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The take-up rate of Disability Living Allowance and Attendance Allowance: Feasibility study

Diana Kasparova
Alan Marsh
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Policy Studies Institute

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Department for Work and Pensions

Research Report No 442

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Diana Kasparova, Alan Marsh and David Wilkinson

A report of research carried out by the Policy Studies Institute on behalf of the
Department for Work and Pensions

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Abbreviations

AA	Attendance Allowance
BHPS	The British Household Panel Survey
CCM	Customer Case Management
DCS	Disability and Carers Service
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
EHCS	English House Conditions Survey
ELSA	English Longitudinal Study of Ageing
EMP	Examining Medical Practitioner
ETU	Earnings Top-up
FRS	Family Resources Survey
GHS	General Household Survey
HEMS	Health Education Monitoring Survey
HMRC	Her Majesty's Revenue and Customs
HSE	Health Survey of England
ICD	International Classification of Diseases
IHS	Integrated Household Survey
LFS	Labour Force Survey
MI	Management Information
ONS	Office of National Statistics

OPCS	Office of Population Censuses and Surveys
PIDMA	Professionalism in Decision Making and Appeals
SHS	Scottish Health Survey
SIC	Standard Industrial Classification
SOC	Standard Occupational Classification
WPLS	Work and Pensions Longitudinal Study
WHS	Welsh Health Survey

Summary

Introduction

There are over four million people in Britain receiving one of two non-means-tested benefits for disabled people: 2.8 million mostly young and working age people receive Disability Living Allowance (DLA) and 1.4 million older people receive Attendance Allowance (AA), although about 800,000 DLA recipients are now over retirement age.¹ Regular social surveys and the 2001 census indicate that a further six million or so have some kind of long-term limiting illness or disability.² Not all these six million have care and mobility needs that would qualify them for DLA/AA if they applied, but some do. Had the population eligible for DLA/AA been known, the take-up rate would have easily been calculated as a ratio of the number of recipients to the number of the eligible.

The accurate identification of the eligible is difficult in the case of DLA/AA for a number of reasons: First, the benefits are non-means-tested and so it is impossible to use existing administrative data on incomes to determine the eligible population. Second, the eligibility criteria are based on a person's mobility and care needs which may often be difficult to identify, not least because these needs change over time. Furthermore, the impact of disability on their needs is self-reported and hence, the award decision depends on the ability of the potentially eligible to accurately assess and report these needs. Their failure to do so may introduce uncertainty into the process and require decision makers to seek additional evidence from a medical professional or another source. Finally, since health conditions are difficult to quantify, especially where the problems are multiple, the information on which DLA/AA decisions are based is more open to interpretation than is the case for

¹ Those with care and mobility needs who were awarded DLA under the age of 65 may continue to receive it after reaching this age, as long as their needs have not changed.

² The 2001 Census records 10.3 million people in private households with a long-term limiting illness or disability; 7.1 million are of working age. Government statistics show there are 770,000 disabled children, who are seven per cent of all children (PMSU, 2005).

other benefits. This genuine uncertainty implies that the decision on DLA/AA may also bear a subjective element on the part of a decision maker.

These complexities explain why the 'truly' eligible population is difficult to define. For example, the DLA/AA eligible population in the Family Resources Survey (FRS) Disability Follow-up Survey consisted of the disabled people who may or may not have been in receipt of an award; it excluded those who may have been in receipt of an inappropriate award, even though these people were included in the number of recipients when calculating the take-up rate (Craig and Greenslade, 1998). Although this survey was undertaken with the purpose of estimating the DLA/AA take-up rate, the results were not robust³ and there is no reliable estimate of the size of the eligible population and hence, the take-up rate. There are suggestions to define a pool of the eligible on the basis of the decision makers' assessment of DLA/AA claims obtained via a survey (Purdon *et al.*, 2005). This approach would incorporate uncertainty into the definition of eligibility.

Estimating the size of the eligible population and the take-up rate is a difficult, if not impossible, task. This study is part of the wider research that aims to assess whether such a task is feasible.

The scope of the study

This project represents the first of potentially three stages of research on the feasibility of estimating the DLA/AA take-up rate and a complementary study to it. Progress to each subsequent stage depends on the successful completion of the tasks of the previous stage. The outcome of the research (i.e. stage three) will consist of a detailed proposal suggesting an approach to estimating take-up. Being methodological in nature, this research does not question the current level of fraud and error. Nor does it aim to suggest whether or how the policies and/or practices relating to the benefits in question should change. Describing the three stages of research in greater detail:

- Stage one aims to analyse existing data and experience of estimation to date in order to recommend an approach to estimating take-up in principle.
- Stage two refines the recommended approach and tests some practicalities of its implementation.
- Stage three consists of piloting the recommended approach and developing the final proposal on estimating take-up.

The complementary study aims to help formulate appropriate policies to increase take-up and is centred on non-claimants: who they are, and why they do not claim.

³ The take-up estimates ranged between 40 and 60 per cent in the case of AA, between 30 and 50 per cent in the case of the DLA care component and between 50 and 70 per cent in the case of the DLA mobility component (Craig and Greenslade, 1998).

Although these objectives are different from the goal of estimating the take-up rate, both the complementary study and the take-up research require an accurate identification of the population of eligible non-claimants. For this reason, the complementary study should be interlinked with the three-stage feasibility research and the take-up estimation itself. Analysis of barriers to claiming in the course of the complementary study would inform an accurate identification of the eligible population and hence, estimation of the take-up rate. If the take-up estimation is feasible, some data collected for this purpose will shed light on the profile of the non-claiming population. The relations between the feasibility research, the complementary study and the take-up estimation should be established at stage one of the feasibility research (this study), while the outputs of the complementary study and the take-up estimation itself are to be produced in the course of two separate projects.

This report presents the findings relating to the first stage of the project which aims to assess the feasibility of developing an approach to estimating take-up.

Research question, methods and outputs of the study

The study examines whether an estimation of the DLA/AA take-up rate might be feasible, given the complexities of decision making and claiming processes, such as the:

- presence of judgement in both decision making and claiming processes;
- changing nature of the needs of a disabled person over time;
- possibility of changes in existing award practices and/or policies;
- possibility that the potentially eligible may choose not to claim;
- complexity and open-ended nature of the claim;
- need for evidence and for a proxy/third party.

These features of decision making and claiming processes require thorough understanding and analysis because they determine the choice of the take-up measure, which, in turn, shapes an approach to estimating it.

The approach to estimation also depends on the availability of data required for estimation, whether these are collected administratively or via a survey. This study provides a list of data that would be required for the take-up estimation and investigates existing administrative and survey data sets against these requirements.

Previous disability-related surveys and research on the approaches to estimating the DLA/AA take-up rate are also examined. Their analysis provides an input to developing an approach to estimation in this study.

The methods of analysis include:

- a desk-based review of documentation relating to claims;
- interviews with key stakeholders, involving decision makers, key personnel in the Department for Work and Pensions (DWP), medical professionals, welfare rights organisations, social workers and data holders;
- investigation of existing data relevant to claiming and decision-making processes;
- analysis of potential approaches to estimating take-up of DLA/AA suggested by previous research and disability-related surveys.

The output of the study consists of:

- a description of the process, from claiming to decision making and analysis of its complexities in terms of implications for estimating take-up;
- an assessment of existing data in terms of its usefulness in representing the process and allowing the estimation of the take-up rate;
- an examination of potential approaches to estimating take-up;
- a recommendation of an approach to estimating take-up;
- a description of requirements of a sample and sub-samples;
- recommendations regarding the next steps of feasibility assessment.

These outputs are now described in turn.

Claiming and decision-making processes

The analysis of claiming and decision-making processes aims to enable the development of a take-up measure that takes account of their complexities. It is based on a desk-based review of documentation relating to claims, further in the text referred to as claim packs. At its fullest, a claim pack consists of a DLA/AA claim form completed by the claimant or a third party, additional evidence submitted by the claimant and/or a third party, documentation completed by adjudicator(s) and, where necessary, appeals panels. The information obtained during the interviews with DWP officials and decision makers also feeds into the analysis of claiming and decision-making processes.

The analysis points out that, in order to account for complexities of existing claiming and decision-making practices, the take-up measure should reflect subjectivity and uncertainty present in both of them. These features imply that different decisions can be made on the basis of similar information, without anyone actually having made a mistake. In the case of DLA/AA, regardless of the fraud and error problems, eligibility does not equate with receipt. Therefore, any definition of eligibility for DLA and AA has to be based on the assumptions about the treatment of uncertainty and subjectivity.

