered

The patient's right not to be registered with a GP conflicts with the public health approach that everyone should be automatically registered.

Removal of patient from GMS services

There was one example given of a patient in a rural health board who was removed from GMS and asked to attend the local district general hospital if he had any health needs. This was a unique and extreme case and has not been replicated in Scotland. The patient attended the hospital a couple of times but the hospital is a long way from his home. His behaviour had been extreme. The health board were planning to take the GMS removal decision to the Scottish Executive but it didn't reach there. PSD are not sure what happened to the patient; he may be back in GMS services now.

Suggested future changes for system

Explicit rules

A contract setting out what to expect from general practice and what general practice expects of patients would give clearer guidelines for patients and practice behaviour; but time would be needed to do that.

Sanctions for negative behaviour

Setting limits on RD patient's contact with services may be an option; threatening or imposing removing the right to phone the GP for example. It wasn't clear if this would be a positive or negative influence on RD patients

Payment incentive to practices

Change legislation so that once a patient is identified as RD you would pay practices an incentive for a practice to keep them on; a reward for the perceived extra resources that RD patients use.

Special service for RD patients

A central point where RD patients could be seen and given time and more opportunistic care; but it would need to be properly financed. The potential problems are expecting patients to travel long distances give that it would be unlikely to provide a house call service to attend and the potential stigma such a service would bring.

Reasons patients stop revolving

All patients

Patients may stop revolving because they move away from the area altogether, go to prison, or they form a good relationship with a GP and have their health needs met. Practice staff may treat the patient without prejudice and set aside their previous negative ideas about the patient to help build a relationship.

They may have increased support provided through attending a day centre (although in the example given this idea was sabotaged by frequent changes of GP and did not happen).

Drug misusing patients

The GP may opt to negotiate treatment options and work with the patient. Sometimes a GP will decide to keep a patient no matter what their behaviour and work with them; sometimes a patient will realise they will not access drug treatment any faster through purposively moving round practices. It may be that patient's drug seeking lifestyle has changed; they have matured or become too unwell to engage in the same risk taking and chaotic behaviour that used to result in their removal.

Appendix 7 Instructions for unanonymising the CHI



University of Glasgow | General Practice
& Primary Care

“Revolving door” patients in General Practice **Contact details**

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Planned process for data linkage

1. The (Revolving door) RD cohort is file name *anon.RDpatientsfor ATOS.July07.xls* (673 patients). Sex and partial DOB remain as a double check that the correct patient is reattached to their unique identifier number.
2. ATOS will use the original cohort (33602 patients) with their unique identifier record to un anonymise the RD cohort
3. This means the RD cohort will have **patient name, sex, DOB, CHI and unique identifier number** for export to ISD Scotland. This will be 673 patients.

4. ATOS Origin to make contact with ISD and arrange to send this patient identifiable data in a secure manner. They will contact the researcher to let her know the transfer of data has occurred successfully.
5. The ISD job number is IR2006-00049
6. ISD will carry out the data-linkage on the 673 identifiable patients then re-export the subsequent data to the researcher re-anonymised.
7. Please contact the researcher with any queries.

Appendix 8 Data interrogation questions for Robertson Centre for Biostatistics

‘Revolving door’ patients in general practice: questions for consideration

The priority work is achieving the output for the hospital admissions and outpatient data. If it were to appear useful then to have the non core comparison group would be great.

<i>Question</i>	<i>Andrea already looked at?</i>	<i>comments</i>	<i>Robertson can look at?</i>	<i>comments</i>
1. Defining ‘revolving door’ patients¹²				
Is the definition of a ‘revolving door’ patient statistically robust?	yes	Makes ‘common sense’ based on interview data		
Is there any means of imputing the missing removal data?	yes	No solution found		
What patients are in the ‘revolving door’ cohort using the definition?	yes	Think it is robust!		
Can the non core patients ¹³ be used as a comparison group for the data below?	Yes briefly	368 ‘revolving door’ patients and 305 non core patients		
2. Demographics of the ‘revolving door’ cohort¹⁴				
by age	yes	Seems straightforward: calculated from 30/06/2005		
by sex	yes	Seems straightforward		
marital status	yes	A bit clunky		
By deprivation score	yes	Used SIMD 2006 deciles		
Patient health board of residence	yes			

¹² Refer to 1. Defining ‘revolving door’ patients. thesis.D10, C focus of research and D detail of methods

¹³ These are patients who were included in the data linkage request but who when the definition was refined did not fit the criteria; they either had more than 3 removal episodes but revolved too slowly or had 3 removal episodes but revolved within the time frame. Refer to uniqueidnumbersofRDandnoncorepatients word doc for Andrea’s cohorts of patients

¹⁴ Refer to 2.3.4.5.6.quantstoryofRDcohortMTTd4.doc for this and subsequent analysis summarised. Refer to 2.CharacteristicsofRDpatients word doc for initial qualitative background.

Can the patient's residence be mapped by data zone?	no	But does have a contact who can provide GIS map based on the data; not sure what they would need data wise		
3. Drug misuse data base				
What proportion of patients have a recorded drug treatment episode?	yes	Underestimates prevalence but still v high		
What are the recorded substances?	yes			
Is there a relationship between patient removal episodes and drug treatment episodes?	no			
Is it possible to quantify how much being on the drug misuse database underreports prevalence of substance misuse?	no	Too complex because of problems with complex large data set; the codes are there in admissions and outpatient files		
Is it possible to break this down by substances misused?	yes	Have looked at this for the patients who died		
4. Hospital admissions data (SMR01)				
How many hospital admissions do the patients have?	yes	Based on coding of record files		
What is the time frame for these admissions?	no			
Is there a pattern to the missing data for hospital admissions?	no	Too complex for me; is there a time when recording got better? Should this provide a cut off for considering hospital admissions?		
Is there a relationship between occurrence of patient removal episodes and hospital admissions?	no			
Is it possible to look at prevalence of irregular discharges?	no			
What are the main clinical categories for hospital admissions for the cohort?	yes	Have devised a broad coding scheme based on ICD10 and Read codes ¹⁵ but found data files too complex to be able to summarise ¹⁶		
Is it possible to explore the relationship between the diagnostic codes for each admission?	yes	Really struggled with the complexity; so no output		

¹⁵ Refer to clinicalcodes.variablelabels spss file for labels

¹⁶ Refer to 4.hospadmission.Rdcohortd1 word doc for details

What is the best way to summarise hospital admission data for each patient?	yes	After discussion Andrea going to pursue a qualitative analysis of the hospital admissions and will consider pulling out typical case study examples. Interesting to see how this analysis fits with a robust quantitative analysis.		
5. Outpatient (SMR00) attendances				
How many outpatient attendances do the patients have?	no	Got bogged down in hosp admissions to date!		
What is the time frame for these?	no			
Is there a relationship between occurrence of patient removal episodes and outpatient attendance?	no			
Is it possible to look at prevalence of outpatient attendance and DNA rates?	no			
What are the main clinical categories for outpatient attendances for the cohort?	no	Using same codes for hosp admissions		
What is the best way to summarise outpatient data for each patient?	no	Likely will need to analyse in similar fashion to qualitative analysis of hosp admissions		
6. Patients who have died				
Is there a useful way to summarise the characteristics of the patients who died?	yes	Text description with means summarised in a medically useful way; could be better?		
Is there a relationship between patients revolving status and their likelihood of death?	no			
How do the deaths in the cohort compare to Scottish mortality?	yes	Got stuck; could not work out if SMR is feasible		
7. The disappearance of revolving door patients¹⁷				
Can the data be presented in a more meaningful way?	yes	Presented in a basic format		
Are there any statistical tests that can help explore their significance?	no			

¹⁷ Refer to 7.historicalanalysisofremovals.d1 word doc

Appendix 9 PSD recruitment sheet

Taken off the doctor's list
Listening to patients
November 2009 v3



University of Glasgow | General Practice
& Primary Care

Recruitment sheet for practitioner services staff working in GP allocations

1. When a **request for an allocation comes into the office** consider whether the patient fits the “revolving door” patient criteria:

A revolving door patient has been removed more than three times from practice lists. Each removal episode should be no longer than six months apart; including this episode.

