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In-house Report 129

**MEDICAL EVIDENCE AND INCAPACITY BENEFIT
APPEALS: EVALUATION OF A PILOT STUDY**

**Medical Evidence and Incapacity Benefit Appeals:
Evaluation of a pilot study**

**A study carried out on behalf of the Department for Work
and Pensions**

By

**Roy Sainsbury and Anne Corden
Social Policy Research Unit
University of York**

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Summary

Chapter 1 Introduction

The background to this research was policy concern with current arrangements for collecting medical information from certifying medical practitioners for use in determining entitlement to state incapacity benefits. One area of concern is the relatively high number of incapacity benefit appeals and the high success rate for appellants which might be an indication of poor quality of initial decisions. The Better Medical Evidence Gathering pilot was designed to test whether improvements in decision making might lead in turn to a reduction in appeals (1.1).

Determination of entitlement to incapacity benefit is a complex process involving collection of evidence from the claimant and their General Practitioner (GP), consideration of this documentation by approved doctors, medical examinations for some claimants and decision-making by Jobcentre Plus staff. An important element in decision making is the Personal Capability Assessment (PCA), a 'score' derived from descriptors of ability to perform everyday activities. People whose claim is disallowed are sent a letter giving the decision and the number of points scored (1.2).

Appeals are heard by a tribunal comprising a legally qualified Chair and a medical member. Full sets of the appeal papers are sent to the tribunal members and the appellant in advance of the date set for the hearing. Appellants may choose to attend in person, and may be accompanied (1.3).

The essential difference between usual and pilot arrangements was that rather than asking GPs to provide information to the approved doctor on the standard report forms, medical information was extracted directly from claimants' GP record. Both the claimant and the GP needed to consent to this (1.4).

This study sought views and experiences of 40 claimants who had been disallowed benefit and six tribunal members (1.5; 1.6). An earlier study (Sainsbury, Corden and Finch, 2003) sought views and experiences of claimants awaiting decisions, GPs, approved doctors and decision makers.

Chapter 2 Views and experiences of incapacity benefits claimants

The study group included 25 people selected because they had made an appeal and 15 selected as non-appellants.

2.1 Deciding not to appeal against disallowance

Non-appellants generally had understood their rights to appeal (2.1.1). At the time, they had understood the letter notifying them of the decision, and remembered it as telling them that their medical condition had been considered and it had been decided they were fit to work (2.1.2).

It proved hard for non-appellants to discuss in detail what kind of information and evidence lay behind the decision, but most put greatest emphasis on their medical examination (2.1.3). Reasons for deciding not to appeal (2.1.4) included:

- agreeing with or accepting the decision
- seeing no point on which to appeal, within current rules
- feeling too angry or humiliated to take the matter further
- wanting to avoid stress for health reasons
- wanting not to be identified as a trouble maker
- lack of financial pressure.

2.2 Appealing against the disallowance of benefit

Various influences (2.2.1) led to a decision to appeal:

- being certain about not being able to work
- views from significant other people
- belief that the medical examination had been inadequate or inappropriate
- anger about the emotional experience of the medical examination
- failure to provide language interpretation for the medical examination
- wanting to remove the perceived implications of '*scrounging*' or '*telling untruths*'
- wanting 'justice'
- financial pressure.

2.3 Experiences of and views on the appeal process

Among reasons for deciding not to attend the hearing were poor health and anticipated negative outcomes for themselves (2.3.1) but travel costs could also be a factor. People who did attend usually wanted the opportunity to explain their circumstances and views. Knowing there would be support from an accompanying person could also be important.

Among those who attended the hearing there was general satisfaction with the way in which the tribunal had been conducted (2.3.2).

2.4 Appellants' understanding of and views on the role of medical information

Most appellants had views about the way in which medical information had been used in deciding their entitlement. There was general understanding that there was a points system. People knew that the information they provided themselves had been considered, and that the assessment of the doctor who conducted their medical examination had been critically important. People were less certain about the

possible role of any information from other sources. Some assumed there might be some information from a GP source but there were often hazy ideas as to what kind of information and how this was provided.

2.5 Views on the pilot arrangements

Among those selected as non-appellants there was little recognition of having taken part in pilot arrangements (2.5.1). Among those who had appealed there was greater recollection of having been asked at some stage for permission for medical information to be sought in some way. A small group of appellants were interested to reflect on the new arrangements. The potential advantages and disadvantages perceived were similar to those identified by claimants in the earlier study. On balance, people were generally in favour of using medical information taken from the GP case records. Those who were not, stressed confidentiality issues and thought better information about them would come from asking their GPs (2.5.2).

The key finding in this chapter (2.6) is that, in this study group, knowledge that people had taken part in the pilot arrangements and that medical information had been sought from GPs' records played no part in decisions about whether to appeal.

Chapter 3 Tribunal members and medical evidence

3.1 Introduction

Three tribunal Chairs and three medical members were interviewed for the research about their views and experiences of using medical evidence in hearing incapacity benefit appeals, and particularly their experiences of hearing cases under the pilot arrangements. Research evidence on the pilot itself was somewhat meagre; the tribunal members interviewed had each heard only a few appeals on pilot cases, and recall was limited.

3.2 The role of the tribunal and the place of medical evidence

Tribunal members interviewed described how they perceived their role and the practices and procedures they would generally adopt in dealing with appeals. Appeals were either considered at 'oral' hearings when the appellant and/or a representative attended, or at a 'paper hearing'. Appeal papers were reviewed before a hearing and any areas of conflict, or inconsistencies and gaps in the evidence, were identified. These were pursued with appellants in oral hearings, or discussed with the other tribunal member in paper hearings.

All medical evidence was considered important. Information from GPs was particularly helpful in preparing for the hearing and when considering conflicts in evidence between the appellant and other sources, such as the medical report form, IB85, prepared by the examining medical officer.

3.3 Reflections on the experience of the pilot arrangements

In discussing their limited experience of the pilot arrangements for collecting information from GPs, tribunal members welcomed the chronological presentation of the information extracted from GP case files, and the inclusion of useful information from, for example, hospital tests, consultations and treatments, X-ray examinations, MRI scans, psychiatric reports and physiotherapy reports.

3.4 Comparing the experience of the standard arrangements with the potential of the pilot arrangements

Tribunal members saw the potential of the SB2 for providing them with a comprehensive, chronological medical history over a sufficiently long period to enable them to have greater confidence in their assessments of functionality. It was also recognised that the utility of the SB2 relied in the first instance on the quality of the GP records, and secondly on the skill and judgment of the doctors extracting the information from those records.

3.5 Other lessons from the medical evidence pilot

The principal use of written medical information by the tribunal was in preparing for a hearing, when conflicts, inconsistencies and gaps were identified. However, the list of questions and issues generated in this way could not be pursued with the appellant if the case was to be heard on the papers only. With no opportunity of asking the appellant or a representative any questions, resolving conflicts of evidence had to rely mainly on the discussions and debate between the two tribunal members. It was difficult therefore for an appeal to be decided in the appellant's favour based only on the papers (3.5.1).

Interviews with tribunal members demonstrate that the IB85 medical report is one of the core pieces of medical evidence that they use in deciding incapacity benefit appeals. However, in some cases there were doubts about the quality and content of medical reports (3.5.2).

3.6 Views on how to improve the collection of medical evidence for incapacity benefit

There was a general recognition that the standard arrangements, based around the IB113 form, were sound in principle. However, rarely was high quality information produced. Ideas for improvement included reforming the system of payment for GPs, so that GPs received a direct 'item of service' payment for completing a report, possibly linked to some form of quality control. Some doubt was expressed however over whether direct payments could change the behaviour of GPs who were either reluctant or too busy to complete the forms. There were some suggestions for redesigning the IB113 form to encourage fuller clinical information and to elicit more information about functionality.

Some tribunal members said they would prefer the pilot arrangements to replace the current arrangements in the future. They saw advantages as:

- information extracted from GP medical records was impartial,
- medical evidence would be available on all cases,
- objective clinical information was preferable to opinion unsupported by clinical findings,
- good clinical information could be an indicator of functionality also,
- the burden of paperwork for GPs would be reduced.

Others' preference was to make efforts to improve completion and quality of IB113 forms from GPs, but these also viewed the SB2 arrangements as a viable alternative. One innovative suggestion was that the CD containing the scanned contents of the GP records could be made available to the tribunal in place of the SB2 form. This would circumvent the possibility that some relevant GP information was overlooked in the extracting process.

Chapter 4 Summary and conclusion

We conclude that information from GPs contributes little to people's decisions about whether to appeal against disallowance decisions or their experiences of appealing. The hope that new arrangements for collecting information directly from GPs' case notes might lead to a reduction in the number of appeals is therefore unlikely to be realised. Nevertheless, there was general support among many of the claimants interviewed in this study for the pilot arrangements. Tribunal members' views about the value of the pilot arrangements were based largely on reflections about their general experiences of using medical evidence rather than distinct recall of individual pilot cases. Nevertheless, there was some support, sometimes strong, for the pilot arrangements, which were seen to address many of the shortcomings of the current arrangements.

The study has been valuable for identifying the role that medical evidence, and information from GPs in particular, plays in the decisions of incapacity benefit claimants and in the work of appeal tribunals. It has also produced findings about the importance of the medical examination, the quality of medical reports, and about paper hearings that can inform future policy thinking about incapacity benefit decision making arrangements.

1 Introduction

This report presents findings from qualitative research by the Social Policy Research Unit at the University of York to evaluate the impact of the Better Medical Evidence Gathering Pilot on claimants whose application for incapacity benefit was disallowed during the pilot, and on members of appeal tribunals who hear incapacity benefit cases. The pilot was set up by the Department for Work and Pensions (DWP) in the Sheffield and Rotherham area and ran for most of 2002. Its aim was to test innovative arrangements for providing medical evidence to approved doctors¹ who give advice to decision makers who determine eligibility for state incapacity benefits. These new arrangements would, it was hoped, improve the evidence gathering process for incapacity benefit, and the overall efficiency of the decision making process, including at appeal. Two studies to evaluate the impact of the pilot up to, but not including, the appeal stage were conducted concurrently with the pilot during 2002 and published in 2003. In a report by Sainsbury, Corden and Finch (2003) the experiences of the pilot arrangements of claimants, GPs, approved doctors and decision makers were investigated qualitatively. We make reference to this publication as 'the earlier report' at various points in this report. Marlow and McLaughlin (2003) present statistical analyses of the outcomes of 1030 pilot cases and a comparison group of 1489 non pilot cases.

1.1 The policy context for the pilot

There has been considerable concern for a number of years about the quality of decision making on incapacity benefit claims (Department for Work and Pensions, 2002; Social Security Select Committee, 2000; National Audit Office, 2001). Problems with the administration of the benefit have been thought to be a contributory factor in the rise in the number of claims in payment over the past 15 years or so. It has also been suggested that the high number of incapacity benefit appeals (in comparison with other benefits) and the high success rate for appellants might also be an indicator of poor quality of initial decisions.

Decision making relies on a number of sources of information, including the claimant's General Practitioner (GP). The Better Medical Evidence Gathering pilot was intended to test whether improvements in decision making could be gained by changing the way in which medical information from GPs was collected and used by Departmental medical advisers and decision makers. Improving the quality of decisions on incapacity benefit claims was not only seen as a worthwhile aim in itself but also was expected to lead to a reduction in the number of appeals. The rationale

¹ See Appendix E 'Note on Terminology' for an explanation of the term 'approved doctor'.

behind this expectation was that if claimants were aware that decisions on their incapacity benefit claims were based on full and comprehensive medical information then they would be more likely to accept them as correct and not appeal. The intention was not to discourage appeals from claimants who had grounds for disputing decisions, but to reduce unnecessary appeals from people whose decision would eventually be upheld as correct by a tribunal.

1.2 Incapacity benefit and medical information

Incapacity benefit² is the main social security benefit for people whose health or disability is deemed such that it is not reasonable to expect them to seek work as a condition of receiving benefit. People gain entitlement to incapacity benefit if they have paid National Insurance contributions on their earnings and they satisfy the relevant test of incapacity³. Decisions on claims are made by Jobcentre Plus decision makers on the basis of information collected through self-assessment questionnaires completed by the claimant, medical advice from an approved doctor (which may include evidence collected in a face-to-face examination) and factual evidence from the claimant's own doctor, usually the GP.

The administrative processes for deciding incapacity benefit claims are not straightforward. It is not necessary for the purposes of this report to describe all stages of the decision making process, which are covered fully in the earlier report on the pilot (Sainsbury, Corden and Finch, 2003). The important and relevant part of the process for people whose claim is disallowed is the medical examination carried out in connection with the *personal capability assessment* (PCA). The PCA is the core medical test of eligibility for incapacity benefit receipt. It provides an indication of the extent to which a person's health condition affects their ability to do a range of everyday work-related activities covering:

- physical functions such as walking, lifting, bending or stretching
- sensory functions such as ability to hear
- mental functions such as interaction with other people.

The purpose of the test is to identify people whose health affects their ability to carry out physical and mental functions to such an extent that they should not be expected to seek work as a condition of receiving state financial support. The test is not designed to produce judgments about whether someone is *incapable* of working, and

² Incapacity benefit is a generic term covering contributory incapacity benefit and income support (on the grounds of incapacity). Both provide a replacement income to people below state pension age who have to stop working or looking for work as a result of sickness or disability. If someone has low income, they can claim income support on the grounds of incapacity and some may also be able to get income support to top-up their incapacity benefit where they have no other income.

³ If a person has not paid enough National Insurance contributions but satisfies the relevant medical test, he or she can get National Insurance credits.

in particular is not linked to a person's normal occupation. In Chapter 2 we will examine the extent to which people's understanding of these distinctions affects their decisions about whether to appeal against a disallowance.

Some claimants are automatically exempted from the PCA because they have a terminal illness, are in receipt of the highest rate care component of disability living allowance, or have conditions such as paraplegia, dementia or registered blindness. Other claimants may also be exempt, such as those with mental illness, progressive impairment of cardio-respiratory function, or dense paralysis. Claimants who are not exempted are required to complete the self assessment questionnaire mentioned above (form IB50) in which they are asked to choose between different physical and mental 'descriptors' of their ability to perform everyday activities. The descriptors each have a numerical value that are combined to produce a 'score' for the claimant. A combined score of 10 on the mental health descriptors alone or a score of 15 across all descriptors is required to be eligible for incapacity benefit. An award for incapacity benefit is usually made for a limited period after which a renewal claim is invited for which the assessment procedures will be carried out again.