This study proposes to incorporate uncertainty and subjectivity into the measure of take-up. Consequently, in this report, the term 'eligible' always refers to the 'probably eligible' and the take-up rate is determined by a ratio of the number of benefit recipients to the probable number of those who would receive it if they applied (i.e. including recipients). Another definition used in this report is that of the 'potentially eligible'. These are people who have some disabling conditions but whose (probable) eligibility for DLA/AA is still to be established. Table 1 presents the potentially eligible population. The probably eligible population occupies the shaded area that is comprised of groups A, E, C and G. And the take-up measure that this study proposes is determined by a ratio $(A+E)/(A+E+C+G)$.⁴

Table 1 The potentially eligible population by their benefit receipt and 'true' eligibility status

	Applied for benefit		Not applied for benefit	
	Awarded	Disallowed	Would have been awarded	Would have been disallowed
'Truly' eligible	A	B	C	D
Not 'truly' eligible	E	F	G	H

In addition to reflecting existing claiming and decision-making practices, this measure ensures consistency between the numerator and denominator of the ratio. This is because the denominator identifies those members of the overall population that resemble those who receive the benefits (the numerator) in terms of their characteristics, including their needs.

It is important to stress that the probabilistic approach to the definition of eligibility adopted in this research means that the proposed measure does not question the eligibility of those who receive the benefits. It treats them all as those (probably) eligible, even if some recipients are awarded the benefit in error. Moreover, since the measure of take-up does not aim at identifying weaknesses in practices and/or policies relating to DLA/AA receipt it does not, strictly speaking, estimate the proportions of those who wrongly receive DLA/AA or who wrongly do not receive it. Nor does it require a clear definition of 'truly eligible' or an estimate of the number in this category.

The analysis of claiming and decision-making processes also reveals that the needs of a potentially eligible person may change over time if their health condition deteriorates or improves. Since changes in needs are difficult to predict, the take-up measure that is proposed in this study is a point in time measure, i.e. it refers to the take-up rate at one point in time and does not account for possible changes

⁴ Note that in a situation that disregards legitimate subjectivity and uncertainty in claiming and decision-making processes, $B=E=D=G=0$.

in needs of the eligible population in the future. Nevertheless, it is desirable to develop an approach that is able to shed light on some possible changes in needs in the future.

Being a point-in-time estimation, the take-up measure reflects the current state of decision-making practices and related policies. This implies that if changes to these practices and/or policies are anticipated in the future, they should be incorporated into the approach to estimating take-up at its development stage. At the same time, since the take-up rate is an aggregate estimate it may be more sensitive to some changes (e.g. an introduction of means-testing) than to others (e.g. an increase in the number of disabling conditions to be accounted for in award decisions).

The analysis of claim packs and interviews with decision makers are also used to identify requirements of the data necessary for the estimation of take-up. These data should:

- match that available to decision makers;
- be relevant to the entitlement criteria;
- contain information on all the potentially eligible, regardless of whether they are claiming or not.

These requirements have a number of implications:

- the reasons for non-claiming should be examined in order to enable an accurate identification of the potentially eligible population, i.e. including those reluctant to claim;
- the data should contain information on impairments and medical conditions as well as on the needs of the potentially eligible in order to account for cases where the potentially eligible are not in a position to correctly assess their needs;
- the content of supporting evidence also has to be reflected in the data;
- the information on the needs of the potentially eligible may have to be collected from a variety of sources, including a medical professional and a third party;
- the data collection process may need to take place in stages as this is the case when decision makers seek additional evidence in order to arrive at a decision.

The results of analyses relating to the reasons for non-claiming and to the ability of existing data to provide the required information are the subject of the following two sections.

Understanding non-claiming and the complementary study

In order to assess the take-up rate, the data on the potentially eligible population should include information on those who for some reason do not claim. Identification of these people requires understanding of the possible reasons for non-claiming. The analysis is based on the information and views provided by interviews with DWP staff, a number of welfare rights organisations and social workers. It suggests that there are eight main models of non-claiming:

- delay;
- awareness and comprehension;
- identity and acceptance;
- skill transfer;
- critical mass and social networks;
- threshold or 'trigger events';
- risk aversion or the costs of claiming;
- negative feedback.

These models point to the varied and significant barriers that stand in the way of claiming. Since these barriers to claiming are also barriers to take-up measurement, people's reasons for non-claiming have to be taken into account in the design of the approach to measuring the take-up rate. They also have to be accounted for in the design of the complementary study that centres on non-claimants and investigates their characteristics, including their social location and attitudes towards claiming.

This interrelation between the subjects of the complementary study and this feasibility research allows the complementary study to be developed and tested as part of the development and testing of the approach to estimating take-up. At the same time, the development of an approach to estimating take-up should benefit from the results of the complementary study as they would feed information on non-claimants into the main research.

Data availability and usefulness

The analysis of existing data, in terms of their usefulness in estimating take-up, involves the examination of both administrative and survey information. It is based on interviews with data holders at DWP and Disability and Carers Service (DCS) and a review of the relevant documentation. The list of variables required for the estimation of the take-up rate is developed, noting that the data should relate to all those potentially eligible (both claiming and non-claiming) and include, among other information:

- care and mobility needs linked to the DLA/AA entitlement criteria;
- source of evidence;
- date of the disability onset.

Existing administrative and survey data are examined against the list of required data. The analysis of existing administrative data suggests that no set in its present form enables an estimation of the take-up rate. Accurate administrative data only exist on the number of claimants, the number of recipients and their award rates. Additionally, information obtained during a one-off three-day data collection exercise (described in Section 5.3.1) may help to identify those very likely and those very unlikely to be eligible among the general population. And the data collected during the Customer Case Management (CCM) pilots may be used in an analytical exercise to establish the relationships between various pieces of information required to arrive at a decision. This exercise would be useful if a system of numeric codes was to be developed as a means of representing the information from the claim pack in some more structured way than free text.

Therefore, although administrative data can be used to measure the number of recipients, they lack other data required for identifying eligible non-claimants and estimating the take-up rate.

With regard to a survey as a means of collecting the data to estimate the take-up rate, the analysis of existing social surveys that provide information on the health status of the population aims at identifying their potential to estimate take-up or to inform the design of a survey if this was chosen as a means of collecting the data to estimate the take-up rate. The following surveys are examined in this study:

- the British Household Panel Survey (BHPS);
- the Health Survey for England (HSE), Scotland and Wales;
- the English Longitudinal Study of Ageing (ELSA);
- the General Household Survey (GHS);
- the Labour Force Survey (LFS);
- the House Conditions Surveys for England, Scotland and Wales;
- the Health Education Monitoring Survey (HEMS).

The analysis demonstrates that none of these surveys can be used for estimating the DLA/AA take-up rate because none of them fully covers the population of interest. Some of these surveys have limited geographical coverage, some exclude children, some focus on people aged 50 and over, some do not include those living in residential care. However, the elements of these surveys (e.g. their questionnaires and methods of selecting people into the survey) should be investigated at stage two of the research if a survey approach to estimating take-up is adopted.

Since none of the existing surveys or administrative data sets can be used to estimate the take-up rate, some survey-based approach to collecting the data and estimating take-up should be developed. However, prior to developing such an approach, consideration should be given to the existing experience and research relating to survey-based methods of collecting the disability-related data and estimating the DLA/AA take-up rate.

Disability-related surveys and potential approaches

The methods adopted in previous disability-related surveys, and those suggested by research more recently, are examined in order to assess their suitability for the estimation of the take-up rate. This shows that none of the surveys would produce a required take-up estimate if repeated. Although the aim of the FRS Disability Follow-up Survey was also to estimate the DLA/AA take-up rate, the definition of eligibility and the measure of the take-up rate adopted in that survey are different from the ones proposed in this study. Moreover, the FRS Disability Follow-up Survey excluded people living in residential accommodation. The Office of Population Censuses and Surveys (OPCS) Disability Surveys aimed to estimate the severity of disability in the population but not the entitlement to AA or Mobility Allowance, which pre-dated DLA. Their focus, therefore, is different from the aim of this research.

However, detailed analyses of certain elements of these surveys are likely to inform the research at stage two of the project, if a decision to progress to it is taken. For example, methods of selecting the respondents into the survey and the design of the OPCS Disability Surveys would need to be investigated when developing an approach to identifying the potentially eligible population. The main questionnaire and the methods of presenting the claim form information in some structured way developed for the FRS Disability Follow-up Survey are likely to inform the design of these elements of any survey aiming to estimate the DLA/AA take-up rate.

The analysis of two more recent research proposals put forward by Purdon *et al.* (2005) suggests that one of them (a claims-based approach) is unlikely to achieve the desired result on both methodological and practical grounds and another (a modelling-based approach) should be modified in order to avoid spurious results.

The claims-based approach recommends conducting a survey where respondents (the population of non-claiming potentially eligible people) or someone on their behalf fill in the claim forms and agree to these being submitted to decision makers for an assessment. Decision makers then may seek and obtain additional evidence, if this is required. Their decision determines the respondents' eligibility. This approach addresses the complexity and open-ended nature of the claim form and also the need for evidence. However, it has a number of features that render it unfit for purpose:

First, the authors' recommendation seems to stop at the initial decision of an adjudicator rather than go on to replicate appeals to be lodged by those at first

deemed ineligible. Given subjectivity and uncertainty surrounding the process, the success at appeal is possible and it would alter the size of the eligible population determined by the first round of decisions.