2. **If a patient fits the criteria** then **send a copy of the recruitment letter, patient information sheet and the audio CD to the patient.** (Please write the patient's name on the letter)
3. I do not expect you to provide information to possible participants about the study. If a patient phones seeking this, then **ask them to phone me on (study mobile number) for more information.** (The phone number is on the letter, the envelope and the CD they get through the post.) Please ask the patient to leave their name and phone number and I will phone them back as soon as I can if I don't answer the phone straight away. I am an independent researcher from Glasgow University interested in hearing about patient's experiences of being taken off doctor's lists. The study is not connected to Practitioner Services or the Health Service.
4. Please **note the following** when you contact a suitable patient:

Patient	Patient age	Patient sex	First part patient postcode residence	Date letter sent	Date patient phoned	Notes
01	Eg 31	male	G43	12/01/09	12/01/09	
02						
03						
04						
05						
06						
07						
08						

09						
10						

For ethical reasons I am not allowed to know the identity of the patients until they contact me personally about taking part. **If you are not sure about whether a patient should be recruited please phone me on (study mobile number)** to discuss it (without telling me who the patient is).

Thank you very much.

Andrea Williamson
Researcher, University of Glasgow

Appendix 10 Patient recruitment letter

(headed notepaper)

Dear

Study: Taken off the doctor's list? Listening to patients

Practitioner Services who organise your new GP practice have sent you this letter.

I want to listen to people who have been taken off a doctor's list and are moving to a new GP practice. This is for research I am doing with patients who may have been with several doctors recently.

If you wish to take part or are interested in finding out more about the study then phone me on **(study mobile phone number)**. Please leave a contact telephone or mobile number and I will call you back.

I hope to hear from you soon.

Sincerely,

Andrea Williamson

Researcher

Appendix 11 Patient participant information sheet



University of Glasgow | General Practice & Primary Care

Taken off the doctor's list? Listening to patients

You are being invited to take part in this research. Before you agree to take part you need to know why the research is being done and what it will involve. Please read this carefully and feel free to ask any questions you want.

Who is doing the research?

Andrea is a researcher based in General Practice and Primary Care, University of Glasgow. The study is supported by Greater Glasgow Health Board and Andrea works for both organisations.

What is the purpose of the study?

No one has ever done research asking patients who have been with several GP practices about what they think.

It is important to hear from patients themselves who have been in this situation.

The study is being carried out to understand how patients feel about this and the effect it might have on them.

Why have you been chosen?

Practitioner services have recently organised a new doctor for you and when they were doing this they identified that you have been with several GP practices. I have asked them to contact you because I am interested in hearing what you might say about it.

Do you have to take part?

Nobody has to take part in the study. Taking part is entirely up to you and you are free to stop taking part at any time. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

What does the study involve?

It involves me visiting you at home on a day and time that suits to listen to you. I will have another researcher from the university with me who will be there to make sure that both you and I keep safe. I will record our conversation using a minidisk recorder so that I can remember properly what is said later on. I have done interviews like these lots of times before and although most people are worried at the start they usually relax quite quickly. At all times you only talk about things you are happy to talk about.

Is the research private and confidential?

Yes. Your involvement in the study will be kept completely secret. Your interview will be taped so that I have an exact record of your words. It is normal for the tapes to be stored along with the paper records of the study for five years in a secure place at the University. Then they will be destroyed. Everything you say will be made totally anonymous and your views will be grouped together with those of the other people taking part so that your

identity is hidden. Nothing you say will be reported back to any member of staff or doctor. Information linking who you are with what you say will only be seen by me.

What are the benefits of taking part?

Your help in this study is very important to hear about your experiences of being with several GP practices. There will also be a payment of £20 for taking the time to speak to me.

What will happen if I don't want to carry on with the study?

You can stop taking part in the study at any time. If you do stop, you may decide to allow me to keep the information you have given or ask me to destroy it. Your wishes will be respected.

What if I have concerns or a complaint?

If you have a concern about any aspect of this study, you should first contact me and I will do my best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting: Phil Hanlon, Professor of Public Health, Public Health and Health Care Policy, University of Glasgow, 1 Lilybank Gardens, Glasgow G12 8RZ. (tel no).

What will happen to the results of the study?

The findings will be used to help me write my research degree report. This report will be sent to authorities who may be interested in the findings. It will be published in medical journals too. No one will be able to recognise anyone who has taken part in any reports or publications from this research.

What will happen if you agree to be involved?

After you have phoned me on the number below, I will phone you back and arrange a day and time to visit you. I may need directions to your home. I will ask you to set aside around one hour so that I and my colleague can visit to carry out one interview. We will then arrange another interview a few weeks later that will take around the same amount of time.

Has anyone else checked this research is OK?

The Multi-site ethics committee in Glasgow reviewed the study.

If you do wish to take part, or you require further details about the research before deciding please contact: Andrea on (mobile phone number)

General Practice and Primary Care
University of Glasgow.
1 Horselethill Rd, Glasgow. G12 9LX
[www.gla.ac.uk/departments/general practice/index.html](http://www.gla.ac.uk/departments/general%20practice/index.html)

Appendix 12 GPs recruiting patients letter

(headed notepaper)

21/04/2010

Dear Dr

Research study about “revolving door” patients Study 2: Taken off the doctor's list? Listening to patients

I am carrying out my PhD research into “revolving door” patients in general practice; patients who have been repeatedly removed from GP lists. I am recruiting both patients who are still 'revolving' (GP registration at practitioner services are doing this part) and some patients who may have stopped 'revolving'. The number of patients who are being repeatedly removed has dropped dramatically in recent times and I am keen to try and find out why this may be so.

I am interested in **interviewing patients** who have been **removed more than three times** from practices but who **may have 'settled' in your practice**. These are patients who in the past have been removed at GPs' requests for 'breakdown in doctor patient relationship' or 'violence'; not patients who have moved out of the practice area.

If you can recall any of the patients in your practice who fit this description of ex-“revolving door” patients I would be pleased if you could send **one patient the enclosed recruitment envelope on my behalf**. For ethical reasons I am not allowed to know about possible participants **until they contact me** for further information to take part.

The recruitment envelope contains a letter to the patient with **space for you to write their name and the date**, a patient information sheet and an audio recording of the patient information sheet.

The Glasgow West multi-site research ethics committee approved the study on 2nd December 2008 and NHS management approval has been obtained for Scotland. Ref: 08/50703/1

Please contact me on the above phone number or email address if you have any questions about the study.