Claimants who score lower than 15 on their IB50 or where their choice of descriptors does not appear to be supported by medical evidence are asked to attend a medical examination by an approved doctor (known as an examining medical officer, or EMO). EMOs complete a medical report after the examination (an IB85) in which they make a separate choice of descriptors based on their assessment of the claimant's ability to carry out everyday activities. The IB85 forms part of the case file for the claimant that is used by a Jobcentre Plus decision maker to make a final decision about eligibility.

People whose new or renewal claim is disallowed are sent a letter giving the decision and setting out the number of points scored. The letter also explains that a fuller verbal or written explanation of the decision can be supplied on request and that they have the right to appeal against the decision.

1.3 The appeals process

Claimants wishing to challenge their incapacity benefit decision must lodge an appeal within four weeks of receiving the decision letter. This can be done using a standard appeal form or by writing a letter. Appeals are processed by a separate agency of the DWP, the Appeals Service, and heard by a tribunal comprising a legally-qualified Chair and a medical member.

The Appeals Service prepare the appeal papers which will include all relevant information including the claimant's original claim form and self-assessment questionnaire, medical information collected from the claimant's GP or other sources,

the medical report from the EMO, and any other information collected in the course of processing the claim or supplied subsequently by the appellant. Full sets of the appeal papers are sent to the tribunal members and the appellant in advance of the date set for the hearing. Appellants are required to state whether they wish to attend the hearing in person (known as an 'oral hearing'). If they do not reply the tribunal will hear the case in their absence (called a 'paper hearing'). Appellants at oral hearings may be accompanied, for example by a representative of an advice or welfare rights organisation or by a friend or relative.

In making their decision the tribunal is able to draw on all the information in the appeal papers and, for oral hearings, verbal evidence provided by the appellant and anyone accompanying them. If the tribunal think that further information is needed, they may adjourn the hearing to a later date.

1.4 How the pilot arrangements differed from standard procedures

Medical information from GPs to help inform decision making on incapacity benefit claims can be supplied in two principal ways. First a claimant might request and obtain a Med 4 form from their GP. The medical information on a Med 4 certificate comprises a statement of the claimant's health condition that is the reason for being off work. Further information may be requested from the GP by Jobcentre Plus staff on a specifically designed form, IB113 (replicated in Appendix D). The IB113 seeks factual information, including clinical information on the diagnosis, treatment, medication and prognosis of the GP's patient, information about the effects of medical conditions on daily living (such as self care and mobility), and details relating to mental health. Under their NHS contract GPs are required to provide Med 4 statements to patients and to complete IB 113 reports for a medical officer on request and are paid for doing this work under their general NHS remuneration.

Part of the rationale for establishing the pilot was that IB113 forms were sometimes not returned by GPs, and in other cases were not completed sufficiently well to contribute much to the task of decision making (including the formulation of advice by approved doctors). According to internal information supplied to the research team by DWP, useful IB113 forms are received in only a minority of incapacity benefit cases. A further reason behind the search for an alternative to the IB113 arrangements was that the burden on GPs of paperwork has been a source of concern for policy makers and GPs themselves for a number of years (Ritchie and Hiscock, 2001; Cabinet Office, 2001, 2002; Sainsbury, Corden and Finch, 2003).

Under the pilot arrangements, participating GPs were not required to complete IB113 forms for patients who were also participating in the pilot. Instead GPs made available to the benefit authorities the claimant's medical records. GPs had the choice of either supplying photocopies or complete print outs of records or allowing

the paper records to be removed from surgery premises for a short time while they were scanned onto CDs⁴. The copies were then forwarded to the Leeds Medical Services Centre where specially trained doctors extracted and collated information relevant to the claim. Only information for the five years prior to the claim was examined. The information was entered on a specially designed form, SB2 (see Appendix D), and might include, for example, extracts from the GP's own medical notes, hospital diagnostic tests (such as X-ray or pathology reports), letters from hospital consultants, or reports from other health or related professionals.

SB2 forms were used in a number of ways to inform decision making on incapacity benefit claims. Importantly for this study, they were available to the doctors (EMOs) carrying out medical examinations as part of the PCA process, and to Jobcentre Plus decision makers who make final decisions on claims⁵. People making appeals against decisions would receive a copy of the SB2 in the appeal papers prepared by the Appeals Service.

In the course of 2002, decisions were made on over 1000 claims under the pilot arrangements. Marlow and McLaughlin (2003) report that by March 2003, 198 of these claims had been disallowed following completion of the PCA.

1.5 Research aims and objectives

The overall aim of this second research study on the Medical Evidence Gathering pilot was to investigate the impact of the pilot arrangements on the views and experiences of the principal actors at the appeals stage: claimants of incapacity benefit whose claim had been disallowed (including some who had lodged appeals), and members of appeal tribunals.

The research addressed the following questions in relation to claimants:

- what did people understand about their appeal rights?
- what did people understand about the initial decision on their claim?
- why did people decide to appeal or not to appeal?
- what role did medical information play in people's views and decisions?
- what were people's views about the pilot arrangements?

For tribunal members, the following questions were explored:

- what role did medical information (particularly from GPs) have in the work of a tribunal?

⁴ See Sainsbury, Corden and Finch, 2003, for an account of GPs' experiences of these arrangements.

⁵ See Sainsbury, Corden and Finch, 2003, for a full analysis of the use of SB2 forms in the decision making process up to, but not including, the appeals stage.

- what was their experience of hearing appeals on claims decided under the pilot arrangements?
- what were tribunal members' views and preferences about the collection of medical information?

1.6 Research design and methods

A qualitative approach was appropriate for exploring claimants' and tribunal members' perceptions, views and experiences of the Medical Evidence Gathering pilot arrangements. In-depth interviews were carried out with:

- 25 incapacity benefit claimants who had lodged appeals
- 15 incapacity benefit claimants who had not appealed
- 3 tribunal Chairs
- 3 tribunal medical members.

Interviews were carried out by telephone with claimants and face to face with tribunal members, and tape recorded with the permission of the respondents.

1.7 Structure of the report

Chapter 2 presents the views and experiences of incapacity benefits claimants in the Sheffield and Rotherham area whose claim was dealt with and disallowed under the pilot arrangements during 2002. It explores the extent to which the pilot arrangements contributed to claimants' decisions about whether or not to make an appeal, and whether the collection of medical evidence affected the experiences and views of those who did appeal. Respondents' views about the pros and cons, and the desirability, of the pilot arrangements are also analysed and presented.

In Chapter 3 we initially explore how medical information is used in the work of appeals tribunal members, and the particular use of information obtained from GPs (under both the pilot and standard arrangements). We then focus on views and experiences about the pilot arrangements and present tribunal members' assessments and preferences about how medical information might best be collected in the future.

The concluding chapter draws together the findings from incapacity benefit claimants and tribunal members and discusses the implications of the pilot for developing policy in relation to incapacity benefit and medical evidence.

Appendices provide full details of research methods and the analysis of data. Appendix A includes details of the selection and characteristics of the claimants and

tribunal members who took part in the research. Appendix B contains copies of letters sent to claimants and tribunal members. Appendix C contains topic guides used in interviews with research participants. Two of the most relevant official medical evidence forms, the IB113 and SB2, are reproduced in Appendix D. Appendix E provides a note on some of the technical terms used in the report.

1.8 A note on the use of interview data

In reporting findings from interviews with incapacity benefit claimants and appeal tribunal members in Chapters 2 and 3, we have adhered as far as possible to the use of language adopted by the respondents. For example, claimants did not refer to 'examining medical officers' when discussing their experiences of the medical examination. They most commonly referred to 'the doctor' or occasionally the 'examining' or 'examination' doctor. This use of terms is reflected in Chapter 2. In contrast, tribunal members were more familiar with official titles of roles and often referred to 'EMOs'. Again this is reflected in how we report findings in Chapter 3.

Where we have used the verbatim words of respondents to indicate the way in which people describe their experiences we have put these in italics within single quotation marks.

2 Views and experiences of incapacity benefits claimants

This chapter brings together the views and experiences of incapacity benefits claimants in the Sheffield and Rotherham area whose claim was dealt with and disallowed under the Medical Evidence Gathering pilot arrangements during 2002. The focus of interest is whether the pilot arrangements played any part in claimants' decisions about whether to pursue an appeal after disallowance and whether the way in which medical evidence had been gathered affected the experiences and views of those who went to appeal.

When the pilot was designed it was hoped the arrangements would produce better and more accurate decisions and that claimants would more readily accept these and not appeal because they would have greater confidence in decisions based on information extracted directly from their GP records. In the first part of the chapter we look for any evidence that this happened and report what non appellants said about why they did not appeal against their disallowance. Part 2 is concerned with what influenced those who did decide to appeal, and Part 3 with appellants' decisions about whether to attend the hearing, and the general experiences of those who did. Findings about appellants' understanding of the role of medical information and the way in which it was collected and used is brought together in Part 4. The pilot arrangements were hardly mentioned spontaneously, but interviewers specifically sought respondents' views about these, towards the end of the interviews, and findings here are drawn together in Part 5.

Appendix A explains the selection of the 40 incapacity benefits claimants whose views were sought for this part of the research, and provides a summary of their main characteristics. Twenty-five people in the study group were selected because DWP records indicated they had appealed against the disallowance and 15 because they had not. We use the terms 'appellants' and 'non appellants' for purposes of description of these two sub-groups, and make distinctions between the two groups in the text where appropriate.

2.1 Deciding not to appeal against disallowance

2.1.1 Understanding the right to appeal

In order to appeal against a disallowance people had to know that this was possible and understand how to start. Only one person interviewed as a non appellant said they had not known they could appeal. The right to appeal was otherwise generally understood in this group. People remembered that the letter notifying them of the

decision that benefit had been disallowed made it clear that they had a right to appeal, and explained how to do this. Although some could not remember at the time of interview what they had to do to start the appeal process, they were confident they had been told this in the letter.

Knowledge about rights of appeal and how to do this had often been strengthened in discussions with domestic partners or parents, or a GP. People who got in touch with a benefits office to enquire what would happen next remembered being told about their right to appeal and how to do this. The study group included people who had previous experience of appealing against a benefit decision, or whose partners had done this.

It was not the case that the non appellants, as a group, lacked knowledge that they might appeal or did not know how to do this. The one person who told the interviewer that she had not known she could appeal was not much interested when told, and said she would not have appealed anyway, being *'not that sort of person'*.

2.1.2 Understanding the reason for disallowance

Another reason for deciding not to appeal might have been some confusion about the reasons for disallowance - people might lack confidence in challenging something they felt they did not understand. We found little evidence of this among those interviewed as non appellants. Although some had forgotten the way in which reasons for their disallowance had been presented in the letter notifying the decision, there was general agreement that at the time they had understood the letter and why they had been disallowed. They understood that their medical condition had been considered and it had been decided they were fit to work.

Some people remembered the letter as telling them that they weren't *'in a bad enough category'*; that *'they could do things like walking around, looking after themselves or doing their own shopping'*; that their hospital tests showed *'there was nothing wrong'* or that *'I didn't have the physical conditions I was claiming to have'*. Such phrases show how the content of the letter was recalled; the language actually used in such letters is not known.

Some remembered the letter explaining how they had been assessed in a points system, and had understood that their score was not high enough for entitlement. Recall was variable, both in terms of people's own score and of the number of points required for entitlement. Those who remembered they *'needed 15 points'* or *'didn't get enough points'* included people who said they had scored zero or two, as well as people who were very close to the threshold. On prompting, some of those people who had not mentioned spontaneously being told about the points system did remember reading something about it, but struggled to say much more.

Only one man, approaching retirement age, could remember nothing about the contents of the letter of disallowance except being told about his right to appeal.

2.1.3 Understanding how the assessment had been made

Although most of the non appellants could remember something about the explanations for their being considered fit for work it proved hard for them to discuss in detail what kind of information and evidence this had been based on. Some had not thought about such things for several months, and the experience of the disallowance had sometimes been overlaid by experiences of other claims for various benefits, or had become hazy through time.

Most people put greatest emphasis on the medical examination, in terms of the interaction between the doctor and themselves. People could remember the occasion and some of the components of the physical examination such as being asked to bend down or pick things up. Some remembered the doctor listening to their heart or taking their blood pressure. Some had been surprised that they had not had a physical examination of this kind, and that the doctor had just asked questions.

People found it hard to think about what other information about them the doctor who conducted the examination might have had. The only person in the non appellant group who was confident that the doctor had some information about them from the GP source was a man who had taken part in the earlier study (Sainsbury, Corden and Finch, 2003) and discussed then with a researcher what might happen in a medical examination. One person felt confident that the doctor had no information about her from a GP source when he conducted the medical examination; others did not know. The questionnaires which claimants had filled in themselves were only rarely suggested as information that might have been available to the examining doctor.

In only one interview did the potential contribution of information from the GP emerge as a significant issue when those interviewed as non appellants thought about their medical assessment. This was a person for whom the medical examination had been a bad experience. He thought the doctor had not examined him thoroughly and had not understood the seriousness of his condition and the family history of ill health. He thought the doctor might not have had all the relevant information that was available in his GP file, and that the doctor had not believed him.

Apart from the person last described, people discussed whether they were satisfied with the medical examination mainly in relation only to the interaction between themselves and the doctor. As we might expect, levels of satisfaction were variable. Some had found the examining doctor *'helpful and understanding'* while others said simply that there had been no problems. Feeling that the doctor had not really understood how their condition affected them left some people dissatisfied. People came away angry if they felt they had not been believed.

2.1.4 Deciding not to appeal

Reasons people gave for deciding not to appeal included:

- agreeing with or accepting the decision
- seeing no point on which to appeal within the rules, although disagreeing with the rules
- feeling too angry or humiliated to take the matter further
- wanting to avoid stress, for health reasons
- wanting not to be identified as a trouble maker
- lack of financial pressure.

As we might expect, people who were expecting disallowance or thought it was a real possibility were not surprised when this happened. Some people were looking towards resuming work again after a long period of recovery and rehabilitation and did not expect their claim to be renewed. Included here was one person who had been interviewed in the earlier research, and was then already going for interviews for jobs. Such people felt satisfied with the outcome, and did not consider appealing. They were more interested in moving forwards to try to start work, and some sought further help from the Jobcentre at this point. It could even be a relief to a person to be told that they were considered able to work, for example if a GP or family members were urging caution in resuming work but the person concerned felt ready to try work and was looking for a boost to confidence.