Second, the approach assumes that respondents will agree to claim the benefit and therefore, ignores the possibility that some potentially eligible may choose not to claim. This approach will exclude those eligible non-claimants who will not give permission for the claim to be submitted on their behalf. The estimated take-up rate will therefore not be valid, since respondents' claims cannot be considered by decision makers without respondents' permission to do so. Further, in order to obtain a robust take-up estimate under this approach, some people who have a relatively low probability of success would need to be persuaded to claim. However, it is difficult to envisage a conversation with a respondent where they are told that they are unlikely to be entitled to benefit but need to fill out all the forms anyway just to check.

Third, if respondents are aware that decision makers will consider their cases and arrive at a clear yes or no answer, there is an issue of acting on the decision makers' decision. If the answer is yes, it seems reasonable to abide by it. However, it also seems reasonable that those who are refused an award are informed that another decision maker might have reached an opposite decision on their case. No one though, would be in a position to assess the probability of reaching that opposite decision. Moreover, this would aggravate an ethical problem of raising hopes unnecessarily.

Fourth, claim forms filled in by interviewers may differ in a consistent way from those filled in by claimants (or a third party on their behalf) in, say, how the needs are presented. This may affect the decision makers' judgement and in this case the take-up rate will not accurately reflect existing practices.

Although Purdon *et al.* (2005) do not suggest this, it may be possible to obtain the information required for reaching an award decision using a survey questionnaire and then transfer it into the claim form and submit the form to a decision maker. However, this would raise an ethical issue of respondents' eligibility being assessed without their consent. But even if respondents are not informed about their answers being submitted to decision makers, this approach is unlikely to deliver because decision makers will probably be able to recognise the artificial claims. Their decisions would not be reliable, therefore. In order to avoid these claims being instantly recognised, the artificial claims would have to include names and signatures; the practical difficulties of arranging this would be huge. Moreover, in order to estimate take-up, these artificial claims would have to be taken out of the system. That would also represent a difficulty at a practical level.

Examination of another, modelling-based, approach recommended by Purdon *et al.* (2005) demonstrates the complexity of estimating the DLA/AA take-up rate and suggests that in order to avoid spurious results, the estimation should be conducted in phases and the achievements of each phase be verified before progressing to

the subsequent phase. These principles are observed by the approach this study recommends.

Recommended approach: interpretation of the take-up measure

This study recommends a probabilistic approach to assessing eligibility and suggests that the association between respondents' needs and their probability of being eligible be found by means of statistical modelling. This approach avoids a problem of refusal to claim because the estimated probability is not associated with the respondents' propensity to claim but only with their care and mobility needs. Once the probability of being eligible is determined for each respondent, a simple formula can be used to estimate the take-up rate:

$$TUR = \frac{R}{\sum_{i=1}^n P_i}, \text{ where}$$

TUR – the take-up rate

R – the number of recipients

P_i – the probability of receiving DLA/AA by respondent *i*.

In numerical terms, suppose there are 120 DLA recipients out of 384 potentially eligible people and the statistical model produced the following estimates: 200 people have a 20 per cent chance of being eligible, 100 people have a 50 per cent chance and 84 people have an 80 per cent chance. In this example, the take-up rate is 76 per cent.

$$\frac{120}{(0.2 * 200) + (0.5 * 100) + (0.8 * 84)} = 0.76$$

If this rate were to be the estimated figure it would mean that, given current decision-making practices, there are 3.68 (2.8/0.76) million people in total who are eligible for DLA (including those with low probability of receipt). Under current decision-making practices, 2.8 million of them receive the benefit and 0.88 million do not receive, either because they did not apply or due to error.

Indirectly, this approach to the measurement of take-up enables the analysis of instances where people receive the benefit despite having a low probability of being eligible and vice versa – instances where people do not receive the benefit despite having a high probability of being eligible. This provides a perspective on the extent of error, but not of fraud whereby needs might have been misrepresented. The probability of receiving a certain award rate may also serve as a proxy indicator of the degree of a person's care and/or mobility needs. For example, a person whose probability of receiving high rate DLA care award is estimated to be 90 per cent could be expected to have greater care needs than a person with a

probability of 60 per cent. Availability of such data over a number of points in time may demonstrate the dynamic of changes in care and/or mobility needs of the potentially eligible population. Finally, since no decision maker is involved in the process and because the outcome of statistical modelling is a probability of being eligible, rather than a clear yes or no answer, no one is in a position to inform respondents of the outcome relating to their particular case.

Recommended approach: phases of implementation

The recommended approach to estimating the take-up of DLA and AA is multi-phased, progress to each subsequent phase depending on the successful completion of the tasks of the previous phase. The sequence that should allow for verification of each phase before moving to the next is as follows:

- A** Development of a screening method and a screener that allow all the potentially eligible to be represented in the survey. Development of a survey instrument that allows respondents' answers to a survey questionnaire to replicate the claim form information as closely as possible. Development of the complementary study.
- B** Validation of the survey instrument using the data on claimants.
- C** Piloting the screening method, the screener and the survey instrument on a sample of the potentially eligible, i.e. both claimants and non-claimants. Piloting the complementary study.
- D** Development of a statistical model using the data on claimants.
- E** Piloting the survey and verification of the statistical model on a sample of the potentially eligible, i.e. both claimants and non-claimants.

Phase A

Each phase consists of a number of tasks. At phase A, the development of a screening method and a screening questionnaire should be based on the analysis of social surveys providing information on the health status of the population. This would enable a selection of a sample of the potentially eligible into the main survey. This sample should be representative in terms of its geographic coverage and characteristics of the population of interest (such as demography, type of disabling condition and place of residence). In order to develop a survey instrument (i.e. a main questionnaire including a coding system), the relationships between the award rates (including nil awards), the needs of the potentially eligible and their impairments and disabling conditions have to be identified. All types of evidence that are required by decision makers should also be established and linked to this system of relationships. The information obtained as a result of this exercise should then be presented as a series of questions and possible answers that allow survey respondents to provide data on their needs that are equivalent to the information they would provide if submitting the claim.

All anticipated changes to claiming and decision-making practices (e.g. the number of award rates, the type of required evidence) should be taken into account at this phase. This is to ensure that the estimated take-up rate reflects these practices at the time of the survey. The phase A analysis should also allow for the identification of some of the possible reasons for non-claiming; and the results of this analysis should feed into the complementary study that takes place later as a separate research project. Phase A should include the following tasks:

- select a sample of claim packs, including those disallowed as well as those awarded;
- code the information contained in the claim packs, including additional evidence, so that it was presented in some more structured (preferably, numerically coded) way than the free text;
- determine the associations between the award decisions and claimants' needs, their other characteristics relevant to the entitlement criteria and additional evidence;
- identify instances where a proxy/third party is best placed to provide information required by the DLA/AA claim form;
- design and develop a survey instrument;
- develop a screening method and a screener;
- identify possible reasons for not claiming and develop a questionnaire and a coding system relating to these reasons (as part of the complementary study development).

Phase B

Phase B aims to verify the survey instrument developed at phase A and to identify the weight of medical or other evidence in award decisions. This is achieved by coding a (new) sample of claim packs using the coding approach developed at phase A and asking decision makers to decide on these coded claims. The size of the sample of claim packs should be sufficient for statistical modelling (see below). The purpose of involving decision makers is to ensure that the coded claim packs convey information equivalent to that in the actual claim packs. The success of the task is determined by the degree of similarity between the decisions based on actual and coded claims. In order to exclude the deviation in decisions caused by the difference in decision makers' judgement, it is suggested that the same decision maker who decided on the actual claim is asked to decide on its coded version.

Medical or other evidence that is usually sought by decision makers in addition to the information collected through the claim form may play a crucial role in award decisions. Since some of this information may be impossible to collect during the survey it is vital to establish its importance.

It is suggested that this is achieved by asking decision makers to decide on the coded claims twice but only if the claims contain additional evidence. The first-time decision makers should be working from the coded packs from which information on this additional evidence is removed. These claims would consist of coded DLA/AA claim forms containing information provided by claimants and/or third parties on their behalf. The second-time decision makers should be using the coded claims with full information, i.e. the claims that contain additional evidence. These claims would consist of all coded information from the claim pack except the decision taken on the case. The comparison of their two decisions would indicate the importance of that evidence in reaching the decision made on the actual claim. The real-life decision itself may be the initial decision taken on an original claim, the one taken after reconsideration or the one arrived at by the appeals panels. The most important condition for the success of verification at phase B is that the coded information available to decision makers participating in verification was equivalent to the free-text information they used when arriving at the real-life decision.