Thank you for considering my request.
Sincerely,

Dr Andrea E Williamson
MBChB DTM&H MRCGP MPH FHEA

Appendix 13 Researcher safety protocol

Protocol for researcher safety

- Telephone participant prior to the interview and request background information; age, health issues, who else may be present in the home including pets, directions to their home. This will also provide an opportunity to assess the participant's conversational style and ability to regulate emotions. Inform the participant the researcher will be accompanied. It may be necessary to exclude the participant at this stage if threats are made.
- Schedule the interview for as early in the day as possible and always within office hours and in daylight.
- Check out the location of the home to be visited either through local knowledge (researcher or informant) and familiarise with location, entry and exit from area.
- Ensure that vehicle to be used is in good working order, has sufficient fuel and has no visible items on display prior to visit.
- Carry the minimum equipment necessary to the interview and the minimum amount of cash (participant payment)
- Dress appropriately for the research setting; flat shoes, trousers, smart casual.
- Ensure mobile phone is charged fully and has emergency contact numbers programmed in. Keep phone switched on at all times.
- Ensure personal screech alarm is fully functional and worn within easy access but unobtrusively located.
- Employ research companions that are experienced in working in risky research settings. Brief each other ahead of the interview regarding triggers that will necessitate abandoning interviews.
- Leave full details of the location of the interview with a member of section staff, the time of the interview and how long it is likely to last.
- Agree to phone the section staff member just prior to the interview and phone again when the interview is over and the researcher and companioner have reached a safe area.

- Give the estimated time of the interview and ask the section staff to phone the researchers mobile when the allocated time has passed.
- Agree on a code sentence that if said to the section staff member by phone will trigger an immediate call for the police to attend the interview site.
- An example could be ‘ Mary you will have to cancel my meeting with Graham Watt today’.
- Park the vehicle as close to the home as possible ensuring it is parked so that exit can be prompt.
- Ensure that researcher and accompanier identify the safe exits from the home and conduct the interview in a public room where possible.
- Provide no personal details beyond name and contact number provided on the participant information sheet.

Triggers

These can be considered in terms of threats to physical safety zones and psychological safety zones.

- ⇒ The participant or others in the house are intoxicated with alcohol or street drugs to a degree that the interview cannot be conducted meaningfully or with the risk that the following are more likely to occur.
- ⇒ Actual or perceived threats of physical violence directed against researcher, accompanier or other persons present in house by participant or person in house.
- ⇒ Sexually inappropriate verbalisation that persists such that the researcher or accompanier feels threatened.
- ⇒ Sexually inappropriate behaviour directed against researcher, accompanier or other persons present in house by participant or person in house.
- ⇒ The production or presence of an object that is perceived by the researcher or accompanier to be a weapon that may be used against them.

References: (Davidson, 2008; Paterson, Gregory, & Thorne, 1999; Social Research Association, 2008)

Appendix 14 Patient contact sheet

Telephone contact sheet: participant recruitment

Name:

Address:

Contact telephone number:

Age:

Sex:

Registration office:

Directions to home:

Telephone contact sheet: participant recruitment

Age: Partial postcode residence: Registration office:	Sex:
--	-------------

Participant able to answer the door: YES/NO

Comments:

Anyone else likely to be present at interview: YES/NO

Comments:

Current language and literacy:

Detail risks identified during phone call:

Patient agrees to take part	YES Date:	NO Date:
Patient selected to take part	YES Date:	NO Date:
Patient opts to withdraw	YES Date:	
Permission given to use data to date	YES Date:	NO Date:
Patient withdrawn due to risk	YES Date:	

Comments:

Date and time of first interview: Risks identified? Comments:	Date and time second interview arranged: NO: why not? Risks identified? Comments
--	---

Date Participant payment made:

Name of accompanier:

Reflections on interview(s)

Appendix 15 Topic guide for patient interview

Topic guide for first semi-structured interview: patient participants

Introduction to research: nature and purpose, confidentiality and permission

1. Participant background

- ⊙ Name of participant

2. Participants experience of removal from GP lists

- ⊙ Can you tell me about your experiences of being removed from a GP's list?
- ⊙ Can you tell me about how often it has happened?
- ⊙ Can you tell me about the last time you were removed?
- ⊙ How did it make you feel?
- ⊙ What do you think happened?
- ⊙ What effect did it have on you?
- ⊙ Do you think it could it have been stopped from happening? How?
- ⊙ Have you had any experiences of removal that have really stood out? Can you tell me about them?

3. Participants perception of their health

- ⊙ How would you describe your health?
- ⊙ Are you on treatment for any conditions?
- ⊙ Do you ever go without your medication? Can you tell me about that?
- ⊙ Can you tell me about any worries you have about your health?

4. Participants use of health services

- ⊙ Tell me about who you would usually see if you have a health problem?

- ⊙ Who are you seeing at the moment?
- ⊙ Can you tell me about any other health services that you use?
- ⊙ How often do you use those services?
- ⊙ Can you tell me about the doctors you see?
- ⊙ Can you tell me about the nurses you see?
- ⊙ Can you tell me about a health service you have used that you were very pleased with?
- ⊙ How does this compare with any of the general practices you have been with?

5. Other relationships

- ⊙ Who lives at home with you?
- ⊙ Can you tell me a bit about your family?
- ⊙ Can you tell me a bit about your family background?
- ⊙ Can you tell me about the people you see regularly?
- ⊙ Do you have contact with any services outside health for example housing, social work, etc?
- ⊙ Can you tell me about how you find they work for you?

6. Solutions

- ⊙ Can you remember ever being with a GP practice that you were happy with? Tell me why you were happy?
- ⊙ What do you think a GP practice could do now to make you happy with your care?

8. Closure

- ⊙ Summary and points missed

Appendix 16 Recruitment letter to additional GP key informants

Dr Andrea E Williamson
GP and clinical university teacher

Telephone

E-mail:

00/00/10

Name

Address

..

..

..

Dear

Defining “revolving door” patients: request to take part in a research study

I am undertaking an independent study for my PhD thesis called *'Patients who are repeatedly removed from GP lists: analysing the revolving door'*. I am interested in this topic because of previous clinical experience and research in primary care.

So far the study has aimed to develop a definition of “revolving door” patients, explore their characteristics, and what their existence might mean for the health service. I have looked at CHI data on patient removals, interviewed some key informants and carrying out data linkage with routinely available health service data. I have identified an (anonymised) cohort of “revolving door” patients from 1999 to 2005. The interesting thing is, that when I sought to interview current “revolving door” patients in a follow up study called *'Taken off the doctor's list: listening to patients'* they have disappeared; patients have stopped being repeatedly removed from GP lists.

To bring this 'story' of “revolving door” patients up to date, I am keen to try and find out why patients have stopped being repeatedly removed. I am interested to hear about your experiences of working with ex-”revolving door” patients, and any ideas and opinions you may have about why repeated removals have stopped.

Taking part would involve about one hour set aside out of your normal work day to take part in an interview. The interview would be confidential and for the purposes of the research project only. The study has NHS management and ethics committee approval.

An information sheet sets out the study in more detail and is enclosed along with the proposed consent form.

Please get in touch at the contact number or e-mail above if you wish to discuss any aspect of the study. I will be in touch in a fortnight to discuss whether you have had an opportunity to consider taking part in the study.

Yours sincerely,

Andrea Williamson

Appendix 17 Topic guide for additional GP interviews

Defining “revolving door” patients: Topic guide for semi-structured interviews

Introduction to research: nature and purpose, confidentiality and permission

1. Participant background

- ⊙ Name/sex/ age/professional role of participant
- ⊙ How long have you been in your current post?

2. Definition of “revolving door” patients

- ⊙ What would your **definition** of a “revolving door” patient be? (probe meanings). Can you identify how many times they would need to be removed to become one? Over what time scale would this be?
- ⊙ What **circumstances** do you think led to the production of “revolving door” patients?
- ⊙ What were the **influences** on their production?