Also among those who accepted the decision were people who said they had not been confident they would be allowed benefit, and for whom disallowance would not be a surprise. Included here were people who had been advised at the Jobcentre that they might be entitled and it was worth claiming, but who felt themselves that work might be a possibility for them.

We turn now to those who disagreed with the decision, and had been expecting to be allowed benefit. Included here were people who felt ill and incapable of working, or who had assumed that the nature of their impairment meant they would qualify. One man expected to be allowed benefit because he was unable to work in his previous job, and one man reported that the last words of the examining doctor had been to the effect that he need not worry about his renewal.

Also expecting to get benefit was a man who said he felt he *should* be allowed benefit because he had worked hard all his life, and now that he was nearing retirement age it would be hard to get work he could do. This illustrates well the limited understanding of benefits which some people have.

People who were expecting to get an award but decided not to appeal gave a variety of reasons.

One person understood how his points score had been decided, and did not disagree with this. However he did disagree with the construction of the points system - there were no points to reflect difficulty in *'getting going'* for people like him who could walk eventually but might need two or three hours to get mobile. Under the current rules, however, he felt there was no point on which to appeal.

Some people described feelings of anger, humiliation and frustration, attached to either the medical examination or the decision, which led them to decide to have nothing more to do with the matter. Wanting to avoid any further stress which might make mental health conditions worse could also be a strong influence. Some people were reluctant to initiate any actions which they perceived might risk being identified as a trouble maker, or somebody who made a fuss. Making too much fuss might, one person perceived, put at risk continued receipt of income support. Another person perceived risk to his family security in being identified as a trouble maker from a minority ethnic group.

Finally, some people said availability of an alternative or adequate income source meant that loss of incapacity benefit had little financial impact. Such people said that they might have made a different decision about appealing if there had been financial pressure. Across the group as a whole, however, there was rather little mention of the potential financial impact of disallowance on decisions about appealing, but this may have been because when people were considering whether to appeal they had not yet discovered the full financial impact.

Individual people sometimes described more than one of the above reasons for not appealing, for example feeling too angry to take any further action and at the same time seeing it as important not to be identified as a trouble maker.

Bringing together the findings in this section, there was no evidence that knowing about the way in which medical evidence was collected and dealt with under the pilot arrangements had any effect on decisions not to appeal among the non appellants interviewed in this part of the study. It was the interaction with the examining doctor that was recalled as the most significant source of medical information in the disallowance decision. It should be noted, however, that people were interviewed some time after the medical examination and the disallowance, and it is likely we have only a partial picture which people were able to reconstruct for the interview.

2.2 Appealing against the disallowance of benefit

The hope was, in the design of the pilot arrangements, that knowledge that medical information from the GP records had been made available to the examining doctor might reduce the number of appeals. It was acknowledged, however, that the opposite effect was also possible. Knowing that they had taken part in new

arrangements in a pilot process, or belief that information in the GP records might have had a negative impact on decisions about their entitlement, might have encouraged some people to make an appeal. In this part of the chapter we look for any evidence of such effects on those people who appealed against disallowance of benefit. We also look for any evidence that some people understood how medical information from their GP records had been made available but still went ahead with their appeal.

2.2.1 Deciding to appeal

Most people recruited to the study as appellants explained to the interviewer why they had appealed. Overall, the various influences described included:

- being certain about not being able to work
- views from significant other people
- belief that the medical examination had been inadequate or inappropriate to their condition
- anger about the emotional experience of the medical examination
- failure to provide language interpretation for the medical examination
- wanting to remove the perceived implications of ‘*scrounging*’ or ‘*telling untruths*’
- wanting ‘justice’
- financial pressure.

This section goes on to discuss these different influences on why people appealed. Some people described various contributory strands in their decision, while some focused on one particular issue. (The discussion of appellants’ understanding of and views on the role of medical information comes later in section 2.4 of this chapter.)

Those people who were certain they were not able to work had generally not been expecting disallowance. Included here were people who had long-standing or deteriorating conditions such as angina and arthritis; people who were currently receiving treatment for depression when they were disallowed; and people who had received incapacity benefit for several years and whose condition had not changed. Some of the respondents nearing retirement age combined the effects of age and health problems in their judgement that they were unable to work.

People’s own feelings that they were unable to work could be strongly reinforced by significant other people. Discussions with GPs which people remembered as having included their GP’s opinion that work was inadvisable or might make conditions worse had been influential. Some people said that their domestic partners, or other relatives or friends had agreed that they could not work, or would be very concerned about any attempts to try working. For example, spouses who had major responsibilities for caring for the person concerned could be anxious that conditions such as anxiety or alcohol addiction would be worsened, even by stress in thinking about returning to employment.

Much of the explanations for appealing focused on aspects of the medical examination by the examining medical officer. In retrospect, these examinations had often been considered inadequate or inappropriate to people's conditions. There was a widespread feeling that the doctor had not spent sufficient time on the examination, which was sometimes remembered in terms of '*a few minutes*'. What were perceived to be very short encounters were sometimes contrasted with long periods of time preceding the examinations, when people were kept waiting for appointments. There was also some expectation that when people had conditions which affected their mobility, flexibility, circulation or breathing the doctor would then conduct a thorough physical examination. Some people expected the doctor to listen to their heartbeat or breathing; to look at their bodies for the evidence of arthritis or injury; or to conduct a hearing test. Doctors who did not do what was expected in this way were considered not to be doing their job properly, and not in a position to give a professional view about the person's condition.

Those direct physical investigations which were conducted could sometimes be interpreted as inappropriate, however. If doctors asked people to do something which caused pain or discomfort, such as raising limbs or bending down, then this could be interpreted as poor medical practice, and another example of doctors not doing their job properly. People currently experiencing depression or anxiety had sometimes felt that the doctor had not asked them the questions which would reveal how their condition affected them.

Some people focused more on the way in which they had been treated or spoken to by the examining doctor, which had left them feeling humiliated or angry. Some reported surprise and shock when the doctor had shouted at them; refused to answer their questions, or when they left medical examinations feeling bullied, or considered a '*liar*' or '*malingerer*'. Comments made about their clothes and personal appearance, or those of accompanying children, in relation to the extent of depression this might indicate, were unacceptable to some people.

Some people felt that examining doctors used '*tricks*' instead of asking them directly about their conditions. For example, one person believed that he had been watched from a window while negotiating the external stairs as a test of his claim that it was hard to manage stairs. Some people who had been asked to wait for long periods for the appointment felt that this was a test of their claim that it was hard to sit down for lengthy periods. People were angry to have been treated in this way, especially if such perceived '*tests*' meant they experienced additional pain, exhaustion or stress.

Problems in talking to the examining doctor were reported by one claimant as due to inadequate provision of language interpretation. Although he had asked in advance for an interpreter, nobody arrived to fill that role at his first appointment. At the second appointment the interpreter provided did not speak the appropriate language. The respondent had difficulties trying to communicate with both the interpreter and

the examining doctor, and was frustrated and angry. When he learned about the disallowance he was sure this was due to his inability to talk to the doctor and explain how his condition affected him.

Other reasons for appealing that people described illustrate some of the general misunderstandings which people have about the legal basis of an appeal. There were some feelings that it was *'quite wrong'* that somebody who had worked hard all their lives, paid their National Insurance contributions and never claimed anything should not be entitled to some help when they needed it. In effect, such people might be described as appealing from some sense that natural justice was not being done. One older man said that *'I don't want benefit, I want my rights'*.

There were also people who perceived the disallowance as a judgement that their claim for benefit had been made on the basis of false declarations about their condition and its effects, and were offended and shocked at the implication that this cast them in the role of a *'scrounger'*. They felt they owed it to themselves to appeal, establish that they were *'genuine'* and remove the perceived slur.

The final strand that emerged in this analysis of reasons for appealing were issues associated with financial pressure. People who perceived a significant drop in income with loss of incapacity benefit, believed that it would not be possible for them to work and saw no immediate source of replacement income included people with dependent families, and people with mortgages to service. One respondent thought that her initial disallowance had been made on financial rather than medical grounds, and appealed because she did not have enough money to live on.

The important finding from this section of the chapter is that nobody spontaneously mentioned that the way in which medical information from their GP had been collected or used for the initial decision had influenced their decisions to appeal.

In discussing their reasons for appealing, however, some people did refer to the part played by medical information, and some understood the basis of the points system and talked about their own scores. It is important to remember that by the time of the research interview, these respondents had gathered information and built up their understanding of the role of medical information in a number of ways and from different sources. In addition to the initial letter of disallowance appellants had received copies of the documentation prepared for presentation to the tribunal including the forms and questionnaire they had filled in themselves, the report from the examining medical officer, and information from GP sources. Some had discussed the matter with partners, relatives and friends, some of whom also had personal experience of incapacity benefit. Some had sought advice from solicitors, citizens' advice bureaux or specialist benefit advisers within community health services. Some made appointments with their GP to explain what had happened or seek support for the appeal by asking the GP to write a letter for the tribunal. Those

who attended the hearing in person had further opportunities to learn how medical information was used. There were also some examples of people who had taken part in a research interview in the earlier study, and had discussed with the interviewer at that stage how medical information was or might be used. We return to our analysis of these respondents' understanding of the role of medical information after describing other components of the experience of the appeal process.

2.3 Experiences of and views on the appeal process

2.3.1 Deciding whether to attend in person

Only one person told the interviewer that she had not been aware that she might attend the appeal herself. In retrospect, she suggested that her acute depression at the time may have affected her awareness of what was going on.

Those people who said they decided not to go to the tribunal explained this in terms of:

- being too depressed
- lacking confidence
- wanting to avoid further stress
- expecting no positive outcome
- being unable to afford the travel expenses
- feeling confident in making a case in writing.

For some people severe depression can mean feeling unable to engage with other people or even to leave the house, and some respondents explained that going to an appeal was thus not possible. Others said that the idea of an appeal hearing seemed daunting, and they did not feel confident that they would understand enough to take part. Anticipating the possibility of further stress in answering questions at the tribunal could influence people in deciding not to go. People who already felt badly treated by the system could think they would be wasting their time in doing anything else within that system. Having a very low income from income support had meant one person feeling unable to afford the bus fare to attend the tribunal, but the same person felt confident he could make his case adequately in writing, and sent a long letter to the tribunal.

The reasons given for going to the tribunal by those people who attended the appeal hearing in person reflect to some extent the opposite perspective on some of the above issues. People explained why they decided to go in terms of:

- perception that attendance was expected
- wanting an opportunity to explain their circumstances in person
- feeling able to take part
- having support from partners, advisers or solicitors in going to the hearing.

Not going to the hearing had not seemed an option to some people whose concept of an appeal hearing included personal appearance, or whose experience was that '*an appointment had been made for me*'. Some people had strong feelings that it was important to go in order to make sure that the decision was being reviewed properly on the basis of all relevant information. Among such people were several who felt dissatisfied with the medical examination, and felt that they had not then been asked relevant questions or given an opportunity to explain properly the impact of their condition. Feeling able to attend was mentioned, meaning both feeling well enough and feeling able to deal with the emotional effects. For some, this meant overcoming anxieties about a possibly stressful experience. Support from other people could be very important in preparing for the appeal, and in managing the occasion on the day.

2.3.2 Experience of attending the hearing

From the small sub-group of claimants who attended the tribunal hearing we learn how people understand and experience this process. For example, some said that a 'Chair' had explained procedures, and most thought that one of the people on the tribunal had been a medical doctor of some kind. Beyond this, few remembered more about the members' roles. Nobody remembered a representative of DWP being present. As already explained, partners or a relative, and representatives from advice or support organisations were often also present; or sometimes solicitors.

Only one person was dissatisfied with the way in which proceedings were managed. This was a person with previous experience of tribunals, who said he subsequently made a formal complaint about the attitude of the Chair who he thought had prejudged the case, and did not answer the appellant's questions or let his relative speak. He was left feeling made out to be a liar and a fraud. Otherwise, there was general satisfaction with the way in which the tribunal had been conducted. People said they felt they had been given every opportunity to put their view across. When members had asked them questions about the impact of their condition, these were generally relevant and helpful. People generally talked in terms of the process being '*fair*' and of their treatment being '*decent*'. Some spoke of their appreciation of the recognition that people would be nervous, and of efforts made to help them understand the process and feel relaxed.

Not all the appellants who attended the hearing had a positive outcome, but even those whose disallowance was upheld generally felt satisfied about the conduct of the tribunal. Some had gained further understanding and confidence to go further in the appeals process.

2.4 Appellants' understanding of and views on the role of medical information

As explained at the end of section 2.2, the appellants in the study group had had several opportunities to gain knowledge and understanding of the role of medical information in decisions made about their entitlement. What they discussed with the interviewer drew variously on experiences of the medical examination, letters of disallowance, discussions with advisers, reading the papers prepared for the tribunal and explanations received during and after the appeal hearing.

A small group of appellants were unable to or not interested in discussing with the interviewer how medical information had been used in deciding their entitlement. Most appellants did have ideas about and views on what had happened, and this section is based on findings from this group.

There was general understanding that there was a points system in which their own score was compared with a threshold; those who did not mention this spontaneously generally recognised it when the interviewer reminded them. Some had clear recollection of the initial score which was notified in the letter of disallowance, and how the score had been adjusted by the tribunal or not. This was especially the case among people who had puzzled over the apparent discrepancy between their own assessments of the effects of their condition in comparison with the score awarded after the medical examination. People who had sought advice from solicitors or benefits advisers were among those who retained the clearest and most detailed understanding.

People generally understood that the information they provided themselves on the claim form and questionnaire had been considered in the initial decision. Some could remember how some parts had been hard to fill in. For example, it could be hard to decide which boxes to tick to explain that although some activities were possible for them, in the strict sense of being able to achieve them, actually doing so meant levels of pain or exhaustion that were unacceptable. It could be hard to know how to describe the effects of conditions which made some activities possible on 'good days' but impossible on 'bad days'.