The information on the importance of evidence could guide the development of a training programme for interviewers at phase C (see below). The training programme should enable them to collect the important evidence on the spot when interviewing the pilot participants. The tasks of phase B should include:

- selecting a new sample of claim packs that were decided upon over a recent period and applying the coding approach developed at phase A;
- removing additional evidence from the coded packs that contain it and asking the decision makers who decided on this sample of actual claims to re-assess them (i.e. working from the coded data that excludes additional evidence);
- in those cases where the additional evidence was removed, reinstating it in the coded pack and asking decision makers to re-assess the claims again (i.e. working from the coded data that includes additional evidence);
- establishing the importance of additional evidence by analysing the extent to which decision makers give the same or different answers when working from coded claims with evidence versus coded claims without it;
- refining the survey instrument by analysing the extent to which decision makers give the same or different answers when working from actual versus coded claims;
- developing a draft guide to a training programme for interviewers.

Phase C

Since phase B verifies the instrument developed on the basis of information only on claimants, additional steps need to be taken to ensure that the instrument will be valid when applied to non-claimants as well. The data collection methods also have to be tested. This task is especially important in the case of DLA/AA for such

reasons as sensitivity of some data (e.g. on children) and the need for a proxy to be involved (e.g. in some cases of mental health condition patients). The tasks that belong to phase C include:

- using the screening method and the screening questionnaire developed at phase A, selecting a sample of the potentially eligible (both claimants and non-claimants) into the pilot;
- using the main questionnaire and the coding system, developed at phase A and verified at phase B, interviewing those potentially eligible covering the information used by decision makers to arrive at an award decision;
- asking additional questions on respondents' attitudes to claiming and reasons for not claiming (as part of the complementary study pilot);
- conducting a few face-to-face interviews with non-claimants;
- refining the screening method, the screener and the survey instrument accounting for both claimants' and non-claimants' responses;
- refining the data collection methods and the guide to a training programme for interviewers.

Phase D

Phase D leads to the development of a statistical model that establishes associations between the award decisions and the characteristics of respondents. Once these associations are established (or, in other words, once the parameters of the model are identified), they can be applied to the characteristics of respondents in the main survey in order to obtain the probability of being eligible for each respondent. Various types of modelling techniques can be used depending on the outcome type. The best seems to be modelling the rates of each award because this will indicate the take-up estimate for each award rate as well as potential award rates among eligible non-claimants.

The sample of coded claim packs verified at phase B should be used in modelling. The size of this sample depends on the desired degree of precision of the take-up estimate and on the modelling option. It also depends on whether the analysis is to be carried out across the subgroups (say, separately for men and women): the greater the number of subgroups the larger should be the modelling sample. This implies that the types of subgroup, analyses should be defined in advance of phase D. More precisely, this needs to be decided upon at phase B because the sample of coded claim packs produced at that phase is to be used in statistical modelling. The tasks of phase D are as follows:

- taking the coded claim packs that were verified at phase B;
- developing a statistical model predicting the outcomes of claims, using the coded data.

Phase E

Since the statistical model is being developed using the information on claimants only, the last phase of the proposed approach consists of verifying the model by piloting it on a sample of the potentially eligible population, i.e. both claimants and non-claimants. Similarly to phase B, the verification of modelling results requires the participation of decision makers. However, at phase E, their involvement raises an ethical issue of receiving respondents' consent to being assessed by decision makers, and not being told of the outcome of the assessment.

It is suggested therefore that only those who agree to participate in it on these conditions are selected into the pilot. A subsequent sample selection bias will not distort the results of modelling because, as was explained above, the association between the award decisions and the needs of the potentially eligible is independent of their propensity to claim. At the same time, the consent may not be very difficult to obtain if respondents know that they are asked to participate in a statistical exercise conducted by an independent research organisation. The tasks of phase E include:

- using the screening method and the screening questionnaire, selecting into the pilot, a sample of those potentially eligible who give their consent to being assessed by a decision maker and not being told of the assessment outcome;
- using the main questionnaire and the coding system, interviewing the potentially eligible selected into the pilot;
- applying the parameters of the model developed at phase D to this sample and determining the probability of being eligible associated with each respondent;
- asking decision makers to decide on these cases;
- recalibrating the model;
- investigating approaches to the linking of the survey data to administrative estimates of recipients.

The successful completion of all five phases will allow a positive conclusion on the feasibility of estimating the DLA/AA take-up rate by the three-stage project. Given that this study represents the first stage of the project, the five phases of the recommended approach are distributed across the stages of the project as follows: phases A to C belong to its second stage and phases D and E belong to its third stage.

Since the progress to each subsequent stage depends on a successful completion of the previous stage, the main survey only takes place if all three stages of the project suggest that the task is feasible. If stages two or three do not prove feasible, only the complementary study can be conducted.

Advantages and challenges of the recommended approach

The advantages of this approach over the other methods of estimating take-up are:

- a probabilistic measure of take-up that makes the estimate consistent with existing decision-making practices;
- provision of an accurate take-up estimate, including the potential rates of award among the non-claiming eligible population;
- the ability to indicate circumstances when awards may be granted in error;
- presentation of information used in the decision making process in a more structured form than free text;
- the ability to collect the data on the sample of respondents that is representative of all the potentially eligible, including those who would choose not to claim;
- identification of consistent differences between claimants and non-claimants with regard to their needs and/or the ways they present these needs;
- the ability to provide a first indication of the characteristics of eligible non-claimants and triggers and barriers to claiming among them;
- the availability of additional information on the potentially eligible population that may be relevant to any analysis of disability in the country;
- the ability to exploit the synergy between the complementary study and the main feasibility research and to do it in a cost-effective way;
- integration of the complementary study into the main survey allows for exploiting the synergy to the full extent;
- the opportunity to assess the feasibility of the approach to meet its challenges and deliver a robust take-up estimate before it is applied and thus, save public resources;
- the ability to shed light on the dynamics of changes in the care and mobility needs of the population, if the survey is repeated.

However, the adoption of the approach depends on the ability of research and policy makers to meet its challenges. They are to be explored at the subsequent stages of research and Table 2 demonstrates how the phases of the approach are related to the stages of the feasibility research and which challenges are to be met at each stage.

Table 2 Next steps of the research on feasibility of take-up estimate and their challenges

Stage of the feasibility project	Phase of the recommended approach	Challenge
Stage two	<p>A: Development of a screening method, a screener and a survey instrument, including the coding system. Development of the complementary study</p> <p>B: Validation of the survey instrument, including the coding system, using the data on claimants</p> <p>C: Piloting the survey instrument on the potentially eligible. Piloting the complementary study</p>	<ul style="list-style-type: none"> • Establishing relationships between the award decisions and types of information required for reaching them, including the variety of evidence • Identifying the need for, and the type of, proxy • Establishing the importance of medical and other evidence • Developing a survey instrument • Developing a screener • Developing a screening method • Identifying methods for maximising the response rate to the screener and to the survey • Developing the data collection methods • Minimising the problem of recall among decision makers • Identifying the types of subgroup analysis • Developing a guide to the training programme for interviewers • Accounting for possible changes in decision-making practices in the future • Ethical issues of getting consent to approach the third party and collect sensitive data • Costs of providing a sample of claim packs • Costs of involving trained interviewers • Costs of involving decision makers • Costs of providing incentives to the pilot respondents

Continued

Table 2 Continued

Stage of the feasibility project	Phase of the recommended approach	Challenge
Stage three	D: Development of a statistical model, using the data on claimants E: Piloting the survey and verification of the statistical model on the potentially eligible	<ul style="list-style-type: none"> • Choosing an appropriate econometric technique, functional form and sample size • Ensuring robustness of modelling outcomes • Linking the survey estimates to administrative data on benefit recipients • Ethical issues of getting consent to approach the third party, collect sensitive data and being assessed by decision makers • Costs of providing incentives to the pilot respondents • Costs of involving trained interviewers • Costs of involving decision makers

Requirements of sample and sub-samples

The requirements of the sample and sub-sample sizes refer to the sample of claim packs that should be used in verification of the survey instrument at phase B and statistical modelling at phase D of the recommended approach. As was explained, the size of the sample depends on the desired degree of precision of the take-up estimate, the choice of the outcomes of statistical modelling and the choice of the types of subgroup analysis.

If a decision is taken to model the receipt of various award rates for the overall population of Great Britain, the sample of 618 DLA claim packs and 568 AA claim packs should be made available for coding at phase B and modelling at phase D. This sample size would enable an estimate of the take-up rate at 95 per cent confidence level and 0.05 confidence interval. If a subgroup analysis is required, the sample of claim packs should increase x -fold, where x is the number of subgroups along one dimension. For example, if separate analyses of DLA outcomes are required for men and women, the sample size would increase two-fold, bringing the total to 1,236 DLA claim packs and consisting of 618 DLA claims made by women and 618 DLA claims made by men. These sample requirements explain why the types of subgroups and the modelling outcomes have to be decided upon at phase B.