3. Exploring the disappearance of “revolving door” patients

- ⊙ In your experience are “revolving door” patients still moving around practices? Tell me about this.
- ⊙ What has happened?
- ⊙ What have been the **key influences** on this in your practice?
- ⊙ What have been the **key influences** on this in your locality?
- ⊙ What have been the **key influences** on this in your health board?
- ⊙ What have been the **key influences** on this nationally?

4. Characteristics of “revolving door” patients

- ⊙ 'Can you describe (without breaking confidentiality) **the last case** of a “revolving door” patient that you dealt with?

- ⊙ Was that person a **typical** case?
- ⊙ What **other types** of “revolving door” cases do you come across? Can you **describe** (without breaking confidentiality) a **recent case** like that?
- ⊙ Are there **other types** of “revolving door” patients you can think of? Please give an example (without breaking confidentiality)
- ⊙ Are there any “revolving door” patients that **particularly stick in your mind aside from** the cases you have already described?
- ⊙ If so (without breaking confidentiality) can you **describe their case** and say **why they stuck**?
- ⊙ In your opinion are there **circumstances common to all** “revolving door” patients? If so, please describe the range of circumstances.
- ⊙ Do you think there are **behaviours common to all** “revolving door” patients? If so, please describe the range of behaviours.
- ⊙ Do you think there are **attitudes common to all** “revolving door” patients? If so, please describe the range of attitudes.
- ⊙ Can you describe (without breaking confidentiality) any patients that have become “revolving door” and that do not **completely fit the usual pattern**?

5. Impact on patients

- ⊙ What do you think the impact of being a “revolving door” patient has had on **patients' access to health care**
- ⊙ What do you think the impact of being a “revolving door” patient has had on **patients' quality of health care**
- ⊙ What do you think the impact of being a “revolving door” patient has had on **patients' health**?
- ⊙ What do you think the impact of being a “revolving door” patient has had on **patients' view of themselves**?
- ⊙ What impact do you think the existence of “revolving door” patients has had on **other patients**?

5. Meaning for GPs

- ⊙ Can you offer any insight into **why GPs may have removed** “revolving door” patients from their list?
- ⊙ Are there practices or GPs who were **more likely to remove** patients than others?

- ⊙ If so, why? Can you (without breaking confidentiality) **describe an example** of such a practice?
- ⊙ If not can you identify what the **main precipitator** is?
- ⊙ Are there practices or GPs who are **more likely to keep on** “revolving door” patients?
- ⊙ If so, why? Can you (without breaking confidentiality) **describe an example** of such a practice?

5. Meaning for participant

- ⊙ What is the importance of patients who have been “revolving door” patients for **you**?
- ⊙ What is the importance of patients who have been “revolving door” patients for your **practice**?
- ⊙ What is the importance of patients who have been “revolving door” patients for the **health service**?
- ⊙ What things (if any) have **changed** now that they stay registered with a practice?

8. Closure

- ⊙ How do you see the **future** for “revolving door” patients in general practice?
- ⊙ Can you think of **anyone else it would be useful for me to speak to** about revolving door patients?
- ⊙ **Summary and points missed**

Appendix 18 Synthesis of practical strategies for improving problem doctor patient relationships

It was not a main focus of this study to seek ways to improve problem doctor patient relationships in general practice. However the literature areas the results prompted me to explore did do. I was struck by the similarities and overlap of the strategies that papers across a range of domains suggested. Some of the professional key informants were already utilising some either explicitly or implicitly in their practice.

I therefore decided to synthesise the strategies into a practical guide for how practices might wish to consider working with doctor patient relationships that they identify as being problematic. This is set out below (Balint, Courtenay, Elder, Hull, & Julian, 1993; Groves J, 1978; Hunter & Maunder, 2001; Mathers & Gask, 1995; McDonald & O'Dowd, 1991; Thompson & Ciechanowski, 2003):

Use a **structured approach** once the practice team think there are issues:

1. Establish a supportive discussion with colleagues; what are the problems:

- a) with the patients presentation?
- b) with the practices response?

Keep that supportive discussion going

2. Aim to provide the same level of general practice care as you would with all your patients and return to this principle each time the way forward gets hazy.

3. Accept that working through this is going to take up more time than you want it to, but working it through has positive outcomes and saves time in the long term.

4. Get all practice staff on board (including the manager and reception staff), be consistent with the approaches set out, and revisit the agreement with the patient if it is not working.

5. Aspire for all staff to be sensitively empathic with the patient at all times by being aware of the negative or dangerous emotions the patient is triggering. Encourage staff to leave these emotions outside of each interaction; and provide the support to allow staff to do this.

6. Put in place the practice boundary strategies that will allow the patient to feel consistently cared for. This means re-attuning patient's behaviour so that the team can meet their health needs sufficiently.

(a) Consider using a written contract that sets out the boundaries of what the patient should expect from the practice (the good care they will receive) and what the practice expects from the patient. This should be tailored to each patient. It might include expected behaviour, reasons for the patient to make contact with the practice, what the patient should do in a crisis.

The areas might cover:

The health outcomes you wish to achieve with the patient.

An acceptable level of phone contacts/appointment regularity/house call requests.

The level of verbal aggression tolerated including consideration of staff and other patients.

Who is it acceptable to bring to appointments.

What to do if a patient is going to miss an appointment.

(b) Schedule a specific long appointment to work this through with the patient; this is the practices attempt to better care for the patient in a supportive way.

7. Can the practice team cope with the current level of difficulty? Consider seeking the input of a mental health professional with explicit articulation of the problems encountered. They can look at formal diagnosis (possibly), may have some community based interventions to suggest, and may be able to facilitate the refocusing of the patient's relationships. This can be made explicit in discussions/the contract with the patient and focussed on support for the patient and the practice team.

Figure 22 Synthesis of GP practice strategies to improve problem doctor-patient relationships

Appendix 19 Addendum September 2012

An error in the original statistical calculations was discovered by the statistician in March 2012 when preparing a paper for journal submission. The mean number of days on list had been calculated instead of the median.

The correct calculations have been carried out and the following have been amended:

- Table 8 p144
- Table 22 and numbers in text on p272
- Figure 19 p273
- Figure 20 p274
- Figure 21 p276

These corrections do not alter the text, meaning or conclusions of the thesis.

A handwritten signature in black ink, appearing to read 'A Williamson', with a stylized, cursive script.

Dr Andrea E Williamson

05/09/2012

References

- Alwin, N. 2006, "The causes of personality disorder," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, first edn, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 41-58.
- Balint, E., Courtenay, M., Elder, A., Hull, S., & Julian, P. 1993, *The doctor, the patient and the group: Balint revisited* Routledge, London.
- Barbour, R. 2001, "Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?", *British Medical Journal*, vol. 322, pp. 1115-1117.
- Bennet, D. & Kerr, I. B. 2006, "Personality disorders in other health care setting," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 323-340.
- Birmingham, L. 1999, "Between prison and the community: the 'revolving door psychiatric patient' of the nineties", *British Journal of Psychiatry*, vol. 174, pp. 378-379.
- Bixby, M. B., Konick-McMahon, J., & McKenna, C. G. 2000, "Applying the transitional care model to elderly patients with heart failure", *Journal of Cardiovascular Nursing*, vol. 14, no. 3, pp. 53-63.
- Blackburn, D. 2006, "What is Personality Disorder?," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 21-39.
- Bloor, M. 1992, "Techniques of validation in qualitative research: a critical commentary," in *Content and Method in Qualitative Research*, G. Miller & R. Dingwall, eds., Sage, London, pp. 37-50.
- Borrell-Carrio, F., Suchman, A. L., & Epstein, R. M. 2004, "The biopsychosocial model 25 years later: principles, practice and scientific enquiry", *Annals of Family Medicine*, vol. 2, pp. 576-582.
- Bower, P., Gask, L., May, C., & Mead, N. 2001, "Domains of consultation research in primary care", *Patient Education and Counselling*, vol. 45, pp. 3-11.
- Brannen, J. 1992, *Mixing Methods: Qualitative and Quantitative Research*, first edn, Avebury, Aldershot.
- Brown, W. 2006, *Regulating aversion: tolerance in the age of identity and empire* Princeton University Press.