Everybody was certain that the assessment of the doctor who conducted their medical examination had been critically important. Most understood that it was this person who was most influential in attributing the points although not all realised that it was a Decision Maker's final score which formed the basis of disallowance. The views and opinion of that doctor were thought very important, and often considered to be derived mainly from what happened during the medical examination. Some remembered seeing a copy of the doctor's report, either when they had written themselves to ask for it, or when it was sent to them as part of the appeal papers

prepared for the tribunal. Several people remarked on being unable to read parts of the report because of illegibility of the doctor's handwriting, and some had been very surprised at the doctor's interpretation of what had happened in the examination, for example reading about answers to questions they did not think they had been asked. Such experiences were a powerful influence in strengthening beliefs that the initial decision had been wrong, and reinforcing views that medical examinations had been poorly conducted.

Apart from their own information and the conclusions of the doctor who had conducted their examination people generally were much less certain about the possible role of any information from other sources. Some assumed there might be some information from a GP source, but there were often hazy ideas as to what kind of information and how this was provided. On prompting, people often said they did not remember seeing anything in the appeal papers sent to them before the hearing that had come from a GP or the GP records, but some believed, nevertheless, that the tribunal would have some information from their GP. Indeed, some people had asked their GP specifically to write a letter for the tribunal if they felt that the examining medical officer had not understood properly their illness or its effects.

As the interviewer steered people towards thinking again about any information that might have come from a GP source, at various stages in the overall process, some recognised problems for themselves in this respect. For example, people whose main medical support came through community psychiatric services sometimes rarely had contact with their GP, and thought there would be little recent information in the surgery that might have been helpful. Some people had already learned, from requests for information from the GP for purposes of litigation for compensation for injury, or claiming other benefits, that there was rather sparse information about them in the GP records.

On the other hand, some people thought that their GP knew them well, and had provided considerable help and support, not only in treating illness and managing medical conditions but also in discussing whether or not to work. In these circumstances, people hoped that some information had been available to the tribunal from their GP and thought it would help their case. Few could suggest how such information had been sought or provided. Some people put a lot of trust in beliefs that their GP would do what was required within the system, or that the tribunal would seek the medical information that was needed from a GP, without much idea about how this might happen.

By the time of the research interview, some of the appellants had regained incapacity benefits; some had started jobs or were looking for work; some had gone on to make new claims for incapacity benefit, and some had gone further in the appeals process. From this variety of perspectives and circumstances, people looked back on the initial disallowance and offered reasons for the discrepancy they perceived between

the initial assessment provided by the examining medical officer and their own judgements that they were unable to work. Suggestions offered included:

- development of a different or additional condition since the claim, not taken into account at the medical examination
- the effect of discounting some points awarded for 'overlapping' conditions
- communication problems due to lack of an interpreter
- problems in describing effects of a condition on the claim form
- lack of understanding about how to describe effects of mental health conditions on the claim form and questionnaire
- lack of understanding of a condition or its effects by the doctor who conducted the medical examination
- the doctor's lack of skills in talking to people about their condition and its effects
- a hasty or superficial medical examination
- non-availability of important information (results of hospital tests/Xrays/scans which were awaited)
- having little contact with a GP, who could thus provide little medical information
- sparse medical information kept in GP records.

We see that the above interpretations cover a wide spectrum, ranging across the rules for assessing effects of conditions; administrative arrangements to enable communication; understanding and behaviour of claimants; the practice of doctors conducting medical examinations, and the part played by other potential sources of information.

These interpretations have all been discussed already in the text, with the exception of the first two in the above list - the effects of the rules themselves. This section concludes by describing findings about such effects. There were several examples among the appellants of people who had developed another condition since their initial claim, typically a mental health problem. This had not been referred to, or mentioned only briefly, on the initial claim form, but by the time of the medical examination was perceived as making it impossible to work. For example, for one man what was mild depression at the time of a claim for benefit in relation to physical effects of injury subsequently developed into debilitating clinical depression. He was not asked about this in the medical; the doctor asked only about physical effects of the injury. The man was shocked to be told he had not met the PCA threshold. He learned that he could make a new claim on the grounds of depression, when he went to the social security office to make an appeal. People who had had similar experiences pointed to the waste of time for themselves, benefits and medical staff; the additional stress and anxiety they experienced; and the frustration in trying to understand such a system. Also described was experience of what the respondent called 'overlapping'. The respondent's understanding was that he couldn't get points for separate activities which involved the same affected muscles. As he saw it, his score was reduced as a result below the eligibility threshold. The respondent was

angry about such a rule, and having to dispute which muscles he used for different activities.

In summary, this part of the chapter has shown that although medical information from a GP source could seem important to appellants when they were steered towards reflection, most emphasised first the judgement of the doctor who had conducted their medical examination as the key determinant of the decision about entitlement. Among those who saw a role for medical information from a GP source, there was little understanding about ways in which this might be or had been provided.

2.5 Views on the pilot arrangements

Findings reported so far have shown that in this study group of 40 people nobody said spontaneously that having taken part in a pilot or knowing that medical information had been collected from their GP records had influenced any of their decisions about appealing. Towards the end of the interviews people were encouraged to think again about the pilot arrangements, and what they could remember about them. Views were sought about the suitability of this way of gathering medical evidence for purposes of deciding entitlement to incapacity benefit.

2.5.1 Views of the non appellants

Among those selected for the study as non appellants there was very little recognition or recollection of having taken part in pilot arrangements. Most said they knew nothing about it. People who had taken part in the earlier study (Sainsbury, Corden and Finch, 2003) when the focus of the personal interview was on the pilot arrangements either did not remember anything about the new arrangements at this second interview, or still did not grasp the basis of the different way of gathering information. Only one man thought he remembered something about new arrangements, and when reminded by the interviewer appeared to understand that his claim had been dealt with differently from usual.

It was hard for people who said they knew nothing about the pilot arrangements to grasp these and to understand that they had been taking part when their claim for benefit was being dealt with. This part of the discussion came at the end of the telephone interview. Some people were not interested in discussing the matter further; there were some comments that if people had nothing to hide it did not matter how medical information about them was collected. There was some annoyance from people who thought they had taken part in something without being asked for permission. The interviewers gave explanations about how their permission may have been sought but it was not clear how much of this was understood or believed.

Those people who were interested and appeared to grasp the essential points were generally in favour of the new arrangements. Comments made were that GPs were busy people and might not spend time providing the full information that was available in the records. One person said that her experience was that GPs could make serious mistakes in identifying which patient they were writing about, when asked for medical information by third parties, and there would be less chance of misidentification of this kind under the new arrangements.

One or two people were surprised that medical information from their records had been available during their medical examination, if it had appeared to them that the doctor knew little about them or had asked questions that seemed irrelevant. However, in retrospect, none of the non appellants said they would have done anything differently, either during their medical examination or when they were disallowed benefit, had they properly understood that they had taken part in the pilot arrangements.

2.5.2 Views of those who appealed

Turning now to the views of those people who had made an appeal, there was greater recollection of having being asked at some stage for permission for medical information to be sought. Although people often did not remember how this had been done, or whether it was in relation to the initial claim or the appeal, a small group recalled consenting to their medical records being used. Only one person had clear recall of his initial claim being dealt with under pilot arrangements, and what these involved. As with the non appellants, some people said they knew nothing about the pilot arrangements or that they had taken part. Interestingly, one person who had been interviewed in the earlier study, when he had been interested in the new arrangements and strongly in favour of them, had forgotten all about them by the time of the second interview.

As found in the discussions with non appellants, it could be hard for people to grasp both the basic details of the arrangements and the fact that they had taken part if this was new information from the interviewer. Not everybody was able to or wanted to discuss it further; some said they had no views. There was also some annoyance expressed about having taken part in something without knowing about it, as with the non appellant group.

A small group of people who had made an appeal were interested in reflecting on the new arrangements, and thinking about potential advantages or disadvantages. Among these, potential advantages perceived in gathering medical information directly from GP records included:

- less work for GPs
- availability of fuller information about record of illness and treatment
- inclusion of information from other medical personnel, such as hospital consultants, physiotherapists, psychiatrists

- a better picture of the chronology of a condition
- a way of overcoming problems of poor/new relationships with GPs.

Potential disadvantages perceived included:

- little information in records of people who have little direct contact with GP
- possibly sketchy records kept by some GPs
- GP knowledge of impact of condition not always written into case records
- confidentiality of material in GP case records.

All these potential advantages and disadvantages of the new arrangements were also recognised by some claimants in the earlier study.

On balance, those people who thought about it carefully were generally in favour of using medical information taken from the GP case records. Those people who were not in favour stressed the confidentiality aspects of personal information being passed around, and the fact that a person's GP knew more about the impact of their condition than could be derived by a third party reading the case notes.

Some people reflected further on what it might have meant for their own claim and appeal, now that they understood better how information had been provided. There was some surprise that the doctor who examined them had apparently had more medical information about them than they had thought at the time. The importance of including information from hospital consultants and community mental health services was stressed, and the need for a system which would access information of this kind. Not everybody was confident that full information of this kind reached their GP records. In retrospect, nobody thought that they would have done anything differently with greater understanding of the pilot arrangements. Nobody suggested that the availability of medical information from their GP records had had any influence on the outcome of their claim or appeal, although some said that they would certainly go on thinking about the matter, now that they had greater understanding.

2.6 Summary

The findings from telephone interviews with incapacity benefits claimants who were disallowed benefit provide strong evidence that knowledge that they had taken part in the pilot arrangements generally played no part in decisions about whether to appeal. People described a range of influences on their decisions about appealing, but these did not include the fact that information had been sought about them from their GP records.

People who went to appeal because they disagreed with the decision that they were able to do some work tended to put most emphasis on the way their medical examination had been conducted and the judgements made by the doctor who saw them.

General recollection and understanding of the pilot arrangements was low, however, by the time of the research interview. Only a small group of people were able to and interested in reflecting on the possible advantages and disadvantages of the pilot arrangements. On balance, such people were generally in favour of the new arrangements, but there were some concerns about aspects of confidentiality, and not everybody was confident that a third party would gain more information about a condition from reading case notes than by asking a GP directly.

3 Tribunal members and medical evidence

3.1 Introduction

The aim of interviewing tribunal members was to explore their views and experiences of using medical evidence in hearing incapacity benefit appeals, and particularly their experiences of hearing cases under the pilot arrangements. Six tribunal members were interviewed, including three Chairs and three medical members. As will become clear in the course of this chapter, the research evidence on the pilot itself is somewhat meagre. This is probably for two main reasons. First, the tribunal members interviewed had each heard only a few appeals on pilot cases. They were not unusual in this. Most tribunal members serving the pilot area had heard between two and four relevant incapacity benefit cases only (see further Appendix A for details of the selection process for the study). In the interviews, therefore, there was little experience for them to draw on. Secondly, the few cases that had been heard took place some months before the research interviews. Recall by the respondents therefore became an issue. There was little spontaneous recollection of the pilot arrangements and no spontaneous recall of individual cases. However, memory was prompted by showing the IB113 and SB2 forms to respondents, which led to useful, reflective discussions about the relative merits and potential of the pilot and standard arrangements for collecting GP information.

3.2 The role of the tribunal and the place of medical evidence

The tribunal members interviewed described how they perceived their role and the practices and procedures they would generally adopt in dealing with individual cases. Because appeals are, by definition, disputes, the essential task of the tribunal was generally described as being to identify and resolve areas of conflict between the appellant and the Department for Work and Pensions. Members explained that because eligibility for incapacity benefit was based on a medical test of functionality, the key task of the tribunal was to make decisions about functionality using all the evidence available to them.

For each case tribunal members received a set of appeal papers either several days before the hearing when the appellant had opted for an oral hearing, or on the day of the hearing when the case was to be heard 'on the papers' only. The appeal papers were prepared by the Appeals Service and contained copies of the appellant's claim, an appeal form or letter, the IB85 medical report from the examining medical officer (EMO), information supplied by the appellant's GP, other medical information held by Jobcentre Plus, and any evidence supplied by the appellant prior to the hearing. Tribunal members explained that their initial task was to review the papers and

identify areas of possible conflict, or inconsistencies or gaps in the evidence available. A list of questions or issues to be explored in the hearing was compiled in this way.

Several themes emerged in discussions with respondents about medical evidence, including the importance of independent and impartial information, identifying gaps in medical evidence, and the difference between clinical and functional information.

Respondents explained that it was important for them to have a clear diagnosis of the appellant's health condition or conditions. This was essential contextual information that allowed them to make judgments about the appellant's functionality. Here they were able to draw on GP information, if available, the IB85 medical report from the EMO, other information collected in the course of processing the claim, and any further information supplied in support of the claimant's appeal (often a letter from the GP, or independent medical reports). Whenever there was a need to compare and contrast medical evidence, some respondents described what was for them an issue of 'validity'. They explained that for them the most valid information was independent and impartial, and that information from GP sources could not be assumed to be either.

Medical reports from EMOs and hospital consultants were generally thought to be independent, but information supplied directly from GPs, whether on an IB113 form or in letters of support, was viewed slightly differently. There was a general perception that GPs will sometimes feel pressure when they complete forms or write letters, either directly from their patients or to avoid potential conflict with them. For the medical members such a view was usually based on personal experience of practising medicine and on their working relationships with GPs. Tribunal members interviewed said they were careful therefore to read and interpret GP information in the knowledge that it might not have been written impartially. It was made clear that this did not mean that GP information was discounted or automatically treated as invalid. Rather, in deciding how to use that information alongside other sources of medical evidence, tribunal members became skilled at '*reading between the lines*' of GP forms and letters.⁶ These observations and insights from respondents become particularly relevant later in this chapter when their views of the relative merits of the pilot and standard arrangements are presented.

Reviewing medical evidence before a hearing not only revealed possible conflicts or inconsistencies in information between different sources, but also apparent gaps. For example, a mental health problem might not be mentioned in GP information, but be

⁶ These perceptions of tribunal members do not appear to be groundless. In interviews with GPs carried out for the earlier research on the pilot, some explained that providing information on benefit claims for DWP could affect (sometimes seriously and negatively) relations between themselves and their patients. They might choose therefore to present information in such a way that maintained relationships rather than put them at risk (see Sainsbury, Corden and Finch, 2003, Chapter 2).

referred to in an EMO's report (or vice versa). The point was made by several respondents that mental health problems were often poorly described and explained in GP information, particularly on the IB113 form. It was suggested that part of the reason for this might lie in the design of the form itself. The only direct questions about mental health ask about episodes of self harm, attempted suicide, and threatening or violent behaviour. Other gaps in information might only become apparent during the appeal hearing, such as mental health conditions not previously reported to GPs or mentioned in the medical examination.