The assumption of random sampling methodology on which the calculations are based requires a sample of claim packs available for the analysis to be nationally representative. If the decision to estimate take-up for each award rate is taken, this requirement means that the claim packs with various rates of award (including

nil rate), types of claims, etc. are present in the sample in the proportions that are found in the claimants' population.

Conclusion – Next steps

The next steps recommended by the study refer to the second stage of the feasibility project. At stage two, the tasks that belong to phases A to C have to be completed. The success of this exercise would ensure that the screening method, the screener and the survey instrument are able to deliver information on the potentially eligible population that this population would have submitted if applying for the benefit.

Since the estimate of the take-up rate is a point in time estimation, its development should account for changes in decision-making practices that may take effect at the time of estimation. Therefore, the design of the survey instrument should take into account the introduction of CCM claim forms across the country. Accreditation of decision makers according to the Professionalism in Decision Making and Appeals (PIDMA) programme should also be accounted for if the accreditation is anticipated to change decision-making practices across the country in some consistent way. In this case only those decision makers who are accredited by PIDMA and/or who participated in CCM pilots should be employed at phase B, when the instrument is verified.

To conclude, at phase A, the screening method, the screener and the survey instrument are to be developed, at phase B the survey instrument should be verified and at phase C piloted. Another task of stage two includes the development (at phase A) and piloting (at phase C) of the complementary study. These are the tasks that this study puts forward for the second stage of research assessing the feasibility of estimating the take-up rate of DLA and AA.

1 Introduction: What is the problem?

1.1 Introduction

There are over four million people in Britain receiving one of two non-means-tested benefits for disabled people: 2.8 million, mostly young and working age people, receive Disability Living Allowance (DLA) and 1.4 million older people receive Attendance Allowance (AA), although about 800,000 DLA recipients are now over retirement age.⁵ Regular social surveys and the 2001 census indicate that a further six million or so say they have some kind of long-term limiting illness or disability.⁶ Not all of these six million have care and mobility needs that would qualify them for DLA/AA if they applied, but some do.

At present, the size of the population eligible for DLA/AA and the take-up rate are unknown. Research using the Family Resources Survey (FRS) Disability Follow-up Survey suggested a figure ranging between 40 and 60 per cent in the case of AA, between 30 and 50 per cent in the case of the DLA Care component and between 50 and 70 per cent in the case of the DLA Mobility component (Craig and Greenslade, 1998). These estimates were not robust and they did not include people living in residential care. The MacMillan Group commissioned research

⁵ Those with care and mobility needs who were awarded DLA under the age of 65 may continue to receive it after having reached this age, as long as their needs have not changed.

⁶ The 2001 Census records 10.3 million people in private households with a long-term limiting illness or disability; 7.1 million are of working age. Government's statistics show there are 770,000 disabled children, who are seven per cent of all children (PMSU, 2005).

that suggested about half of those diagnosed with terminal cancer, who qualify automatically under Special Rules⁷, failed to claim (MCR, 2004).

Establishing reliable estimates of the size and composition of this non-claimant population is a difficult task. Its complexities extend beyond those of the ordinarily difficult tasks of measuring people's eligibility for, typically, income-tested benefits and tax credits. A problem specific to DLA/AA consists of incorporating into the estimation the degree of individual judgement used by decision makers and, if need be, by appeals panels in deciding eligibility. This judgement, among many other factors, affects the concept of eligibility and the measure of take-up and calls into question the feasibility of estimating the rate. This study is part of the research that aims to assess this feasibility.

1.2 Background to estimation

There is a sense in which a case for research may be, in itself, a case for a policy for action. If there is sufficient reason to believe that substantial numbers of disabled people are not getting the benefits they are due, and that well-placed informants do not doubt it, then a policy to invest in steps to increase the take-up rate need not wait for further research. On the other hand, research is able to produce findings that are crucial to the development of an effective policy, such as:

- how many eligible non-recipients there are;
- who they are in terms of their social location, the nature of their impairment, etc.⁸;
- the extent of individual need;
- their reasons for not claiming, inferred from their characteristics and stated when probed directly;
- the extent to which they might be receptive to encouragement to claim, to claim accurately, and, where necessary, obtain help to claim.

Previous research on the take-up rates of social security benefits encourages a view that, though technically difficult and sometimes costly, such estimates can be obtained within acceptable confidence intervals of five per cent. For example, PSI's series of surveys estimating the take-up rates of Family Credit (Marsh and McKay, 1993) and the Earning Top-up (ETU) experiment (Marsh, 2001), and later its successor, Working Families' Tax Credit, all found that it was possible to use

⁷ On placing the claim, people who qualify under the Special Rules get the highest rate of the care component of DLA or the higher rate of AA without having to meet the usual qualifying period requirement or having to show that they have care needs. Claims are dealt with very quickly. Also, Special Rules claims do not necessarily involve the claimant knowing they are terminally ill (see Appendix A for more detail).

⁸ It is worth noting that there is no ethnic monitoring of claims for DLA/AA.

field survey techniques to obtain the necessary information from a nationally representative sample of the population. These surveys asked for details of family composition, working status and hours worked, childcare expenditure and household income from all sources. Various attempts at verification indicated high rates of accuracy. For example, allowing for changes since awards were made, the survey data estimated cash entitlements that closely matched the amounts awarded to those who had claimed successfully in the recent past. A follow-up survey indicated that the great majority of eligible non-claimants who later claimed, received an award, and those that did not usually had altered circumstances.

These surveys also overturned quite a lot of the conventional wisdom associated with non-claiming. Thought at first to be the poorest and less able families, eligible non-claimants appeared to be:

- families who really were eligible and proved it by later claiming successfully;
- better-off families who had only small entitlements, which they overlooked;
- families whose circumstances were in flux and who became ineligible very quickly;
- families who, more rarely, were remote in every sense from the social security system and who preferred not to claim.

Thus, paradoxically perhaps, the study of non-take-up contributed positively to the design and development of tax credits and established wage supplementation or 'making work pay' as one of the main pillars of welfare-to-work policy.

It seems possible then to use field studies of one kind or another to achieve these research aims even if the survey effort involved is considerable. On the other hand these studies were able to rely on an arithmetic approach. Eligibility for means-tested benefits rests on a combination of household income and simple contingencies like household composition, which are conceptually straightforward even if they are difficult to measure accurately. A study of DLA/AA take-up rates has to overcome the greater conceptual difficulty of the use of judgement by applicant and decision maker to determine need and eligibility.

Whatever method is used in order to determine the size of the eligible population, simply narrowing down the general population to those who may be eligible (i.e. to those potentially eligible) is a serious challenge. Furthermore, even if no-one eligible for DLA/AA in this sample would deny they had some kind of limiting long-term illness or disability, screening from these a large and reliable sample of people who are likely to succeed in a claim is also a difficult task. The next section provides detail on these difficulties.

1.3 Features of DLA/AA

A usual definition of the take-up rate is that of a ratio of the number of recipients to the number of those eligible. This definition implies that eligibility can be accurately

identified. In the case of DLA/AA, the population of the eligible is unknown and the primary interest of this research is the feasibility of determining its size and estimating the proportion of those who receive the benefit.

The task of estimating the take-up rate is difficult due to the nature of the benefits under investigation (see Appendix A).

First, the benefits themselves are complex: the application forms for AA and especially DLA cover many and various types of needs. The needs may be so diverse that recipients may be entitled to both mobility and care components of DLA, and they may receive these at different rates.

Second, the needs of a disabled person may change over time as their health condition improves or deteriorates. Some disabling conditions may lead to an incurable deterioration of health and the impact of this on people's impairments and, to some extent, needs may be predictable. In these cases, there is an element of certainty around the award decisions and some of these awards may be indefinite. But in other cases, a medical intervention, e.g. surgery on the knee, may be expected to alter the impact of disability on the impairment and the DLA/AA-relevant needs. In these cases, even where the timing of such an intervention can be accurately anticipated, the effect of the intervention on people's needs is much less certain. Consequently, the award decisions that were correct in the past may become wrong in the future. In order to minimise this problem, the award decisions may be limited in time.

Third, the needs of disabled people vary not only over time but also between people with similar disabling conditions and similar impairments. One reason for this is that people cope with their impairments differently. Two people with the same condition causing a back pain may experience a similar impairment to their ability to move; but one person may react to this by doing more exercise, while another person may become less mobile and need help. Another reason is that people's impairments affect their lives in different ways. For example, two people who have similar difficulties walking will have different needs depending on whether they are willing to spend most of their time indoors or outdoors, or where their home is located. There is no reason to assume a match between severity of the underlying disabling conditions, the degree of impairment and the need and hence, the rate of DLA/AA award.

Fourth, the DLA/AA entitlement criteria are not well quantified, making the benefit further open to subjective judgement. For example, judgement is required in order to assess how prolonged (three or four hours) or how frequent (three or four times) the need for attention should be in order for an award to be granted. Additionally, in DLA child cases, where the decision on an award depends on how different the needs of a child are from the needs of an average child of a similar age, the baseline for comparison may have wide and blurred borders, making it problematic to 'anchor' the measurement.