Bucks, R. S., Williams, A., Whitfield, M. J., & Routh, D. A. 1990, "Towards a typology of general practitioners' attitudes to general practice", *Social Science & Medicine*, vol. 30, no. 5, pp. 537-547.

Burns, T. 2006, "An introduction to Community Mental Health Teams (CMHTs): how do they relate to patients with personality disorders?," in *Personality disorder and community mental health teams: a practitioner's guide*, first edn, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 179-198.

Butler, C. C., Evans, M., & the Welsh Philosophy and General Practice Discussion Group 1999, "The heartsink patient revisited", *British Journal of General Practice*, vol. 49, pp. 230-233.

Calnan, M. 1988, "Images of General Practice: the perceptions of the doctor", *Social Science & Medicine*, vol. 27, no. 6, pp. 579-586.

Charlin, B., Boshuizen, H. P. A., Custers, E. G., & Feltovich, P. J. 2007, "Scripts and clinical reasoning", *Medical Education*, vol. 41, pp. 1178-1184.

Charmaz, K. 2006, *Constructing Grounded Theory. A practical guide through qualitative analysis* Sage Publications Ltd, London.

Chipalkatti, N. & Rishi, M. 2001, "External debt and capital flight in the Indian economy", *Oxford Development Studies*, vol. 29, no. 1, pp. 31-44.

Commission for Healthcare Audit and Inspection 2007, *Spotlight on Complaints: a report about second stage complaints in the NHS in England*.

Compact Oxford English Dictionary 2005, Third Edition edn, Oxford University Press.

Confidentiality and Security Advisory Group for Scotland 2002, *Protecting patient confidentiality: final report*.

Conrad, P. 1979, "Types of medical social control", *Sociology of Health and Illness*, vol. 1, no. 1, pp. 1-11.

Crane, M. & Warnes, A. M. 2001, "Primary health care services for single homeless people: Defects and opportunities", *Family Practice*, vol. 18, no. 3, pp. 272-276.

Dale, E. 2010, "Is supervised community treatment ethically justified?", *Journal of Medical Ethics*, vol. 36, p. 271.

Daniels, N. 2001, "Justice, health and healthcare.", *American Journal of Bioethics*, vol. 1, no. 2, pp. 2-16.

Davidson, K. How to carry out risk assessment in research settings. 2008. Personal Communication

Davies, J. B. 2000, *The Myth of Addiction*, second edn, Routledge, England.

Davila, J., Burge, D., & Hammen, C. 1997, "Why does attachment style change?", *Journal of Personality and Social Psychology*, vol. 73, no. 4, p. - 838.

Dennerstein, L., Dudley, E., & Guthrie, J. 2002, "Empty nest or revolving door? A prospective study of women's quality of life in midlife during the phase of children leaving and re-entering the home", *Psychological Medicine*, vol. 32, no. 3, pp. 545-550.

Department of Health, E. Equity and excellence: liberating the NHS, white paper.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf . 2010. 29-3-2011. Electronic Citation

Dozier, M., Cue, K. L., & Barnett, L. 1994, "Clinicians as caregivers: Role of attachment organization in treatment", *Journal of Consulting & Clinical Psychology*. Vol.62(4)(pp 793-800), 1994. no. 4, pp. 793-800.

Duany, J. 2000, "Nation on the move: the construction of cultural identities in Puerto Rico and the Diaspora", *American Ethnologist*, vol. 27, no. 1, pp. 5-30.

Elston, M. A., Gabe, J., Denney, D., Lee, R., & O'Bierne, M. 2002, "Violence against doctors: a medical(ised) problem? The case of National Health Service general practitioners", *Sociology of Health and Illness*, vol. 24, no. 5, pp. 575-598.

Emerson, R. M. & Pollner, M. 1976, "Dirty work designations: their features and consequences in a psychiatric setting", *Social Problems*, vol. 23, pp. 243-254.

Feldman, R. 2006, "Primary health care for refugees and asylum seekers: A review of the literature and a framework for services", *Public Health*, vol. 120, pp. 809-816.

Fink, P. & Rosendal, M. 2008, "Recent developments in the understanding and management of functional somatic symptoms in primary care", *Current Opinion in Psychiatry*, vol. 21, pp. 182-188.

Flowerdew, R., Graham, E., & Feng, Z. The production of an updated set of Data Zones to incorporate 2001 census geography and data. www.sns.gov.uk . 2004. Scottish Executive. 9-8-2010. Electronic Citation

Foldi, E. 1999, "The revolving door patient in lymphology-the possibilities and the limitations of the treatment and of the motivation of the patients under inpatient and outpatient conditions.", *Wiener Medizinische Wochenschrift*, vol. 149, pp. 99-100.

Fonagy, P. & Bateman, A. W. 2007, "Mentalizing and borderline personality disorder", *Journal of Mental Health*, vol. 16, no. 1, pp. 83-101.

Fonagy, P., Steele, M., Steele, H., Leigh, T., Kennedy, R., Mattoon, G., Target, M., & Gerber, A. 1996, "The relation of attachment status, psychiatric classification, and response to psychotherapy", *Journal of Consulting & Clinical Psychology*. Vol. 64(1)(pp 22-31), 1996. no. 1, pp. 22-31.

Fossati, A., Feeney, J. A., Donati, D., Donini, M., Novella, L., Bagnato, M., Carretta, I., Leonardi, B., Mirabelli, S., & Maffei, C. 2003, "Personality disorders and adult attachment dimensions in a mixed psychiatric sample: A multivariate study", *Journal of Nervous & Mental Disease*, vol. 191, no. 1, pp. 30-37.

Frank, A. W. 1995, *The wounded storyteller. Body, illness and ethics*. The University of Chicago Press, Chicago.

Fresan, A., Apiquian, R., Nicolini, H., & Garcia-Anaya, M. 2007, "Association between violent behaviour and psychotic relapse in schizophrenia: once more through the revolving door?", *Salud Mental*, vol. 30, no. 001, p. 25.

Frischer, M., Goldberg, D., Taylor, A., & Bloor, M. 1997, "Estimating the incidence and prevalence of injecting drug use in Glasgow", *Addiction Research*, vol. 5, no. 4, pp. 307-315.

Geller, J. L. 1992, "A historical perspective on the role of state hospitals viewed from the era of the 'revolving door'", *American Journal of Psychiatry*, vol. 1992, no. 149, pp. 11-1526.

General Practice Committee of British Medical Association 2005, *Removal of patients from GP lists*.