The tribunal members interviewed were invited to comment on the relative importance of clinical, diagnostic information and information about an appellant's functionality. The distinction between these types of information was recognised and acknowledged, but both were considered essential. Information about functionality was crucial because the main medical criterion of eligibility for incapacity benefit was the extent to which functionality was affected by health or disability. However, assessments of functionality could only be made in the context of a person's health condition. It was recognised that functional data from GPs was generally less comprehensive than clinical data, and often absent altogether. The principal source of functional information, prior to an appeal hearing, was the medical report from the EMO.

Overall, the tribunal members interviewed agreed that some GPs provided medical evidence that was clear, comprehensive and demonstrated impartiality. Particularly valued was information from doctors who knew their patients well, either through a long association with their surgery or through more recent but frequent contact. When GPs provided information of such quality the job of the tribunal was helped considerably. In the majority of cases, however, tribunal members had to manage with at best partial information, and at worst no information at all from GPs.

3.3 Reflections on the experience of the pilot arrangements

As mentioned in the introduction to this chapter, the tribunal members interviewed did not spontaneously recall individual appeal cases that would have included an SB2 form in the set of appeal papers. However, when they were shown a blank copy of the SB2 during the interview most of the respondents said that they remembered seeing and using it.

Two positive features of the pilot arrangements were particularly mentioned. First, the presentation on the SB2 of the extracted medical information chronologically, with dates, was welcomed. Some tribunal members felt that information presented in this way helped them get a comprehensive picture of the development and treatment of an appellant's medical condition. In contrast, IB113 forms only asked for the date when the GP last examined their patient in connection with the cause of their

incapacity. Secondly, it was felt that SB2 forms contained more information about hospital tests, consultations and treatments than was usually included on an IB113. Extracts from X-ray examinations, MRI scans, psychiatric reports and physiotherapy reports were all recalled as being useful.

The only other observation made about the SB2 forms was from a Chair who said that he remembered not understanding the technical medical terminology on one form. Hence he had waited until the hearing itself to ask his medical colleague for an explanation. This was described more as an inconvenience than a serious shortcoming in the pilot arrangements.

3.4 Comparing the experience of the standard arrangements with the potential of the pilot arrangements

In the interviews the tribunal members were reminded of the pilot arrangements and how they differed from the standard arrangements for collecting medical information from GPs, and, as mentioned earlier, were shown sample copies of the SB2 and IB113 report forms. The respondents all made a range of useful comments and observations about the alternative arrangements.

Several commented on the potential of the SB2 for providing them with a comprehensive, chronological medical history over a sufficiently long period (five years) to enable them to have greater confidence in their assessments of functionality. However, it was also recognised that the utility of the SB2 relied in the first instance on the quality of the GP records, and secondly on the skill and judgment of the doctors extracting the information from those records. A concern that some important piece of information might be missed by a GP completing an IB113 form was not completely dispelled by pilot arrangements that relied on a third party.⁷

However, the IB113 held out the possibility, if filled in diligently, of providing the tribunal not only with the requisite clinical information but also useful and important information about functionality. In the view of the respondents it was unlikely that many GP records would contain much, if any, information about functionality.

In assessing the relative merits of the pilot and standard arrangements, the tribunal members interviewed couched their responses in two ways. They compared the potential of the pilot arrangements firstly with the potential of the standard arrangements, and secondly with their actual experience of the standard arrangements. On the basis of the first comparison, there was general support for the

⁷ This concern is interesting in the light of one of the findings from the earlier study in which approved doctors extracting information from GP notes were found to have contrasting approaches to the task, which affected the amount and type of information included on SB2 forms (see Sainsbury, Corden and Finch, 2003, Chapter 5).

existing system based on the collection of GP information using the IB113 form. However, on the second comparison, it was generally felt that a system that could guarantee some medical evidence on all cases held an advantage over a system that had low levels of compliance and produced wide variations in the quality of information.

3.5 Other lessons from the medical evidence pilot

3.5.1 Dealing with paper hearings

The principal use of written medical information for the tribunal was in preparing for a hearing, when conflicts, inconsistencies and gaps were identified. However, the list of questions and issues generated in this way could not be pursued with the appellant if the case was to be heard on the papers only.

One respondent described his approach to preparing for a paper hearing in the following way. A comparison would be made between the points scored on the IB85 medical report form from the EMO (which by definition would be below the threshold for a successful claim) and those based on the appellant's self assessment form, the IB50. If the self assessment also scored lower than the threshold then the appeal would in most cases fail for lack of any evidence to reconsider the decision. Occasionally the appellant's appeal form or letter may contain useful information or the appellant may have supplied further written medical evidence, but this happened infrequently. However, if the IB50 score was above the threshold information from the GP would be examined carefully for evidence that might either support the appellant's or the EMO's assessment of functionality.

With no opportunity of asking the appellant or a representative any questions, resolving conflicts of evidence had to rely mainly on the discussions and debate between the two tribunal members. One Chair remarked that it was difficult for an appeal to be decided in the appellant's favour on the papers only, particularly if the original points assessment from the PCA was low. He contrasted this with oral hearings where he had had experience of the tribunal increasing an appellant's score from two or three (and sometimes zero) points to the threshold after hearing verbal evidence.

3.5.2 Quality and content of EMO reports

Tribunal members interviewed explained that for an initial decision to be overturned at appeal, the tribunal must award the appellant a higher points score than that arrived at by the Decision Maker who would have taken account of all the available evidence including the EMO's report based on the medical examination. Some respondents reflected that this could raise doubts about the quality of EMO examinations when information elicited from the appellant during a tribunal hearing could, and perhaps should, have been obtained by the EMO. This view was qualified

by two considerations. Firstly there was a recognition that EMOs work under time pressure that might militate against drawing out everything of relevance from the claimant. This might happen particularly when the claimant had multiple health conditions, or a combination of physical and mental health conditions. Secondly, tribunal members described cases they had heard where it became apparent that claimants had not provided EMOs with full or accurate information. This might be for a number of reasons including embarrassment, a lack of understanding of the relevance and importance of some aspect of their condition, or simply that the EMO had not asked them an appropriate question. Sometimes they had a feeling that the EMO could have elicited more information with either more time or by asking different questions.

One respondent commented on the variable quality of IB85 medical reports in terms of the amount and relevance of what was written by EMOs in support of their choice of descriptors, particularly those relating to mental health. Occasionally tribunal members saw IB85 reports that contained a piece of information that was demonstrably inaccurate, which could undermine their confidence in the rest of the report.

Interviews with tribunal members demonstrate that the EMO report is one of the core pieces of medical evidence that they use in deciding incapacity benefit appeals. In the final chapter we consider the implications of the research findings for the future of incapacity benefit decision making arrangements.

3.6 Views on how to improve the collection of medical evidence for incapacity benefit

In the last part of the research interviews tribunal members were asked to reflect on the pilot and the standard arrangements for collecting GP information and invited to offer views on whether it would be better to base future arrangements on one or the other. The respondents used several different points of reference in exploring how medical evidence gathering might develop in future, including:

- earlier discussion comparing the pilot and standard arrangements,
- views about the work of GPs and their dealings with their patients,
- the structure of incapacity benefit and current decision making arrangements.

There was a general recognition that the standard arrangements, based around the IB113 form, were sound in principle. However, rarely was high quality information produced. The principal reasons for this shortcoming suggested by tribunal members interviewed included:

- GPs worked under severe time pressure which led some to fill in the forms superficially, or not complete them at all,

- some GPs were antipathetic to providing DWP with information, particularly where there was a perception that they received no payment for providing these reports,
- the design of the form encouraged superficial answers by using phrases such as 'give brief details',
- IB113 forms sometimes contained opinions that were not backed by clinical findings,
- GP information might not be impartial.

Ideas for improvement included reforming the system of payment for GPs, so that GPs received a direct 'item of service' payment for completing a report. This could possibly be linked to some form of quality control so that only adequately completed forms would attract payment. Some doubt was expressed however over whether direct payments would change the behaviour of GPs who were either reluctant or too busy to complete the forms.

There were some suggestions for redesigning the IB113 form to encourage fuller clinical information and to elicit more information about functionality. However, there were doubts expressed by some respondents about whether functional data would be impartial. There were also divergent views on whether IB113 forms would be better if GPs called the claimant in for a consultation before completing the form. One view was that the quality of the forms would increase as a result, but an opposing view was that impartiality could be compromised if a GP and claimant effectively negotiated and agreed responses.

Tribunal members reflected on the types of information that they found useful and reflected on how this might be obtained. Included here for example were hospital consultant letters, X-ray and MRI scan reports, physiotherapy reports, and psychiatric reports from doctors or community psychiatric nurses. Drawing on their current experience of IB113 forms some thought that the pilot arrangements were more likely to generate this kind of information.

Although spontaneous recall of cases involving SB2 forms was limited the tribunal members interviewed were generally positive about their potential. Some respondents said they would prefer the pilot arrangements to replace the current arrangements in the future. Others' preference was to make efforts to improve completion and quality of IB113 forms from GPs, but these also viewed the SB2 arrangements as a viable alternative.

Preference for the pilot arrangements was explained in a number of ways:

- information extracted from GP medical records was more likely to be impartial,
- medical evidence would be available on all cases,

- objective clinical information was preferable to opinion unsupported by clinical findings,
- good clinical information could be an indicator of functionality also,
- the burden of paperwork for GPs would be reduced.

As mentioned earlier, there was a view that the pilot arrangements were dependent on GP medical records being of a high standard, and on the skills and judgment of the medical officers in the Leeds Medical Services Centre extracting the information on to SB2 forms. It was recognised that the former was not within the direct influence of DWP, but that the latter was, through training and monitoring procedures. One innovative suggestion was that the CD containing the scanned contents of the GP records could be made available to the tribunal in place of the SB2 form. This would circumvent the possibility that some relevant GP information was overlooked in the extracting process.

3.7 Summary

The essential role of tribunal members is to assess the evidence available to them, make judgments about what constitutes the facts of each case, and apply the appropriate legislation in order to reach a decision. Tribunal members explained that they have to carry this out using the evidence in the appeal papers and, in oral hearings, with the verbal evidence of the appellant and his or her representatives. They must not physically examine appellants, but only ask them questions.

Broadly speaking the decision making process for incapacity benefit that has been in operation since 1995, was, designed to generate objective clinical data and, where required, information on functionality. However, the findings from the interviews with tribunal members is that, in practice, tribunals have to accomplish their task with varying amounts of medical evidence, which can also vary in terms of its quality and reliability. Improving the flow and quality of clinical data from GPs and other health professionals was seen as highly desirable, whether through changes to the existing arrangements or by introducing new arrangements such as those tested in the pilot.

4 Summary and conclusion

In the first part of this final chapter we return to the research questions set out in the introduction and summarise and reflect on the findings from the interviews with incapacity benefit appellants and non appellants, and appeal tribunal members. Secondly, we identify a number of issues that emerged in the course of the research which might contribute to policy thinking about the future of incapacity benefit decision making arrangements.

4.1 Summary and discussion of findings in relation to claimants

4.1.1 People's understanding about decisions and appeal rights

In the interviews with both appellants and non appellants, people discussed the initial decision on their claim in different ways. People's understanding of why their claim was disallowed included references to assessments about their ability to work, their capability in regard to everyday activities such as walking or lifting, and their failure to reach the points threshold for eligibility. People put most emphasis on the medical examination carried out by the examining medical officer (EMO). Sources of written medical evidence from GPs or other health professionals were rarely mentioned.

From people's accounts it appears there was a good understanding that eligibility for incapacity benefit is based on ability to work and to carry out everyday activities. Among the 40 claimants interviewed for this study, all but one knew they could appeal about their disallowance. Many referred to the decision letter as the source of their information. Some knew about appeal rights from previous claims or the experiences of family or friends or from DWP staff consulted about loss of benefit. From this selection of incapacity benefit claimants, therefore, there is no evidence that current methods of providing information about appeal rights are inadequate or ineffective.

4.1.2 Why people decide to appeal or not to appeal and the role of medical information

The analysis of the reasons offered by the study group for making or not making an appeal generated a wide range of interesting and useful findings. It is possible to distinguish four kinds of reasons for decisions about appealing:

- reasons connected with the decision
- reasons connected with the personal experience of claiming
- reasons connected with a sense of justice
- financial reasons.

Figure 4.1 below sets out the range of reasons within each of these categories for appellants and non appellants.

Figure 4.1 Why people decide to appeal or not appeal

<i>REASONS CONNECTED WITH THE DECISION</i>	
<p>Non appellants</p> <ul style="list-style-type: none"> • accepting or agreeing with the decision • seeing no point on which to appeal within the rules, although disagreeing with the rules 	<p>Appellants</p> <ul style="list-style-type: none"> • being certain about not being able to work • strong views about not being able to work from significant other people • belief that the medical examination had been inadequate or inappropriate to their condition
<i>REASONS CONNECTED WITH THE PERSONAL EXPERIENCE OF CLAIMING</i>	
<p>Non appellants</p> <ul style="list-style-type: none"> • feeling too angry or humiliated to take the matter further • wanting to avoid stress, for health reasons • wanting not to be identified as a trouble-maker 	<p>Appellants</p> <ul style="list-style-type: none"> • anger about the emotional experience of the medical examination • failure to provide language interpretation for the medical examination • wanting to remove the implications of ‘scrounging’ that people attached to disallowance
<i>REASONS CONNECTED WITH A SENSE OF JUSTICE</i>	
<p>Non appellants</p>	<p>Appellants</p> <ul style="list-style-type: none"> • feeling that justice had been denied after a lifetime’s working and paying contributions
<i>FINANCIAL REASONS</i>	
<p>Non appellants</p> <ul style="list-style-type: none"> • no negative financial impact of disallowance 	<p>Appellants</p> <ul style="list-style-type: none"> • negative financial impact of disallowance

One of the aims of the pilot arrangements was to reduce the number of incapacity benefit appeals against disallowance decisions. It is not possible from this qualitative study to assess if this aim has been achieved, but it is possible to indicate the extent to which information from the GP formed part of people's deliberations about whether to appeal. We have not been able to identify from this study that such information plays any part in people's thinking. If there were any such evidence we might have expected it to emerge from claimants who had made their decision to appeal or not to appeal after a consideration of the merits of their decision, rather than from, for example, feelings about the way they were treated in a medical examination or financial consequences. For example, someone who accepted the decision to disallow as correct might have come to that judgment because they were aware that information extracted from GP medical records contributed to that decision. No one described his or her acceptance of disallowance in that way. As indicated in Figure 4.1 (and explained in detail in Chapter 2) people's acceptance of the decision was most usually based on agreement with the assessment that they were fit to work or with the assessment of their physical and mental capabilities. Similarly, explanations of the decision to lodge an appeal made no reference to information from GPs. No one, for example, said that they appealed because information extracted from their GP notes was incomplete or inaccurate. As mentioned earlier, where there was disagreement with the decision, this was usually linked to the medical examination and based on the claimant's own assessment, or that of significant other people, of their fitness for work or their ability to perform everyday activities.