Finally, the impact of disability on claimants' mobility or ability to care for themselves is self-reported. Since health conditions are difficult to quantify, especially where the problems are multiple, the decision on benefits is open to subjective influence not only of the decision maker but also of the claimant. Disability and Carers Services (DCS), the agency of the Department for Work and Pensions (DWP), acknowledges the problems associated with eligibility for DLA/AA and works on the improvement of the service to its customers. Since 2005, under the Change Programme, it has already piloted two initiatives that aim at increasing the professionalism of decision makers and improving the accuracy and consistency of their decisions (for detail on these initiatives see below).

The fact, however, remains that compared with other benefits, entitlement to DLA/AA is more dependent on the decision maker's judgement about the applicant's needs. That judgement can be aided by a wide range of information, including information from third parties such as social workers, medical staff, and so on. However, its presence means that different decisions can be made on the basis of similar information, without anyone actually having made a mistake. This is not to deny the fact that people may fail to provide sufficient or sufficiently accurate information to allow a correct award decision. And as is the case with any other benefit, some people may be denied or awarded in error.

1.4 Definition of eligibility

These features of DLA/AA imply that, whatever method is used to determine the eligible population, there will inevitably be people who having been denied the benefit by one decision maker, might have been awarded it by another decision maker. The extent to which such people are included in the estimate of the eligible population, and hence the estimate of the take-up rate, is a matter for judgement. That is why the 'truly' eligible population is difficult to define and the term 'probably eligible' may be more appropriate. The meaning of this term is explained in greater detail now.

Among any candidate population of significantly disabled people, some will be 100 per cent eligible for DLA/AA, others zero per cent; so that any system would respectively award or deny them benefit. This means that repeated applications or applications with a different presentation of the same information sent by, or on behalf of, these people to different decision makers would return with unvarying 'yes' or 'no' replies. The benefit system that bases its award decisions on the information that is less open to interpretation than DLA/AA would count the vast majority of its potential applicants in these 100 per cent or zero per cent groups.

In the case of DLA/AA some people have a greater than zero but less than 100 per cent chance of an award. These are recipients whose claims might have been disallowed had a different decision maker considered their case or had information in their application been presented differently. Out of 100 claimants with identical needs relevant to the DLA/AA criteria, some, say 80 claimants, may be awarded

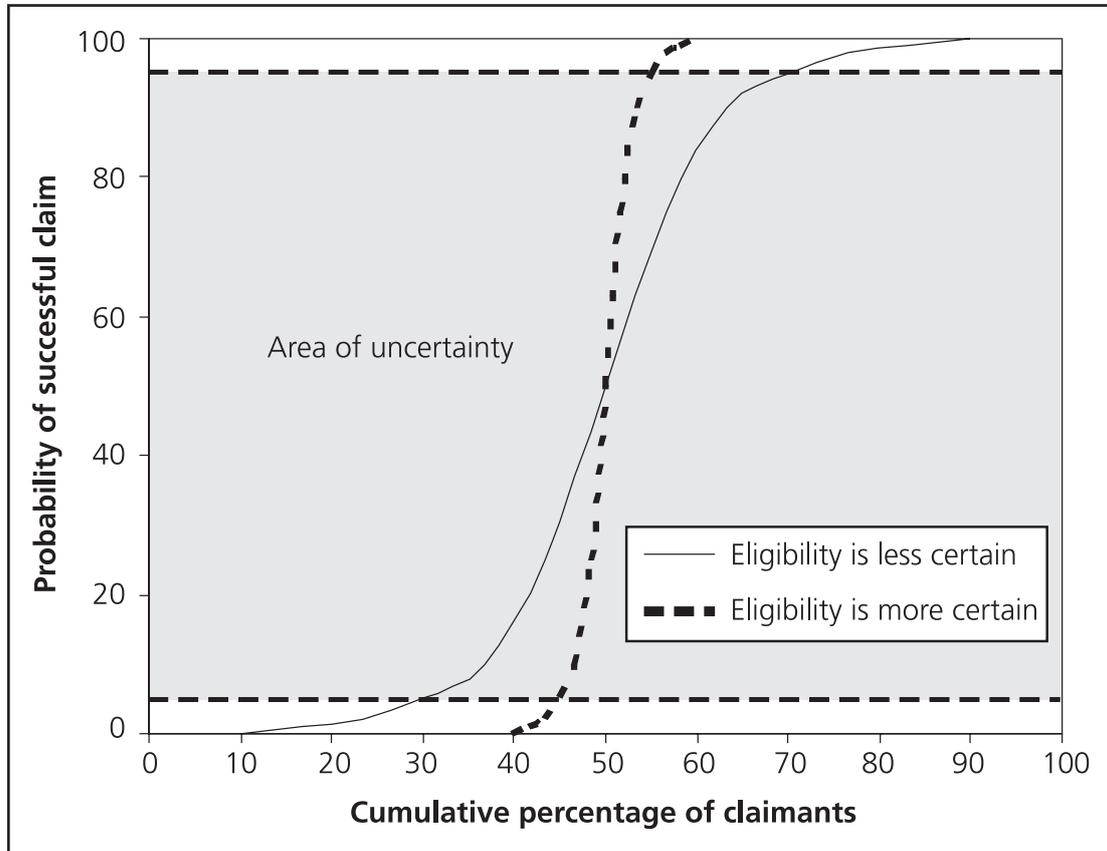
the benefit and the rest may be disallowed. Whatever is the 'true' eligibility of this population of 100 claimants (with identical needs), one part of it (20 claimants or 80 claimants) does not seem to conform to it. The natural interpretation of eligibility would suggest that since their needs are identical all 100 claimants are either 'truly' eligible or 'truly' ineligible and should all be either awarded or not.

However, in the case of DLA/AA, the split of 100 claimants with identical needs into recipients and non-recipients is not necessarily due to a mistake on the part of decision makers. Given the same information about these claimants, two decision makers may arrive at opposite decisions on the basis of their different interpretations and judgements. Moreover, since the needs of a claimant are to be reported in a free-text format, the same decision maker may arrive at opposite decisions on the same case depending on the ways the claimant's needs are presented. The most important point to stress is that both interpretations and both decisions may be valid, even if they disagree with each other. The fact that only 80 claimants receive the benefit means that all these 100 claimants have an 80 per cent probability of being eligible.

These features of the benefit introduce the probability, or uncertainty, into the definition of eligibility for DLA/AA. The number of people who have a greater than zero but less than 100 per cent chance of being eligible is important and so is their distribution across the probability range. The solid line in Figure 1.1⁹ is used as an example in order to illustrate the point. It shows ten per cent of people who have no chance of succeeding if they claimed, a further 20 per cent of people who if they applied 100 times would not succeed more than five times (up to five per cent chance), another ten per cent who would definitely succeed (100 per cent chance), and an additional 20 per cent who have a chance of between 95 and 99 per cent (i.e. they would succeed in 95 to 99 times out of 100). The remaining 40 per cent of the population in this example have a chance of succeeding that varies between five and 95 per cent. Obviously, the greater the proportion of people in this range ('the area of uncertainty'), the more uncertainty is associated with eligibility. On the contrary, the greater the proportion of people with a very low and a very high chance of success (i.e. the closer the solid line is to the dotted line in Figure 1.1), the less uncertainty surrounds the eligibility.

⁹ With acknowledgement and thanks to Professor Richard Berthoud.

Figure 1.1 Distribution of claimants by their probability of entitlement



This discussion illustrates that regardless of any fraud and error problems, in the case of DLA/AA, eligibility for those who claim does not necessarily equate with receipt. Consequently, a choice of the take-up measure depends on the assumptions underpinning the definition of eligibility. There are suggestions, for example, of defining a pool of the eligible on the basis of decision makers' assessment of DLA/AA claims obtained via a survey (Purdon *et al.*, 2005). The eligible population in the FRS Disability Follow-up Survey that was mentioned above consisted of the disabled people who may or may not have been in receipt of an award; it excluded those who may have been in receipt of an inappropriate award, even though these people were included in the number of recipients when calculating the take-up rate (Craig and Greenslade, 1998).

This research takes uncertainty surrounding eligibility as given and adopts a probabilistic approach to its definition. This means that references to the 'eligible' population are always references to the 'probably eligible' population. Another definition used in the report refers to the population of the potentially eligible. These are people who have a disabling condition that may, or may not, render them (probably) eligible for DLA/AA. For example, a person with arthritis may be potentially eligible but will enter the pool of the (probably) eligible if their arthritis gives rise to mobility or care needs that meet the DLA/AA eligibility criteria.

At present, the size of the potentially eligible population is unknown. The number of the probably eligible and their distribution across the probability range is not known either. The feasibility of identifying these and estimating the DLA/AA take-up rate is the subject of this research and this study is part of it. The next chapter provides detail about the research and the place of this study in it.