General Register Office for Scotland. Alcohol-related Deaths - the Coverage of the Statistics. <http://www.gro-scotland.gov.uk/statistics/deaths/alcohol-related-deaths/alcohol-related-deaths-the-coverage-of-the-statistics.html> . 14-8-2008. Electronic Citation

General Register Office for Scotland. Annex A. The definition of drug-related deaths used for these statistics (the GROS implementation of the "baseline" definition for the UK Drugs Strategy). <http://www.gro-scotland.gov.uk/files2/stats/drug-related-deaths/drug-related-deaths-in-scotland-in-2008.pdf> . 2009a. 28-7-2010a. Electronic Citation

General Register Office for Scotland. Table 6.14 Average age at death, selected causes, Scotland, 1977 to 2008. <http://www.gro-scotland.gov.uk/files2/stats/vital-events-ref-tables-2008/ve-2008-t6-14.pdf> . 2009b. 21-6-2011b. Electronic Citation

General Register Office for Scotland. Marital status population estimates. <http://www.gro-scotland.gov.uk/statistics/publications-and-data/population-estimates/special-populations/marital-status.html> . 17-5-2010. 17-5-2010. Electronic Citation

Gillies, J. C. M., Mercer, S. W., Lyon, A., Scott, M., & Watt, G. C. M. 2009, "Distilling the essence of general practice: a learning journey in progress", *British Journal of General Practice*, vol. 59, pp. 356-363.

Goddard, M. & Smith, P. 2001, "Equity of access to health care services: theory and evidence from the UK", *Social Science & Medicine*, vol. 53, no. 9, pp. 1149-1162.

Greene, J. & Hall, J. N. 2010, "Dialectics and pragmatism," in *SAGE Handbook of Mixed Methods in Social and Behavioural Research*, Second edn, A. Tashakkori & C. Teddlie, eds., SAGE, Thousand Oaks, pp. 119-143.

Groves J, E. 1978, "Taking care of the hateful patient", *The New England Journal of Medicine*, vol. 298, no. 16, pp. 883-887.

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. 2003, "Continuity of care: a multidisciplinary review", *British Medical Journal*, vol. 327, pp. 1219-1221.

Hahn, S. R., Thompson, K. S., Wills, T. A., Stern, V., & Budner, N. S. 1994, "The difficult doctor-patient relationship: Somatization, personality and psychopathology", *Journal of Clinical Epidemiology*, vol. 47, no. 6, pp. 647-657.

Harrison, L. D. 2001, "The revolving prison door for drug-involved offenders: challenges and opportunities", *Crime and Delinquency*, vol. 47, no. 3, pp. 462-484.

Hay, G., Gannon, M., Casey, J., & McKeganey, N. Estimating the National and Local Prevalence of Problem Drug Misuse in Scotland.
<http://www.drugmisuse.isdscotland.org/publications/abstracts/prevalence2009.htm> . 2009. University of Glasgow Scottish Executive Report. 23-6-2010. Electronic Citation

Haywood, T. W., Kravitz, H. M., Grossman, L. S., Cavanaugh, J. L., Davis, J. M., & Lewis, D. A. 1995, "Predicting the 'revolving door' phenomenon among patients with schizophrenic, schizoaffective and affective disorders", *American Journal of Psychiatry*, vol. 152, pp. 856-861.

Heyes, A. G. 2003, "Expert advice and regulatory complexity", *Journal of Regulatory Economics*, vol. 24, no. 2, pp. 119-134.

Hiday, V. A. & Scheid-Cook, T. L. 1991, "Outpatient commitment for 'revolving door' patients: compliance and treatment", *The Journal of Nervous and Mental Disease*, vol. 179, no. 2, pp. 83-88.

Hofmann, W., Gougleris, G., Panzer, M., Tigiser, E., Warken, R., & Zimmer, F. P. 1992, "Multiple admissions to the psychiatric hospital- a study about the so called 'revolving door patients'", *Psychiatrische Praxis*, vol. 19, no. 6, pp. 217-224.

Hopkins, L. IR 2006-00049: probability matching. 26-3-2010. Personal Communication

Hora, P. F. 2002, "A dozen years of drug treatment courts: uncovering our theoretical foundation and the construction of a mainstream paradigm", *Substance Use and Misuse*, vol. 37, pp. 12-13.

Hunter, J. J. & Maunder, R. G. 2001, "Using attachment theory to understand illness behaviour", *General Hospital Psychiatry*, vol. 23, pp. 177-182.

Information Services Division NHS National Services Scotland. Alcohol Statistics Scotland 2007.

http://www.alcoholinformation.isdscotland.org/alcohol_misuse/files/Alcohol%20Bulletin.pdf . 2007a. 29-3-2011a. Electronic Citation

Information Services Division NHS National Services Scotland. Deprivation Background. <http://www.isdscotland.org/isd/3207.html> . 2007b. 9-8-2010b. Electronic Citation

Information Services Division NHS National Services Scotland. NHS hospital data quality: towards better data quality from Scottish hospitals; an assessment of SMR01 and associated data 2004-2006.

<http://www.isdscotland.org/isd/2737.html> . 2007c. 29-3-2011c. Electronic Citation

Information Services Division NHS National Services Scotland. Deprivation: Geographical Units. <http://www.isdscotland.org/isd/3209.html> . 2010a. 9-8-2010a. Electronic Citation

Information Services Division NHS National Services Scotland. Improving data collection for equality and diversity monitoring; Ethnicity Completeness in SMR01 and SMR00.

<http://www.isdscotland.org/isd/5826.html> . 1-2-2010b. 28-7-2010b. Electronic Citation

Information Services Division NHS National Services Scotland. Patient removal data including repeat removals from GP lists in Scotland, 1999 to end of March 2010. 2010c. Personal Communication

Information Services Division NHS National Services Scotland. Waiting times statistical publication notice 22nd February 2011.

<http://showcc.nhsscotland.com/isd//6531.html> . 2011. 18-6-2011. Electronic Citation

Information Services Division NHS National Services Scotland & Information Services Division NHS National Services Scotland 1999, *Patient removals from GP lists, year ending 31 March 1999*, Information Services Division, NHS Scotland, number 99/10.

Innes, A. D., Campion, P. D., & Griffiths, F. E. 2005, "Complex consultations and the 'edge of chaos'", *British Journal of General Practice*, vol. 55, pp. 47-52.

Johnson, P. Description of Health Board boxplot of removal and reinstatement dates for the "revolving door" cohort. 2011a. Personal Communication

Johnson, P. Description of missing diagnosis data in SMR01 and SMR00 for the 'revolving door' patient cohort. 2011b. Personal Communication

Johnson, P. Exploring patterns to missing data in the CHI patient removal database 1999 to 2005. 2011c. Personal Communication

Johnson, P. Interpreting the histograms that explore the relationship between patient removal episodes and health service utilisation. 2011d. Personal Communication

Johnson, P. 2011e, *Revolving door analysis report: analysis of patients who are repeatedly removed from GP lists*, Robertson Centre for Biostatistics, University of Glasgow, version 7.

Ka, M. 2006, "Attachment theory in adult psychiatry. Part 1. Conceptualisations, measurement and clinical research findings.", *Advances in Psychiatric Treatment*, vol. 12, pp. 440-449.

Kastrup, M. 1987, "The use of a psychiatric register in predicting the outcome of 'revolving door patient'", *Acta Psychiatrica Scandinavica*, vol. 76, pp. 552-560.

Kelly, M. P. & May, D. 1982, "Good and bad patients: a review of the literature and a theoretical critique", *Journal of Advanced Nursing*, vol. 7, pp. 147-156.