4.1.3 Views about the pilot arrangements

Views expressed about the pilot arrangements in this study matched those expressed by the claimants in the earlier study. Knowledge of the pilot was very limited and there were very few memories of consenting to take part in the pilot. Some of those people who had made an appeal had some recollection of being asked permission for something to do with obtaining medical information in relation to their claim or appeal but it was not clear whether or not this was connected with the pilot. Some respondents were annoyed to learn that they had been part of a pilot about which they had no recollection

The interviewers tried to explain to as many people as possible the difference between the pilot and standard arrangements. Some respondents grasped the details well and engaged in discussion about their relative advantages and disadvantages. Other respondents were not much interested and little discussion ensued.

Among those people who did reflect on the advantages and disadvantages of the pilot arrangements, most were generally in favour of using medical information taken from the GP case records. Advantages were perceived in terms of better information about their health conditions and a reduced burden on GPs. People who were not in favour thought that their GP was best placed to provide information about them, and

had separate concerns about the confidentiality of personal information being passed between different people.

4.2 Summary and discussion of findings in relation to tribunal members

4.2.1 Experiences of cases decided under the pilot arrangements

When interviewed for the research, none of the tribunal members had a clear memory of individual appeal cases heard under the pilot arrangements. This is perhaps not surprising given the low numbers of pilot cases heard by each tribunal member, and the time that elapsed between the relevant hearings and the research interviews. It has not been possible, therefore, to gather views about the quality and quantity of the information extracted by approved doctors in Leeds Medical Services Centre on to the new SB2 forms. Nor has it been possible to explore tribunal members' experiences of the impact of the pilot arrangements on the decisions they make.

However, respondents were able to discuss the potential usefulness of the pilot arrangements based on their own knowledge and experience of when and how medical information from GPs and other sources is used at various points in the appeal process.

4.2.2 The role of medical information in the work of a tribunal

Medical evidence is at the heart of the work of tribunal members. All appeals are, in essence, disputes about medical evidence, either concerning clinical judgments and assessments (for example, about diagnoses, severity or prognoses) or concerning the assessment of a person's functionality. Tribunal members interviewed explained that information from GPs contributed to the work of the tribunal in distinct ways. First it was used in preparing for a hearing to identify questions or issues that might be pursued with an appellant attending an oral hearing, or discussed with the other tribunal member in a paper hearing. Secondly, information from GPs was used to help resolve conflicts in evidence about diagnosis or functionality.

Looking at how information from GPs is used in these ways suggests why the pilot arrangements, which hold out the promise of relevant, objective data extracts from GP medical records, found considerable support from the tribunal members interviewed. Although there was little recall of individual cases involved in the pilot, tribunal members were attracted by the pilot arrangements, particularly compared with their experience of the current arrangements, which frequently produced limited, partial information or no information at all from GPs.

4.2.3 Views and preferences about the collection of medical information

The views about the relative advantages and disadvantages of the pilot and the standard arrangements for collecting information from GPs were similar to those put forward by approved doctors and decision makers (reported in the earlier report on the pilot, Sainsbury, Corden and Finch, 2003).

It was recognised that the standard arrangements did in some cases generate comprehensive and useful medical evidence that covered both clinical findings and information about functionality, but in practice ‘good IB113s’ were uncommon. The current arrangements were generally seen as sound in principle but flawed in operation.

The pilot arrangements were seen to have a number of advantages over the current arrangements. Some information from the GP was guaranteed on virtually all appeal cases, information extracted from the case notes was perceived to be objective and much less likely to be influenced by GP-patient relationships, extracts would include important information from other medical sources, especially hospital consultants, and it was possible to build a comprehensive medical history of the appellant going back five years. Some tribunal members qualified their support with the observation that the effectiveness of the pilot arrangements relied on the quality of the source material, i.e. the GP records, and on the skill and judgment of the approved doctors extracting the relevant data. These were potential limitations that needed to be thought through if the pilot arrangements were adopted more widely.

Where strong views were expressed they were in favour of adopting the pilot arrangements. Such views were based partly on the perceived advantages of having objective information extracted from GPs’ case notes available to the tribunal, and partly on what was seen as a realistic assessment of the chances of increasing the flow and quality of IB113 forms from GPs, which were thought to be slim.

4.3 Issues relevant for policy

The principal reasons for setting up the Medical Evidence Gathering pilot were concerns with standards of incapacity benefit decision making, the relatively high rate of appeals by disallowed claimants, and the high rate at which decisions were overturned by appeal tribunals. In this section we draw on the research evidence from this and the earlier study to offer some insights that might contribute to policy thinking about dealing with these concerns.

4.3.1 Appeal rates of disallowed claimants

As mentioned earlier, it was hoped that one effect of the pilot arrangements would be to reduce the number of incapacity benefit appeals. However, the conclusion that can be drawn from this study is that changing the way in which medical evidence is

collected from GPs is unlikely to have an impact on decisions by disallowed claimants about whether to appeal.

The interviews with appellants and non appellants has however, produced insights into decision making that might be taken forward into further policy thinking. Some claimants did not have a full and clear understanding of the principles and rules of incapacity benefit. The basis of the personal capability assessment, which is to identify those people who should not be expected to look for work as a condition of receiving state benefit, seemed not to be well understood by many. Whether increased understanding might lead to greater acceptance of disallowances, and therefore fewer appeals, is unclear. People's motivations for appealing, whatever these were based on, were usually strong, and might not be influenced by a greater understanding of why they were disallowed.

4.3.2 The central role of the medical examination in incapacity benefit decision making

What emerges from the analysis of interview data from incapacity benefit claimants and tribunal members in this study, and from the findings of the earlier research study on the pilot, is that the medical examination undergone by claimants plays a crucial role in initial decisions on claims, on thinking by claimants about whether to appeal, and on the work of tribunals. In this section we reflect on how the medical examination comes to play such a central role and the implications of this for policy.

In the stages of incapacity benefit decision making prior to the appeal stage, the medical examination, and the IB85 medical report form, are a powerful source of both clinical, diagnostic information and functional information about a claimant. Independent diagnostic information is also available in many cases from medical certificates or IB113 forms completed by GPs. On some claims however EMOs will effectively have to make their own diagnoses, which they will record on the IB85 report. The other principal source of information about functionality is the claimant's self assessment form, IB50. Other potential sources, including the IB113 form completed by the GP or the SB2 under the pilot arrangements, do not always provide reliable or consistent functional information. Before the appeal stage, therefore, the IB85 medical report can, in many cases, effectively determine the outcome of the PCA.

For the appeal tribunal, however, decision making is qualitatively different from that of Jobcentre Plus decision makers. In oral hearings at least, there is an opportunity for collecting functional data direct from the appellant. Furthermore, the medically trained member can make professional assessments and judgments about content and quality of the EMO report in the light of the appellant's verbal evidence. To a large extent therefore an appeal hearing can serve as a powerful scrutiny of the quality of medical examinations and medical reports. The evidence from both

claimants and tribunal members in this research study suggests that the quality of those examinations and/or reports is sometimes less than adequate or acceptable. The purpose of this section has principally been to demonstrate the key role that the medical examination and report play in initial decision making on incapacity benefit claims and in any subsequent appeal. If we consider some of the reservations and criticisms of IB85 reports from both claimants (see Chapter 2) and tribunal members (Chapter 3) then a case emerges for policy makers to look closely at the medical examination stage and to review whether procedures and practices are sufficiently robust to ensure high quality reports.⁸

4.3.3 Paper hearings

Tribunals can only make decisions based on the information and evidence available to them. The interviews with tribunal members in this study have indicated how their task of making informed appeal decisions relies heavily on the verbal evidence from appellants in oral hearings (a similar finding to that of the President of the Appeals Service⁹). It is also known that appellants who attend their hearing, with or without a representative, are far more likely to succeed in their appeal than those who do not attend.¹⁰

In the interests of promoting high quality decision making at the appeals stage, therefore, there is arguably a strong case for encouraging as many appellants as possible to attend their hearings. One policy option might be to revise the information given to appellants about attending the hearing and to review the procedures for them to access an oral hearing.

4.4 Conclusion

In building an understanding of why incapacity benefit claimants decide to appeal or not to appeal disallowance decisions we have been able to offer a range of explanations for why information from GPs is unlikely to affect those decisions. People have little knowledge or understanding of how medical information contributes to benefit decisions and usually have sight of information from GPs only *after* they have appealed and received the appeal papers. The hope that new arrangements for collecting information directly from GPs' case notes might lead to a reduction in the number of appeals is therefore unlikely to be realised.

⁸ The President of the Appeals Service, Judge Harris, has also raised the problem of 'inadequate' medical reports (Appeals Service, 2002).

⁹ In his latest annual review of the work of tribunals, the President of the Appeals Service comments in relation to incapacity benefit appeals: 'a common theme ... was that oral evidence of the appellant had a considerable impact on the decision of the tribunal' (Appeals Service, 2002, p.23).

¹⁰ In the quarter ended March 2003, the success rates for appellants were 60 per cent where the appellant attended alone, 73 per cent where the appellant and a representative attended, but 14 per cent when the appeal was heard on the papers only (DWP, 2003).

Nevertheless, there was general support among many of the claimants interviewed in this study for the pilot arrangements. Tribunal members' views about the value of the pilot arrangements were based largely on reflections about their general experiences of using medical evidence and their assessments of the potential of using extracts from GP files rather than distinct recall of individual pilot cases. Nevertheless, there was some support, sometimes strong, for the pilot arrangements, which were seen to address many of the shortcomings of the current arrangements.

Although this study might not have identified effects from the pilot that policy makers would have liked, it has been valuable for identifying the role the medical evidence, and information from GPs in particular, plays in the decisions of incapacity benefit claimants and in the work of appeal tribunals. It has also produced findings about the importance of the medical examination, the quality of medical reports, and about paper hearings that can inform future policy thinking about incapacity benefit decision making arrangements.

Appendix A - Methodology

A Interviews with incapacity benefits claimants

The aim was to talk to people whose claim for incapacity benefits had been disallowed after being dealt with under the pilot arrangements, including some who had gone on to appeal against this decision, and some who had not. The initial intention was to talk to approximately 20 non appellants and 20 appellants in telephone interviews.

At the beginning of July 2003 the DWP research management team sent to SPRU the sampling frame comprising all 189 people whose claim had been disallowed after being dealt with under the pilot arrangements, 60 of whom were recorded as having lodged an appeal. On receipt of the lists letters of invitation from the DWP were sent from SPRU. The letters (Appendix B) reminded people about the pilot arrangements for collecting medical information from their GP. It went on to invite people to take part in a telephone interview to talk about what they thought of the new arrangements, from their perspective as a person who had appealed (or not) against the decision.

After two weeks, those people who had not opted out of the research were considered for inclusion in the study group. The researchers attempted to contact people quickly by telephone. Fieldwork was conducted in the last two weeks of July 2003.

A.1 Building a study group

A purposive study group was built, aiming towards equal numbers of appellants and non appellants, with a spread of ages, a gender balance reflecting that of the sampling frame, and representation of people from minority ethnic backgrounds. It was hoped that the group of appellants would include some people who had opted for an oral hearing and some who had attended the tribunal themselves; as well as successful and unsuccessful appellants.

In the event, it proved hard to be selective in this way, because not everybody listed was accessible by telephone. The same issues arose as reported in the earlier study of the pilot (Sainsbury, Corden and Finch, 2003). It was common for people to be ex-directory, and it was not unusual for telephone numbers that were available to have answer-phones running for what appeared to be large parts of the day and early evening. A few people who were contacted declined to take part, on the grounds of privacy, feeling too tired or depressed. Some people who said they had lost appeals or not bothered to appeal declined to take part because of dissatisfaction with what had happened to their claim. Some telephone calls were dealt with by domestic

partners of claimants, who said that their husbands were not available or would not be able to take part because of impairments or limited spoken English and who then declined any further discussion about whether ways might be found to enable their husbands to participate.

The researchers sent some letters of invitation to people they could not initially reach by telephone, inviting them to offer a telephone number and suggest a suitable time for an appointment. This proved fruitful in recruiting appellants, but not non appellants.

As a result of these issues, as in the earlier study, it is not possible to report a 'response rate' in the way that has been traditional in this kind of research. We do not know how many people received messages left on answer-phones or sent by mail and effectively 'refused' by taking no further action.

Overall, it proved easier to recruit appellants than non appellants.

A.2 Conducting the telephone interviews

The researchers asked all those contacted to suggest a suitable time for a 20-30 minute discussion. Some people wanted to go ahead straight away, but others preferred to make an appointment for a later date.

Topic guides (Appendix C) were used to steer the discussion across the main areas of interest:

Appellants

- personal circumstances and claim history
- understanding of the original disallowance
- reasons for appealing
- experience and views of the hearing
- overall views of the pilot arrangements.

Non appellants

- personal circumstances and claim history
- understanding of the original disallowance
- understanding of right to appeal
- reasons for not appealing
- overall views of the pilot arrangements.

Throughout the discussions respondents were asked about the impact of medical information on their experiences and decisions and particularly about information provided by their GP.

The interviews varied in length between 15 and 45 minutes, generally being shorter among the group of non appellants. Two of the longer discussions were with people for whom English was not a first language, where issues took longer to explain and discuss. Some respondents who did not want to speak directly to the researcher themselves, because of memory loss or problems they perceived in speaking in English, asked relatives to speak on their behalf.

Sometimes other members of the household listened to the interview, on telephone extensions or by sitting close to the phone, and respondents often involved such partners or relatives, for example to check details of the claim history or bring partners into the discussions.

Interviews were tape recorded with the permission of the respondents. Those who took part in the research received a gift of £15 to acknowledge their help.