1.5 Summary

This chapter lays the ground for the research into the feasibility of estimating DLA/AA take-up and explains the difficulties associated with the estimation. It demonstrates that the task of estimating the take-up rate is very difficult due to the nature of the benefit under investigation. The benefit is complex and relates to the needs of a disabled person that may not only change over time but also vary across the people with similarly disabling conditions and even similar impairments. The entitlement criteria are not well quantified and in the case of a child, additionally, it is problematic to 'anchor' the measurement. This makes the benefit open to the interpretation and judgement of decision makers. The self-reporting aspect of the benefit also makes it vulnerable to the ability of claimants to accurately assess and report their needs. Consequently, regardless of the fraud and error problems, DLA/AA features do not always allow eligibility to equate with receipt. This explains the probabilistic definition of eligibility adopted throughout this report.

The report starts with identification of the scope of this study, its relation to the overall research on the feasibility of take-up estimation, the research question this study tackles, the methods it uses and the outputs it produces. It then illustrates how the probabilistic nature of eligibility influences the choice of a take-up measure and the following chapters demonstrate how the complexities of decision making and the claiming process shape this choice. The likely problems associated with an attempt to measure take-up are also discussed. This is followed by a review of resources available to the task and analysis of existing knowledge and experience of estimating the rate. The report puts forward an approach to estimating the take-up rate, assesses its advantages and challenges and suggests the next steps in assessing its feasibility.

2 Scope of the study, its research question, methods and outputs

2.1 Introduction

This chapter first explains the place of the study in the context of wider research on the feasibility of estimating Disability Living Allowance (DLA)/Attendance Allowance (AA) take-up. Having identified its scope, it then focuses on the research question, which essentially consists of the feasibility of developing an approach to estimating the DLA/AA take-up rate, given the complexities of claiming and decision-making processes. This is followed by a description of the methods employed in this study in order to achieve the outputs determined by its scope.

2.2 Scope

The previous chapter described the features of DLA/AA that distinguish the benefit among other benefits and imply that there is no straightforward way to determine the eligibility for it and hence, the take-up rate. The complexity of the issue is such that even the feasibility of estimation is difficult to determine. The answer to this question requires a (potentially) three-stage research project, of which this study is part, and a complementary study to it. Each stage of this research aims to provide a greater understanding of the feasibility of estimation, so that the project could stop at any stage if the conclusion was reached on the impossibility of the task. In the best-case scenario, the output of the project will consist of a detailed proposal on the approach to estimating the take-up rate. In the worst case, it will consist of a clear exposition of the reasons why this approach is not feasible.

The DLA/AA features give rise to questions about the level of error and fraud in the system more than any other benefits. Understandably, this leads to calls for research into policies and/or practices relating to the benefits. However, it is

important to stress that, being methodological in nature, this research does not question the current level of fraud and error. Nor does it aim to suggest whether or how DLA/AA policies and/or practices should change. Its pure concern is with the development of an approach to estimating the take-up rate, given the complexity of the issue.

This study relates to the first stage of the feasibility research and aims to examine whether some robust approaches to estimation can be recommended in principle. To achieve its aim, it focuses on the analysis of processes that lead to an award decision, existing data and experience of estimation. If it reaches a positive conclusion on the feasibility of developing an approach, at the second stage, the recommended approach has to be refined and tested in terms of some practicalities of its implementation. Subject to the successful completion of these tests, the third stage takes place. It consists of piloting the recommended approach and refining it further. A successful completion of the third stage results in a detailed proposal on a recommended design of estimating the take-up rate.

The complementary study to the research aims to help formulate appropriate policies to increase take-up and focuses on non-claimants. It seeks to establish who they are and why they do not claim. Although these objectives are different from the goal of estimating the take-up rate, the findings of the complementary study are very important to an accurate identification of the (probably) eligible and hence estimation of the take-up rate. For this reason the complementary study is interlinked with the three-stage feasibility research and the take-up estimation itself. Analysis of barriers to claiming in the course of the complementary study would inform an accurate identification of the (probably) eligible population and hence estimation of the take-up rate. If the take-up estimation is feasible, some data collected for this purpose will shed light on the profile of the non-claiming population. The relations between the feasibility research, the complementary study and the take-up estimation should be established at stage one of the feasibility research (this study). However, the complementary study and the take-up estimation itself are two separate projects and their outputs are not produced as part of the three-stage feasibility research.

Since the progression to each subsequent stage is subject to successful completion of the tasks of the previous stage, the start of the second stage of the feasibility project depends on the results and recommendations of this study. The following sections describe its research question, methods and outputs.

2.3 Research question and aims

As described in the previous chapter, the presence of judgement introduces a probabilistic element into the measure of eligibility. But it also has implications for the measure of recipients, explaining why eligibility does not equate with receipt. In view of the complexity associated with both the numerator and denominator in the take-up ratio, the question is whether it is possible to estimate the rate altogether.

The answer to this question should start with the development of a take-up measure that would account for the uncertainty of eligibility and other complexities of claiming and decision-making processes. The complexities to be considered include the:

- presence of judgement in both decision making and claiming processes;
- changing nature of the needs of a disabled person over time;
- possibility of changes in existing award practices and/or policies;
- possibility that the potentially eligible may choose not to claim;
- complexity and open-ended nature of the claim form;
- need for evidence and for a proxy/third party.

The development of the take-up measure requires thorough understanding and analysis of decision making and claiming processes and the possible reasons for not claiming. The design of the approach to its estimation is then shaped by the availability of data required for estimation, whether these are collected administratively or via a survey. Therefore, existing administrative and survey data in terms of their usefulness to the task in hand have to be investigated. Finally, in order to recommend an approach, previous attempts at estimation as well as existing research on the issue have to be examined. This should improve awareness of the available data and potential problems at each stage of estimation. These are the aims of this study that should help it to conclude on the feasibility of developing an approach to estimating take-up.

2.4 Methods and outputs

The outputs of the study are consistent with its aims and include:

- a description of the process from claiming to decision-making and analysis of its complexities in terms of implications for estimating take-up;
- an assessment of the availability of existing data and its usefulness in representing the process and allowing the estimation of the take-up rate;
- an examination of potential approaches to estimating take-up;
- recommendation of an approach to estimating take-up;
- a description of requirements of a sample and sub-samples;
- recommendations regarding the next steps of feasibility estimation.

The methods of research include a desk-based review of documentation relating to claims; interviews with key stakeholders; and the investigation of the availability of data relevant to the claiming process.

During the desk-based review, 27 claim forms and other relevant documentation were examined, including eight AA Normal Rule cases, nine DLA Normal Rule

cases, one Special Rules case, two DLA child cases and seven cases from the areas participating in the Customer Case Management (CCM) pilots. Another desk-based review investigated existing experience and research on DLA/AA take-up. Nineteen interviews with key stakeholders involved three Department for Work and Pensions (DWP) officials, seven welfare rights organisations¹⁰, six decision makers, one medical professional from ATOS Origin¹¹ and two social workers (a care specialist and a psychiatric specialist). The investigation of the availability of data relevant to the claiming process entailed four interviews with the data holders at DWP and a desk-based review of information concerning the health-related social surveys. The topic guides used during the interviews are provided in Appendix B.

These methods complement each other to deliver the outputs of the study. For example, the desk-based review of the claim documentation informs the scope of interviews with key stakeholders as well as indicating what data may be required to map the process and to estimate the take-up rate. Likewise, knowledge acquired through interviews and examination of the data helps to identify the types of claim cases that are to be additionally reviewed.

2.5 Summary

This chapter defines the scope of the study and places it within a potentially three-stage research project assessing the feasibility of estimating the DLA/AA take-up rate. Such a multi-stage approach to the assessment is required because of the complexity of the task. In order to be confident that the recommended approach to estimation is feasible, the progress to each subsequent stage of the research is dependent upon successful completion of the tasks of the previous stage.

A complementary study to this three-stage project is also envisaged. It relates to the main project because its focus is on non-claimants, examining who they are and why they do not claim. However, its outputs are produced in the course of a separate project.

This research relates to the first stage of the feasibility project and aims to examine whether it is feasible to develop an approach to estimating the take-up rate. This task requires understanding of the claiming and decision-making processes, knowledge of the available data and awareness of the potential problems at each stage of estimation. In order to achieve these aims, the following methods of research were employed: a desk-based review of documentation relating to

¹⁰ These were Citizens Advice Bureau, Age Concern, Disability Alliance, MacMillan Cancer Relief, Royal National Institute for the Deaf, Royal National Institute for the Blind and Newham Social Regeneration Unit.