Kendrick, S. The development of record linkage in Scotland: the responsive application of probability matching. www.nap.edu/booksearch.php Chapter 10, 319. 1997. Washington DC, The National Academic Press. Proceedings of the 1997 record linkage workshop. 25-3-2010. Electronic Citation

Khandwala, S. S. Primary care for the perimenopausal woman. Primary Care Update for Obstetrics and Gynaecology 5[1], 43-49. 1998. Abstract

Kirmayer, L. J., Groleau, D., Looper, K. J., & Dominice Dao, M. 2004, "Explaining medically unexplained symptoms", *Canadian Journal of Psychiatry*, vol. 49, no. 663, p. 672.

Klein, D., Njaman, J., Kohrman, A. F., & Munro, C. 1982, "Patient characteristics that elicit negative responses from family physicians", *Family Practice*, vol. 14, no. 5, pp. 881-888.

- Koch, T. 1994, "Establishing rigour in qualitative research: the decision trail.", *Journal of Advanced Nursing*, vol. 19, pp. 976-986.
- Langdon, P. E., Yaguez, L., Brown, J., & Hope, A. 2001, "Who walks through the 'revolving-door' of a British psychiatric hospital?", *Journal of Mental Health*, vol. 10, no. 5, pp. 525-533.
- Ledoux, Y. & Minner, P. 2006, "Occasional and frequent repeaters in a psychiatric emergency room", *Social Psychiatry and Psychiatry Epidemiology*, vol. 41, p. 115.
- Lewis, T. & Joyce, P. R. 1990, "The new revolving door patients: results from a national cohort of first admissions", *Acta Psychiatrica Scandinavica*, vol. 82, pp. 130-135.
- Lichtenberg, P., Levinson, D., Sharshevsky, Y., Feldman, D., & Lachman, M. 2008, "Clinical case management of revolving door patients - a semi-randomized study", *Acta Psychiatrica Scandinavica*, vol. 117, pp. 449-454.
- Lopez, F. G. & Brennan, K. A. 2000, "Dynamic processes underlying adult attachment organization: Toward an attachment theoretical perspective on the healthy and effective self", *Journal of Counseling Psychology*, vol. 47, no. 3, pp. 283-300.
- Loxterkamp, D. 2008, "Why rivers run: on the headwaters of family medicine", *British Medical Journal*, vol. 337, p. a2575.
- MacKinnon, C. Discussion about possible explanations for disordered chronology in CHI removal and reinstatement dates. 23-4-2007. Personal Communication
- Main, M. 1996, "Introduction to the special section on attachment and psychopathology: 2. Overview of the field of attachment.", *Journal of Consulting & Clinical Psychology*, vol. 64, no. 2, pp. 237-243.
- Mair, J. Patient removal data accurate and robustly retrievable from 1999. 7-12-2005a. Personal Communication
- Mair, J. Practitioner services staff know the 'revolving door' patients well. 28-6-2005b. Personal Communication
- Makins, M. e. 1995, *Collins Concise Dictionary* Harper Collins, Glasgow.
- Malcolm, R., Foster, H. K., & Smith, C. 1997, "The problem patient as perceived by family physicians", *The Journal of Family Practice*, vol. 5, no. 3, pp. 361-364.
- Maseide, P. 1991, "Possibly abusive, often benign, and always necessary. On power and domination in medical practice", *Sociology of Health and Illness*, vol. 13, no. 4, pp. 545-561.

Mathers, N. J. & Gask, L. 1995, "Surviving the heartsink experience", *Family Practice.*, vol. 12, no. 2, pp. 176-183.

Mathers, N. J., Jones, N., & Hannay, D. 1995, "Heartsink patients: a study of their general practitioners", *British Journal of General Practice*, vol. 45, no. 395, pp. 293-296.

May, D. & Kelly, M. P. 1982, "Chancers, pests and poor wee souls: problems of legitimization in psychiatric nursing", *Sociology of Health and Illness*, vol. 4, no. 3, pp. 279-301.

McDonald, P. S. & O'Dowd, T. C. 1991, "The heartsink patient: a preliminary study", *Family Practice.*, vol. 8, no. 2, pp. 112-116.

Mechanic, D. 1970, "Practice orientations among general medical practitioners in England and Wales", *Medical Care*, vol. 8, no. 1, pp. 15-25.

Moorey, J., Davidson, K., Evans, M., & Feigenbaum, J. 2006a, "Psychological theories regarding the development of personality disorder," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 59-89.

Moorey, J., Davidson, K., Evans, M., & Feigenbaum, J. 2006b, "Psychological therapies for personality disorder," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, M. J. Sampson, ed., John Wiley and sons, England, pp. 92-123.

Morse, J. 2010, "Procedures and practice of mixed method design," in *SAGE Handbook of Mixed Methods in Social and Behavioural Research*, Second Edition edn, A. Tashakkori & C. Teddlie, eds., SAGE, Thousand Oaks, pp. 341-352.

Munro, J., Sampson, F., Pickin, M., & Nicholl, J. 2002, *Patient de-registration from GP lists: and patient and professional perspectives. Final report to the Department of Health*, Medical Care Research Unit, University of Sheffield.

Munro, J. & Skinner, J. 1998, "Unwelcome customers? The epidemiology of removal from general practitioners lists in Sheffield", *British Journal of General Practice.*, vol. 48, pp. 1837-1839.

Nesheim, R. 1982, "Caring for patients that are not easy to like", *Postgraduate Medicine*, vol. 72, no. 5, pp. 255-266.

Newton-Howes, G. 2006, "Pharmacotherapy and personality disorders," in *Personality Disorder and Community Mental Health Teams: a practitioners guide*, M. J. Sampson, R. A. McCubbin, & P. Tyrer, eds., John Wiley and sons, England, pp. 143-157.

- O'Dowd, T. C. 1988, "Five years of heartsink patients in general practice", *British Medical Journal*, vol. 297, pp. 528-530.
- O'Reilly, D., Gilliland, A., Steele, K., & Kelly, C. 2001, "Reasons for patient removals: Results of a survey of 1005 GPs in Northern Ireland", *British Journal of General Practice*, vol. 51, no. 469, pp. 661-663.
- O'Reilly, D. & Steele, K. 2005, "The removal of patients who live outside the practice boundary", *British Journal of General Practice*, vol. 55, pp. 384-386.
- O'Reilly, D., Steele, K., Merriman, B., Gilliland, A., & Brown, S. 1998a, "Effect of fundholding on removing patients from general practitioners' lists: Retrospective study", *British Medical Journal*, vol. 317, pp. 785-786.
- O'Reilly, D., Steele, K., Merriman, B., Gilliland, A., & Brown, S. 1998b, "Patient removals from general practitioners lists in Northern Ireland: 1987-1996", *British Journal of General Practice*, vol. 48, pp. 1669-1673.
- Onwuegbuzie, A. J. & Combs, J. P. 2010, "Emergent data analysis techniques in mixed methods research," in *SAGE Handbook of Mixed Methods in Social and Behavioural Research*, Second edn, A. Tashakkori & C. Teddlie, eds., SAGE, Thousand Oaks, pp. 397-430.
- Parliamentary and Health Service Ombudsman. Guidance note: removal of patients from a GP's list.
http://www.ombudsman.org.uk/about_us/FOI/whats_available/documents/procedural/removal_98.html . 1998. 27-7-0005. Electronic Citation
- Parry, G., Van Kleemput, P., Peters, J., Moore, J., Walters, S., Thomas, K., & Cooper, C. The Health Status of Gypsies & Travellers in England. A report to the Department of Health.
<http://www.shef.ac.uk/content/1/c6/02/55/71/GT%20final%20report%20for%20web.pdf> . 2004. Report of Department of Health Inequalities in Health Research Initiative. Electronic Citation
- Paterson, B. L., Gregory, D., & Thorne, S. 1999, "A Protocol for Researcher Safety", *Qualitative Health Research*, vol. 9, p. 259.
- Pickering, M. 2001, *Stereotyping: the politics of representation* Palgrave, England.
- Pickin, M., Sampson, F., Munro, J., & Nicholl, J. 2001, "General practitioners' reasons for removing patients from their lists: postal survey in England and Wales", *British Medical Journal*, vol. 322, no. 7295, pp. 1158-1159.
- Practitioner Services Division, N. S. Pro-forma patient removal letter. 2004. Generic

Rabinowitz, J., Mark, M., Popper, M., & Slyuzberg, M. 1995, "Predicting revolving door patients in a nine year sample", *Social Psychiatry and Psychiatric Epidemiology*, vol. 30, pp. 65-72.