A.3 Characteristics of the study group

The study group eventually included 25 people selected because records showed they had appealed against their disallowance and 15 people who had not. By the time of the interview some of those selected as non appellants had appealed a decision on a subsequent new claim.

The group included 23 men and 17 women, as shown in Table A1. This largely reflects the composition of the samples supplied to SPRU.

Table A1 Membership of the study group

<i>Appellants</i>		<i>Non appellants</i>	
Men	Women	Men	Women
15	10	8	7

The 25 appellants included 11 people who had won their appeals and 14 whose disallowance was upheld. The ‘success rate’ for appellants in the sample, 44 per cent, matches the rate for all incapacity benefit appeals of 44 per cent (DWP Statistics, 2003).

The study group included people from all age groups, as shown in Table A2.

Table A2 Ages of people in study group

	<i>Appellants</i>	<i>Non appellants</i>
Under 30 years	2	-
30-39 years	3	4
40-49 years	4	3
50-59 years	5	5
60 years and over	7	3
information not available	4	-
TOTALS	25	15

People's family and household circumstances may influence views about incapacity benefits, medical evidence and whether to appeal. Table A3 shows the family and household circumstances of 36 people in the study group for whom this information was available.

Table A3 Family and household circumstances

	<i>Appellants</i>	<i>Non appellants</i>
Lives with partner	7	3
Lives with partner and dependent children	5	4
Lone parent	-	1
Lives with adult child	2	1
Lives with partner and adult relatives	3	1
Lives with adult relatives	-	1
Lives alone	5	3
information not available	3	1

Information about tenure is available from 35 of the 40 people in the overall study group. Twenty-one lived in owner-occupied homes; 11 were local authority tenants; one had a private landlord; one was a housing association tenant and one person lived alone in a house owned by parents.

Two of the appellants and one of the non appellants described a minority ethnic background.

A.4 Health and impairment

The aim was to achieve a study group that included people with a history of health conditions and impairments that fell into a number of broad categories. Not everybody interviewed talked in detail about current or past health circumstances or impairments that affected their capacity to work. We made no attempt to categorise

people in this study group in terms of diagnoses of illness or type of condition. As a result of what people talked about, however, we know that the study group included people with a range of conditions which they felt had affected their capacity to work at the time of the claim for incapacity benefits, including musculo-skeletal conditions; heart and circulatory problems; stroke; kidney disease; mental illness; accidents and injuries; respiratory, and digestive conditions.

This study group included several men who had experienced serious industrial injury and accident. This was also noted as a feature of the group of incapacity benefits claimants recruited for the earlier study of the pilot (Sainsbury, Corden and Finch, 2003). The Sheffield/Rotherham area has a history of industrial and mining employment, and there are still some areas of concentration of heavy industry and manufacturing.

B Interviews with tribunal members

In designing this element of the study two options were considered: convening two separate focus groups of tribunal Chairs and medical members, and carrying out face to face interviews with selected tribunal members. In discussion with the Appeals Service administrative staff in Leeds it was thought that the difficulties of convening groups which might include busy medical and legal professionals argued in favour of conducting individual depth interviews.

The Appeals Service supplied a list of the tribunal members who had heard the 60 appeals on cases in the pilot. This comprised 21 different doctors and 18 Chairs. All but one member (a Chair who had sat on 12 cases) had heard cases in single figures. Most had heard between two and four cases.

The aim, within the resources available for the study, was to interview three Chairs and three medical members. Letters of invitation (Appendix B) were sent to six tribunal members selected from those who had heard at least four cases. One declined the invitation and one was not available during the period allocated for fieldwork. Two substitutes were selected and letters sent. Table B1 shows the range of experience of hearing appeals on pilot cases of the final achieved sample.

Table B1 Experience of tribunal members of pilot cases

	<i>No of cases heard from pilot cases</i>
Chair A	12
Chair B	4
Chair C	4
Medical member A	4
Medical member B	4
Medical member C	4

Interviews were all held in October 2003. A topic guide (Appendix C) was used to ensure all relevant areas of importance were covered. These included:

- the role of GP information in the work of tribunal members
- experience of the pilot arrangements
- views and preferences about collecting medical information in the future.

Interviews were tape recorded with the permission of the respondents.

C Analysis

Analysis of material from each part of the research was handled separately, but the approach was similar in each case. Analysis began with listening to the tape-recordings and reading fieldnotes, and arranging material under key headings, reflecting the main topics for enquiry and additional themes emerging from the data. A series of thematic charts was drawn up, for appellants, non appellants and tribunal members and data from each recording summarised under the appropriate heading.

The method has been developed and refined within SPRU over many years, alongside the 'Framework' approach (Ritchie and Spencer, 1994) initiated by Social and Community Planning Research, now the National Centre for Social Research, which takes a similar analytic approach in the context of conducting applied qualitative research.

Ordering data in this way means that the accounts of all respondents can be explored within a common thematic framework, grounded in the data collected. It helps to highlight the full range of perceptions, beliefs, experiences and behaviours described by the respondents, and enables exploration of the factors that underpin them. The method enables within-case and between-case analysis, essential for drawing out a full interpretation of the data. The final stage of the analysis involves

reviewing the data mapped in the thematic matrix, comparing accounts from individuals, and identifying patterns and explanations within the data.

Appendix B

Letters

OPT OUT FOR APPELLANTS

Dear

Benefits and medical records

I am writing to ask for your help with some important research that is being carried out among people who have made a claim for incapacity benefit in the last year or so. The Department for Work and Pensions has been testing a new way of collecting medical information for benefit claims by using GP medical records, and we would like to find out what people think about it. The research is being carried out on behalf of the Department by an independent research organisation, the Social Policy Research Unit at the University of York.

We are particularly interested in your views because we understand that you appealed against the decision and your case was considered by a tribunal.

A researcher from the Social Policy Research Unit may contact you soon to see whether you are willing to be interviewed over the telephone as part of the study, and if so to arrange a time to call you. The interview would last about 20-30 minutes. Anything you say to the researcher will be strictly confidential; no personal details will be passed to any government department or anyone else. Everyone who is interviewed will be sent £15 as a small token of thanks for their help. Taking part in this study will not affect any benefit you receive, or any dealings you may have with any government department or agency.

When the researcher gets in touch they will tell you more about the research and answer any questions you might have. Please let us know if there is anything we can do to make it easier for you to take part.

I do hope you decide to take part in the study – the value of the research depends on people's willingness to help. If, however, you do not wish to take part, please let us know by [DATE] quoting the reference number at the top of this letter. You can either write to us at the FREEPOST address above, or telephone Anne Corden from the research team on 01904 432626. If you would like to know more about the research, you can also call me, Jo Bacon, on 0207 962 8003.

Thank you for your help. I hope you will be able to take part in this important study and enjoy talking to the researcher.

Yours sincerely



Jo Bacon
Senior Research Officer

OPT OUT FOR NON APPELLANTS

Dear

Benefits and medical records

I am writing to ask for your help with some important research that is being carried out among people who have made a claim for incapacity benefit in the last year or so. The Department for Work and Pensions has been testing a new way of collecting medical information for benefit claims by using GP medical records, and we would like to find out what people think about it. The research is being carried out on behalf of the Department by an independent research organisation, the Social Policy Research Unit at the University of York.

A researcher from the Social Policy Research Unit may contact you soon to see whether you are willing to be interviewed over the telephone as part of the study, and if so to arrange a time to call you. The interview would last about 20 minutes. Anything you say to the researcher will be strictly confidential; your name and personal details will not be passed to any government department or anyone else. Everyone who is interviewed will be sent £15 as a small token of thanks for their help. Taking part in this study will not affect any benefit you receive, or any dealings you may have with any government department or agency.

When the researcher gets in touch they will tell you more about the research and answer any questions you might have. Please let us know if there is anything we can do to make it easier for you to take part.

I do hope you decide to take part in the study – the value of the research depends on people's willingness to help. If, however, you do not wish to take part, please let us know by [DATE] quoting the reference number at the top of this letter. You can either write to us at the FREEPOST address above, or telephone Anne Corden from the research team on 01904 432626. If you would like to know more about the research, you can also call me, Jo Bacon, on 0207 962 8003.

Thank you for your help. I hope you will be able to take part in this important study and enjoy talking to the researcher.

Yours sincerely



Jo Bacon
Senior Research Officer

**MASTER LETTER TO CHAIRS AND MEDICAL
MEMBERS OF TRIBUNALS**

Telephone (01904 433608)
Fax (01904) 433618
E-Mail: SPRU@york.ac.uk

Dear

Evaluation of Medical Evidence Gathering for Incapacity Benefit pilot

As explained in Sandra Macdonald's letter, the Department for Work and Pensions has commissioned the Social Policy Research Unit to conduct research on the pilot project on Medical Evidence Gathering for Incapacity Benefit. We would very much like to interview you as a tribunal member about the role of medical information in the tribunal process, and about your views of the pilot. We know that not many pilot cases have been to appeal but we would like to talk to you because you have heard more cases than most of your colleagues.

As you may recall, the pilot has tested a new way of collecting medical information from GPs for the use of Medical Services doctors, Jobcentre Plus decision makers, and appeal tribunals. For pilot cases, the claimant's GP has not been sent an IB113 form to complete in the usual way but has been asked to send the claimant's medical notes to the Leeds Medical Services centre where a trained doctor has extracted relevant medical information. This might, for example, be in the form of GP notes, hospital reports, or consultants' letters.

The research project is in two parts. For part one we interviewed incapacity benefit claimants; GPs and surgery administrative staff; Medical Service doctors in Leeds; examining medical officers; and administrative staff involved in the pilot. Our report on their experiences and views of the pilot was published in the summer (and is on the DWP web site at <http://www.dwp.gov.uk/asd/asd5/rrep189.asp>). Part two of the project is focusing on appeals. So far we have interviewed 40 appellants and non appellants by telephone and we are currently analysing the interview data. The final part of the project is interviewing tribunal members, after which we will prepare a second research report for the DWP.

We understand that you will be sitting in [LEEDS/SHEFFIELD/YORK] on [DATE] and hope that either myself or my colleague, Anne Corden, would be able to see you then. We know from the Allocations section at York House that you have a full session of cases booked but perhaps we could see you either before the morning session, at lunchtime or after the afternoon session. We aim to take no more than 30 minutes of your time. Alternatively we could arrange some other time and venue to suit you. It would be helpful if you could let us know when you would like us to visit you. My direct line at York is 01904 433603 or my secretary can take a message on 01904 432626.

We hope you find the research interview interesting. If I can answer any queries beforehand please do get in touch.

With thanks.

Yours sincerely

Dr Roy Sainsbury

Appendix C

Topic Guides

Topic guide - Interviews with appellants

INTERVIEWER'S INTRODUCTION

You were invited to take part in this research because you made a claim for incapacity benefits in the Sheffield/Rotherham area and made an appeal against the decision. In this area the Department for Work and Pensions is trying a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear what you think about this and whether it had any effect on your appeal.

- Remind about SPRU
- Explain the issues to be covered
 - About you and your household
 - About your claim and appeal in relation to incapacity benefit
 - Experiences of making an appeal
 - Thoughts about the trial
 - Your ideas about how to improve how your claim/appeal is dealt with (might want to bear this in mind as we proceed)
- Discussion will last around 20-30 minutes – check that this is OK
- Explain confidentiality, and how the material will be used.
- Explain discussion will have no effect on current claim, on any other benefits, or dealings with DWP, Inland Revenue, Employment Service, Child Support Agency etc., or any dealings with your own GP.
- Ask for permission to use tape-recorder.
- Any questions or concerns?
- Explain that money gift will be sent as postal order.

1. PERSONAL CIRCUMSTANCES, CLAIMS HISTORY

Details of household

- household members; age
- responsibility for children
- tenure

Claim history

Check rough chronology of current claim (for reference later in interview)

- initial or renewed claim
- PCA
- Decision
- Lodgement of appeal
- Hearing date

Check type of appeal

- Attended? - who
- Papers only

2. LODGING THE APPEAL

When you got the letter saying your claim was disallowed did it explain why?

If yes: Probe for

- understanding, reactions (feelings)
- links between medical evidence and decision.

Did you make an appeal straightaway or did you do something else first? E.g. seek further explanation.

If did not appeal immediately, probe for who (or what) was contacted, and

- understanding, reactions (feelings)
- discussions about role of medical evidence.

Can you explain why you decided to appeal?

Allow spontaneous responses initially

Probe fully any mention of trial arrangements and GP information.

If no mention of trial arrangements, ask:

You have not mentioned the trial arrangements for collecting GP information.

Did this have any bearing on your decision not to appeal?

Probe fully.

Interviewer note: if asked about trial, say that you will explain later in the interview. But first you will ask about the tribunal hearing.

3. THE APPEAL HEARING

Ask 3a for people who attended their hearing

Ask 3b for people who did not attend and whose case was decided on the papers only

3a - Attenders

Check who was at the hearing.

Check tribunal membership

Check attendance of DWP representative.

Can I first ask about your overall views of the hearing?

Allow spontaneous responses, and probe fully any mention of trial arrangements and GP information.

Can I now ask you about some different aspects of the hearing?

First, what information were you sent before the hearing?

Probe for copies of IB113, SB2, IB85, other medical information.

- Was this useful?
- How?

In the hearing, did the tribunal ask you about your health condition?

- what information was sought
- how was information sought (eg questions only or physical examination)

Was it explained to you what information the tribunal had been given prior to the hearing?

- any reference by tribunal to information before it?
- was information from GP mentioned? Probe.

Did you (or representative) produce any further information for the tribunal?

Probe for details.

How was medical information discussed in the hearing?

(Interviewer note: the aim here is to get an indication of the role of GP information in the discussions between tribunal, appellant and representative, and DWP presenting officer, in comparison with other information such as new evidence or the report of the medical examination.)

Can I just check about your views about the hearing:

- relaxed/nervous
- did they participate/say all they wanted. Probe if not.
- satisfaction
- fairness

Result:

- when told
- views
- understanding of decision
- further action

Looking back, would you have done anything differently? Probe.

If no mention of trial arrangements in responses about the hearing, ask:

You have not mentioned the trial arrangements for collecting GP information.

Did this have any bearing on your experience of the hearing?

Probe fully.

3b - non attenders

Why did you choose not to attend?

Probe fully.

What information were you sent before the hearing?