Ridd, M., Shaw, A., Lewis, G., & Salisbury, C. 2009, "The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives", *British Journal of General Practice*, vol. 59, pp. 268-275.

Riley, A. J., Harding, G., Underwood, M. R., & Carter, Y. H. 2003, "Homelessness: A problem for primary care?", *British Journal of General Practice*, vol. 53, no. 491, pp. 473-479.

Ritchie, J. & Lewis, J. 2003, *Qualitative Research Practice. A Guide for Social Science Students and Researchers*, first edn, Sage Publications, London.

Ross, J. S. 1952, *The National Health Service in Great Britain*, first edn, Oxford University Press, Oxford.

Sampson, F., Munro, J., Pickin, M., & Nicholl, J. 2004, "Why are patients removed from their doctors' lists? A comparison of patients' and doctors' accounts of removal", *Family Practice*.21(5):515-8.

Sandelowski, M. 2003, "Tables or tableaux? The challenges of writing and reading mixed methods studies," in *Handbook of mixed methods in social and behavioural research*, first edn, A. Tashakkori & C. Teddlie, eds., SAGE Publications, Thousand Oaks, pp. 321-350.

Scambler, G. 1998, "Stigma and disease: changing paradigms", *The Lancet*, vol. 352, pp. 1054-1055.

Schafer, S. & Nowlis, D. P. 1998, "Personality disorders among difficult patients", *Archives of Family Medicine*, vol. 7, no. 2, pp. 126-129.

Schwenk, T. L., Marquez, J. T., Lefever, D., & Cohen, M. 1989, "Physician and Patient Determinants of Difficult Physician-Patient Relationships", *The Journal of Family Practice*, vol. 28, no. 1, pp. 59-63.

Schwenk, T. L. & Romano, S. E. 1992, "Managing the difficult physician-patient relationship", *American Family Physician*, vol. 46, no. 5, pp. 1503-1507.

Scottish Executive. The National Health Service (Choice of Medical Practitioner) (Scotland) Regulations 1998.
<http://www.legislation.gov.uk/ukxi/1998/659/regulation/1/made> . 1998.
29-3-2011. Electronic Citation

Scottish Government. The National Health Service (General Medical Services Contracts) (Scotland) Regulations 2004.
<http://www.legislation.gov.uk/ssi/2004/115/regulation/1/made> 2004 No. 115 (schedule 5 part 2 paragraph 15.1). 2004. 18-5-2011. Electronic Citation

- Seivewright, N. 2000, *Community treatment of drug misuse: more than methadone*, first edn, Cambridge University press, Cambridge.
- Shaw, I. 2004, "Doctors, 'Dirty work' patients and revolving doors", *Qualitative Health Care Research*, vol. 14, no. 8, pp. 1032-1045.
- Smith, L. 1997, "The 'workshy'.", *Psychodynamic Counselling*, vol. 3, no. 4, pp. 419-432.
- Smith, S. 1995, "Dealing with the difficult patient", *Postgraduate Medical Journal*, vol. 71, pp. 653-657.
- Smits, F. T., Wittkamp, K. A., Schene, A. H., Bindels, P. J. E., & Van Weert, H. C. P. M. 2008, "Interventions on frequent attenders in primary care", *Scandinavian Journal of Primary Health Care*, vol. 26, no. 2, pp. 111-116.
- Social Research Association. A Code of Practice for the Safety of Social Researchers. http://www.the-sra.org.uk/staying_safe.htm . 2008. 9-7-2008. Electronic Citation
- Steinmetz, D. & Tabenkin, H. 2001, "The difficult patient as perceived by family physicians", *Family Practice*, vol. 18, no. 5, pp. 495-500.
- Stokes, T., Dixon-Woods, M., & McKinley, R. K. 2003, "Breaking up is never easy: GPs' accounts of removing patients from their lists", *Family Practice*, vol. 20, no. 6, pp. 628-634.
- Stokes, T., Dixon-Woods, M., & Williams, S. 2006, "Breaking the ceremonial order: patients' and doctors' accounts of removal from a general practitioner's list", *Sociology of Health and Illness*, vol. 28, no. 5, pp. 611-636.
- Stokes, T., Dixon-Woods, M., Windridge, K. C., & McKinley, R. K. 2003, "Patients' accounts of being removed from their general practitioner's list: qualitative study", *British Medical Journal*, vol. 326, no. 7402, p. 1316.
- Stokes, T., Dixon-Woods, M., & McKinley, R. K. 2004, "Ending the doctor-patient relationship in general practice: a proposed model", *Family Practice*, vol. 21, no. 5, pp. 507-514.
- Stokes, T. & McKinley, R. K. 2001, "Removal from a GP's list: qualitative research is needed", *British Medical Journal*, vol. 323, p. 754.
- Strauss, A. & Corbin, J. 1998, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* Sage Publications.
- Strong, P. M. 1980, "Doctors and dirty work-the case of alcoholism", *Sociology of Health and Illness*, vol. 2, no. 1, pp. 24-47.
- Sweeney, K. & Heath, I. 2006, "A taxonomy of general practice", *British Journal of General Practice* p. 386.

Taylor, R. E., Mann, A. H., White, N. J., & Goldberg, D. P. 2000, "Attachment style in patients with unexplained physical complaints", *Psychological Medicine.*, vol. 30, no. 4, pp. 931-941.

Thompson, D. & Ciechanowski, P. S. 2003, "Attaching a new understanding to the patient-physician relationship in family practice", *Journal of American Board Family Practice*, vol. 16, pp. 219-226.

University of Glasgow. Code of Good Practice in Research.

<http://www.gla.ac.uk/R-E/pub/reports/index.html> . 2000. 19-4-2006.

Electronic Citation

Waller, E., Scheidt, C. E., & Hartmann, A. 2004, "Attachment Representation and Illness Behavior in Somatoform Disorders", *Journal of Nervous & Mental Disease.*, vol. 192, no. 3, pp. 200-209.

Walsh, D., Smalls, M., & Boyd, J. 2001, "Electronic Health Summaries-Building on the Foundation of Scottish Record Linkage System", *Studies in Health Technology and Informatics*, vol. 84, no. part 2, pp. 1212-1216.

Walter, R. 1998, "The revolving door of hospital readmissions", *Caring*, vol. 17, no. 3, pp. 56-59.

Williamson, A. E. 2004, *Welcome mat or revolving door? Achieving new patient registration with a GP practice*, Master of Public Health dissertation, University of Glasgow.

Womersley, J. 1996, "The public health uses of the Scottish Community Health Index (CHI)", *Journal of Public Health Medicine*, vol. 18, no. 4, pp. 465-472.