Probe for copies of IB113, SB2, IB85, other medical information. Was this useful? How?

Did you get help or advice after you lodged the appeal and before the hearing?

Probe fully.

Did you get, or try to get, any further information before the hearing?

- What, if any, information was sent to the tribunal?

Views about the paper hearing:

- satisfaction
- fairness

Result:

- when told
- views
- understanding of decision
- further action

Looking back, would you have done anything differently? Probe.

If no mention of trial arrangements in responses about the hearing, ask:

You have not mentioned the trial arrangements for collecting GP information. Did this have any bearing on your experience of the hearing?

Probe fully.

4. KNOWLEDGE OF TRIAL ARRANGEMENTS

Remind respondent of trial arrangements using crib sheet.

Make sure respondent understands that the special doctors looked at the actual medical notes which the GP makes and keeps in the surgery, and wrote a report that was used by the examining doctor instead of asking the GP to fill in forms

Do you know what information is kept in GP records?

Seek unprompted answers first. If necessary, prompt:

- GP's own notes
- Hospital letters
- Test results

Having learned about the trial now, do you think you might have done anything differently

- Deciding whether to appeal

Now that we have talked about this trial in detail, do you think it is good idea?

- Perceived advantages
- Perceived disadvantages

Having learned about the trial now, do you think you might have done anything differently?

- Deciding whether to appeal
- Preparing for the appeal
- Choice of oral/paper hearing
- Conduct in hearing

Now that we have talked about this trial in detail, do you think it is good idea?

- Perceived advantages
- Perceived disadvantages

Thank you for taking part.

Topic guide - Interviews with non appellants

INTERVIEWER'S INTRODUCTION

You were invited to take part in this research because you made a claim for incapacity benefits in the Sheffield/Rotherham area. In this area the Department for Work and Pensions is trying a new way of collecting information for deciding whether people are eligible for incapacity benefits. We would like to hear what you think about this and whether it had any effect on your appeal.

- Remind about SPRU
- Explain the issues to be covered
 - About you and your household
 - About your claim and appeal in relation to incapacity benefit
 - Thoughts about the trial
 - Your ideas about how to improve how your claim/appeal is dealt with (might want to bear this in mind as we proceed)
- Discussion will last around 20 minutes – check that this is OK
- Explain confidentiality, and how the material will be used.
- Explain discussion will have no effect on current claim, on any other benefits, or dealings with DWP, Inland Revenue, Employment Service, Child Support Agency etc., or any dealings with your own GP.
- Ask for permission to use tape-recorder.
- Any questions or concerns?
- Explain that money gift will be sent as postal order.

1. PERSONAL CIRCUMSTANCES, CLAIMS HISTORY

Details of household

- household members; age
- responsibility for children
- tenure

Claim history

Check rough chronology of current claim (for reference later in interview)

- initial or renewed claim
- PCA
- Decision

2. EXPERIENCES OF DISALLOWED CLAIM

When you got the letter saying your claim was disallowed did it explain why?

If yes: Probe for

- understanding, reactions (feelings)
- links between medical evidence and decision

What did you do after getting the letter? E.g. seek further explanation.

Where appropriate, probe for who (or what) was contacted, and

- understanding, reactions (feelings)
- discussions about role of medical evidence.

Can I check whether you lodged an appeal against the disallowance decision?

Did you know you could appeal?

- Sources of information

Can you explain why you decided not to appeal?

Allow spontaneous responses initially

Probe fully any mention of trial arrangements and GP information.

If no mention of trial arrangements, ask:

You have not mentioned the trial arrangements for collecting GP information.

Did this have any bearing on your decision not to appeal?

Probe fully.

3. KNOWLEDGE OF TRIAL ARRANGEMENTS

Remind respondent of trial arrangements using crib sheet.

Make sure respondent understands that the special doctors looked at the actual medical notes which the GP makes and keeps in the surgery, and wrote a report that was used by the examining doctor instead of asking the GP to fill in forms

Do you know what information is kept in GP records?

Seek unprompted answers first. If necessary, prompt:

- GP's own notes
- Hospital letters
- Test results

Having learned about the trial now, do you think you might have done anything differently

- Deciding whether to appeal

Now that we have talked about this trial in detail, do you think it is good idea?

- Perceived advantages
- Perceived disadvantages

Thank you for taking part.

Topic guide for tribunal members

[Props:

- *Letter of invitation*
- *Copy of first report*
- *SB2 and IB113]*

Interviewer introduction

We are evaluating the medical evidence pilot that started in early 2002 (refer to letter sent via Leeds Appeals Service office). To recap: The research project is in two parts. For part one we interviewed incapacity benefit claimants; GPs and surgery administrative staff; Medical Service doctors in Leeds; examining medical officers; and administrative staff involved in the pilot. Our report on their experiences and views of the pilot was published in the summer.

Part two is focusing on appeals. Some of the claimants who took part in the pilot had their cases decided by a tribunal this year, though no new claimants have joined the pilot since November 2002. So far we have interviewed 40 appellants and non appellants by telephone and we are analysing the interview data. The final part of the project is interviewing tribunal members. You have been selected because, of the tribunal members in the region, you have heard more of such cases than your colleagues.

- Remind about SPRU
- Explain the issues to be covered
 - # The role that medical information, and particularly information from GPs, plays in the tribunal process in relation to personal capability assessments
 - # Your experiences of hearing cases that have been through the pilot procedures
 - # Your views about how the provision of medical information might be improved.
- Discussion will last around 30 minutes
- Explain confidentiality, and how the material will be used
- Ask for permission to use tape-recorder
- Ask if any questions or concerns?

[Interviewer note: it might be necessary to outline the pilot arrangements at some point. Use same crib sheet that was used for claimants.]

1. The role of GP information

[Interviewer note: The aim of this initial set of questions is to explore the role that GP information plays in the tribunal's work in relation to other sources of information.]

Can you characterise what the job of the tribunal is? Prompt:

- to look at new evidence?
- to review past decisions?
- to resolve conflicts? Probe to explore nature of conflicts (for example between appellant's evidence and EMO or GP; or between medical practitioners)

Can I just check, what information are you supplied with in the tribunal papers? Expect mention of the following:

- claim forms
- IB85 medical reports
- Jobcentre plus decision maker's decision
- (possibly a review decision if claimant has asked for one)
- Med 3, 4 and 5 forms
- IB113s
- Appeal letter/form
- Additional information from appellant (including medical information)
- Other correspondence

Probe: what information comes from the claimant's own GP?

Are there any circumstances or types of case where GP information would be particularly useful or important? Probe for examples.

Prompt for differences between oral and paper hearings.

Conversely, are there circumstances or types of case where GP information becomes marginal, or even irrelevant? Probe for examples.

Again prompt for differences between oral and paper hearings.

What medical information does a tribunal need to do its job?

What is essential?

What is desirable?

Is *diagnostic* information more or less useful than information about *functionality*?

2. Experience of the pilot arrangements

Can I check whether you remember any of the cases in which there was an SB2 form among the papers?

(SHOW COPIES OF SB2 AND IB113)

IF NECESSARY REMIND RESPONDENT OF DETAILS OF RELEVANT CASES (NAME OF APPELLANT, DATE, VENUE, NAME OF OTHER TRIBUNAL MEMBER).

If no recall whatsoever, skip to section 3.

Interviewer: I want to ask about two aspects of the SB2 form – first the quality of the information, and secondly about whether the information is useful or not.

As a (Chair/medical member) do you have a view on the *quality* of the information in the SB2s? Probe.

(Interviewer: check whether comments are about GP extracts or annotations etc of the Medical Services doctors.)

Was legibility a problem?

How would you judge the *usefulness* of the SB2 information?

Probe: how/when was the information useful?

Prompt for (a) in preparing for hearing, (b) during the hearing, (c) in decision making, and (d) providing oral/written explanations.

Have appellants ever referred to information in SB2s (a) during a hearing, or (b) in any additional information provided before a hearing. Probe for examples.

Any difference in use/usefulness between oral and paper hearings? Probe fully.

How would you compare SB2s with IB113s? Probe fully.

Have SB2s has an *impact* on decisions?

- have decisions been 'better' in any sense? How?
- any effect in your confidence about the correctness of decisions? Probe.
- any impact on written or oral explanations given to appellants? Probe.

3. Preferences/the future

Is the current system satisfactory (i.e. for obtaining factual information from the GP to support the PCA decision making process)?

In an ideal world, what would you change? What would be the most important change?

Do you prefer the SB2 arrangements or using the IB113 system? Or would you prefer something different?

Appendix D

Official Medical Evidence Forms

Incapacity for work

Office stamp

Our phone number is

Code Number Ext

If you have textphone, you can call on

Code Number

If you get in touch with us, tell us this reference number

Date
 / /

About your patient

Surname Address Other names NI number Date of birth

 Postcode
Dear Doctor,

Your patient has claimed benefit due to incapacity and we now have to assess their capacity to perform any work, not just their own job, using the Personal Capability Assessment procedures. People with certain severe medical conditions can be accepted as meeting the threshold of incapacity for benefit purposes without undergoing the Personal Capability Assessment or, if the assessment has to be applied, without undergoing a medical examination.

From the information you have provided on a medical statement (for example for Med 3), or information otherwise available to the medical officer, it appears that this may be such a case. In order to advise the Benefits Agency decision maker in accordance with the law, the medical officer requires further factual information. We would be obliged if you would answer the medical officer's questions overleaf indicating on a separate sheet, any medical evidence that you think would be harmful to the patient's health. An example of what may be harmful information is a diagnosis that is not known to your patient such as malignancy, progressive neurological conditions or major mental illness.

Your patient has given written consent on their claim form to allow us to approach you for this information.

If you have agreed to treat this patient under the NHS (General Medical Services) Regulations 1992 as amended March 1998 and equivalent regulations in Scotland, and have issued, or refused to issue, a medical certificate to them, you are obliged by your terms of service to supply clinical information to a medical officer. A similar obligation applies to most hospital and community doctors working within the NHS. You are not obliged to do this if you have not agreed to treat the patient under the NHS but any information you are willing to provide will be much appreciated. Unfortunately, we will be unable to pay you for it.

A reply within 7 days will be appreciated and a business reply envelope is enclosed for your use. If you have any queries about this form please contact the medical officer at your local Medical Services Centre, see leaflet **IB204** *Guide for Registered Medical Practitioners*.

Thank you for your help.

Yours sincerely

On behalf of the Manager
For the Medical Officer

An Executive Agency of
the Department of Social Security

For official use	
DO	Ref Type
First day of incapacity	
/	/

Your reply to the Medical Services doctor

Please answer the following questions from the information which is currently available to you.

1 Date patient was last seen or examined for the condition(s) causing incapacity.

2 Diagnosis of all relevant conditions and date(s) of onset.

3 **Factual details of patient's condition.**

Where possible, please include brief factual details of:

- § present medical condition
- § medication and other treatments (eg attendance at day care centre, hospital outpatient)
- § outlook for your patient and any proposals for future management.

About your patient - continued

- 4 Where available to you, please give brief details of what the patient has been told about the likely clinical course of their condition(s), and any future treatment.

5 Any other information.

- § If you have evidence which indicates that, as a result of their medical condition, your patient would not be able to attend an examination by using public transport or by taxi please include this here.
§ Any additional information about the effects of the medical conditions on daily living (self care, indoor mobility, judgement and compliance with medication) would be very helpful.

Only complete the section below if you have diagnosed a psychiatric condition at question 2.

- 6 Where available to you, please give brief details of any history of recent or serious attempts at suicide or other self injury, or any history of threatening or violent behaviour towards others.

Declaration

I understand that if this person appeals, or asks for an explanation or reconsideration of the decision made by the Benefits Agency, a copy of the information I have given here may be sent to the person, their legal representative and the Appeals Service

I also understand that the only information that can be withheld is medical evidence that would be harmful to the person's health. I have stated any medical evidence that I think may be harmful to the person's health on a separate sheet of paper.

Your signature

Signature

Name

Dr

Date

/ /

Doctor's stamp

Extract(s) of Case Notes for the purpose of Incapacity Benefit

PLEASE INSERT RELEVANT EXTRACTS FROM THE GP CASE NOTES FOR THE CLAIMANT NAMED BELOW.

Claimant Details

Surname	<input type="text" value="XXXX"/>	
Other Names	<input type="text" value="xxxxxx"/>	
NI Number	<input type="text" value="X"/> <input type="text" value="X"/> <input type="text" value="0"/> <input type="text" value="0"/> <input type="text" value="0"/> <input type="text" value="0"/> <input type="text" value="0"/> <input type="text" value="0"/>	<input type="text" value="X"/>
Date of Birth	<input type="text" value="01/01/1901"/>	
Case Notes Reviewed	<input type="text" value="01/01/1946"/>	<input type="text" value="01/01/2011"/>

Information for Examining Doctor:

This form has been completed by a specially trained doctor, approved by the Secretary of State.
The form has been completed in accordance with current guidance as issued by Medical Services.

Dr's Name	<input type="text" value="Dr. XXXXX"/>	Dr's Signature	<input type="text"/>	For Official Use	
Date	<input type="text" value="11/11/2002"/>			DO	Ref Type
				First day of incapacity / /	

Extracts of relevant entries in chronological order

Appendix E - Note on terminology

Medical practitioners play a variety of roles in the administration of incapacity benefit. These are referred to in this report as *approved doctors*. The key role of the *approved doctor* in the Medical Evidence Gathering Pilot included:

- preparing a data extract from GP case files (on form SB2),
- advising decision makers, including following an examination of the claimant (when they act as an Examining Medical Officer (EMO)).

Incapacity benefit approved doctors may be:

- employed by the DWP directly (in DWP Corporate Medical Group),
- employed by SchlumbergerSema Medical Services (the company contracted to provide Medical Services to DWP), or
- subcontracted to Medical Services.

In relation to medical evidence gathering for incapacity benefit NHS general practitioners' terms of service require them to provide certain information to a DWP 'medical officer' on request. The relevant legislation defines that a medical officer may be a doctor employed by DWP directly or by an organisation contracted to provide approved doctors' services to DWP. Doctors such as NHS general practitioners, who provide advice and statements of incapacity (so-called sick notes) to their patients as part of their clinical practice are known as 'certifying medical practitioners.' NHS GPs have a contractual obligation to provide such statements to their patients and to provide information subsequently requested by a DWP medical officer (DSS/DWP, 2000).

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