¹¹ Atos Origin are contracted by DWP to provide medical disability assessment advice to the decision makers. Decision makers may also ask an examining medical professional from ATOS to visit a claimant for an assessment.

claims; an analysis of existing experience and knowledge relating to DLA/AA take-up estimation; interviews with key stakeholders, involving welfare rights organisations, DWP officials, decision makers, a medical professional and data holders; and investigation of the availability of data relevant to the claiming and decision-making processes. The outputs of this study are considered in turn, the next chapter examining the claiming and decision-making processes and implications of their complexities for estimating take-up.

3 Claiming and decision making

3.1 Introduction

In order to develop an approach to estimating Disability Living Allowance (DLA)/ Attendance Allowance (AA) take-up, it is necessary to first choose a measure of the rate that would account for the uncertainty, or probability, of being eligible; and second, assess the extent to which the replication of claiming and decision-making processes among the potentially eligible but not claiming population may be feasible. This is impossible without understanding how award decisions are reached and this chapter aims to provide such understanding.

The analysis is based on a desk-based review of documentation relating to claims, further in the text referred to as claim packs. At its fullest, a claim pack consists of a DLA/AA claim form completed by the claimant or a third party, additional evidence submitted by the claimant and/or a third party, documentation completed by adjudicator(s) and, where necessary, appeals panels. The information obtained during the interviews with DWP officials and decision makers also feeds into the analysis of claiming and decision-making processes. Their views relating to claiming cannot be checked against the claimants' accounts. However, given that the interest of this chapter is in the process from the time when the claim is submitted to the time when the outcome on the application is reached, the available information suffices. The chapter describes the claiming and decision-making processes in turn and then focuses on the implications of their complexities for the choice of the take-up measure and feasibility of its estimation.

3.2 Claiming process

The process starts when a claimant (or a third party) acquires awareness of the benefits, fills in the claim form (on their own, or with the help of a third party, or the third party does it on their behalf), obtains supporting evidence and submits the claim form and other relevant documentation. Each stage of this process has its complexities:

- First, the claimant may not have access to information about the benefits.
- Second, even when they know about the benefit, the claimant may decide not to apply. Decision makers' view on the reasons for that is that some potentially eligible may think that they do not qualify for it (either because they do not consider themselves 'sufficiently' ill or because they do not admit even to themselves that they are disabled). Others may know that they qualify but decide not to claim for such reasons as lack of time to fill in the form or fear of being placed in residential accommodation. The views of welfare rights organisations on the reasons for not claiming are described in the following chapter.
- Third, those who do claim may be aware of the benefit but not of the entitlement criteria and therefore they do not provide information that is necessary and sufficient for a decision.
- Fourth, open-ended questions in the claim form require claimants to comprehensively describe their disabling conditions, impairments and needs, and this may be difficult for some categories of disabled people.
- Fifth, due to the complexity of the claim form some claimants may require help to complete it. In this case they have to identify and approach a source of such help and sometimes wait for the assistance to become available.
- Sixth, there may be problems associated with obtaining supporting evidence because the claimants need to be able to identify the source of the right evidence, approach this source and wait for the evidence to arrive.

Only those potentially eligible who pass all these hurdles submit a claim.¹²

3.3 Decision making process

Having received a new claim, a decision maker has to assess, preferably within certain time and cost limits, whether the claimant's needs satisfy the entitlement criteria. The outcome of this assessment consists of three elements: a decision on whether to award; a decision on the level of the award; and a decision on whether the award should be time limited and if so, for how long.

These decisions are not always straightforward. Claimants may have one impairment (e.g. sight loss) caused by a number of disabling conditions (e.g. eye injury and eye disease) or they may have a number of impairments (e.g. inability to walk and inability to cook the main meal) caused by one disabling condition (e.g. stroke). Decision makers have to be aware of the possible relationships between disabling conditions and impairments. However, since the DLA/AA decision is concerned with needs rather than impairments and such needs differ from one claimant to another, decision makers also have to build an holistic picture of the claimant in

¹² At the same time, decision makers feel that there are claimants who, although ineligible, keep reapplying, perhaps trying to exploit the presence of the subjective element in the claiming and decision-making processes.

order to be able to assess the impact of impairments on care and mobility needs in each particular case.

The decision makers' training enables them to judge, to a certain degree¹³, whether the information on medical conditions, medication and its dosage, impairments and needs all match in a consistent way. The Disability Handbook also provides them with a description of the symptoms and needs with regard to the major disabling conditions. However, due to the complexities of the claiming process described above, not all the necessary information may be available to decision makers and some evidence may conflict. In all cases where decision makers need more information, they may:

- phone up the customer; and/or
- ask for advice of the doctors that are available on-site; and/or
- approach someone who is most likely to have the relevant knowledge of claimant's impairments and needs (e.g. a medical professional, social worker, community psychiatric nurse, nursery/school/college, a family member); and/or
- ask an examining medical practitioner (EMP) to visit and examine the claimant.

Gathering additional evidence, especially through the latter two routes, has resource implications in terms of time and financial costs. The party approached for additional evidence may take some time to respond and some payment may also be required where GPs and EMPs are concerned. An EMP report is said to be the most comprehensive piece of evidence because it contains information from both clinical and functional points of view but it is the most costly one. In those cases where for some reason decision makers cannot obtain the required evidence, they take decisions in the conditions of uncertainty, on the balance of probabilities.

Additional evidence may sometimes change the decision maker's initial judgement. If such evidence becomes available after a decision has been taken, the decision may be revised. However, since DLA/AA is relatively open to differences in judgement on whether the claimant's needs meet the entitlement criteria, even where the amount of evidence submitted by the applicant is sufficient, different decision makers considering the same case may arrive at differing decisions.

Inconsistencies in decisions prompted DWP/Disability and Carers Service (DCS) to pilot Customer Case Management (CCM) in 2005/06. The CCM pilots only covered new DLA claims submitted in Bootle and Manchester by disabled people of working age. A new claim form was developed so that more questions were pre-coded compared with the existing form. Under CCM, decision makers entered the information contained in the claim into an IT-based system (Curam), which

¹³ At the given level of information, less experienced decision makers may be less able to decide on the case without some help than more experienced decision makers.

provided them with guidance on (multiple) medical conditions, their severity and type of required evidence. This guidance helped decision makers to decide whether the impairments reported by the claimant were a likely consequence of the reported conditions.

An increase in the contact with customers and a reduction in the need for additional evidence from the sources other than claimants themselves are said to have been observed in pilot areas. At the time of writing, the decision to roll out a CCM claim form has been taken. Another outcome of the pilot was a revision of the guidance in the Disability Handbook for some conditions. Decision makers are said to feel that the new edition is much better than the old version but it remains to be seen whether the introduction of the new Disability Handbook will impact on the decision making process across the country.

Another DWP/DCS pilot aimed at improving the accuracy of decisions relates to the accreditation of decision makers according to the Professionalism in Decision Making and Appeals (PIDMA) programme. The pilot started in 2006 and its evaluation is expected in 2007/08. PIDMA is a modular work-based learning programme of continuous professional development. It aims to bring professionalism into decision making through the facilitation, support and application of decision maker learning. The programme provides decision makers and their managers with the knowledge, skills and competencies they need in order to do their job to nationally recognised standards of excellence. Accreditation is awarded by the University of Chester, an external partner of DCS.

Both pilots aim to improve current decision-making practices by addressing problems of communication with claimants, completeness of information on the case and accuracy and consistency in decisions. It is possible that their successful implementation in the country will decrease the uncertainty surrounding eligibility by increasing the proportions of claimants with a zero and a 100 per cent chance of an award. The improved accuracy of decisions and a more responsive service is expected to increase customer confidence in decision making and reduce the number of customer complaints and cases overturned at appeal.

If the claimant considers the decision to be wrong they may apply for reconsideration of their claim within four to six weeks. The claim form and the relevant documentation, including additional evidence if it is submitted, are considered by another decision maker. Following this reconsideration the original decision may be revised or upheld. If claimants do not agree with the results of this reconsideration, they may ask for an appeal within one month. This goes to a third decision maker and if the decision remains unchanged, the third decision maker refers the case to an appeals tribunal.

The most common reason for decisions to be revised is said to be the availability of evidence that was not available at the time of the original decision or at the time of reconsideration. However, the decision may also be overturned if a decision maker who is reconsidering the claim has a different judgement. It should also be noted that this decision maker may arrive at the same decision as was reached by

the previous decision maker but give different reasons for their decision. Moreover, if they make a different decision having received additional evidence, it cannot automatically be assumed that the change is because of the new evidence.

When asked about their own ability to assess the condition of a claimant, decision makers felt that face-to-face contact with customers might have assisted the decision making where physical conditions were concerned. Cases where expert opinion was considered to be paramount referred to most mental health condition cases where the severity and fluctuation of the condition and needs are very difficult to assess. But even in these cases, the appearance of the customer (e.g. undernourished, unkempt, poor personal hygiene and unwillingness to communicate) was thought to be a factor that might have provided an insight into the validity of the claim. However, there are cases where even a face-to-face contact with a medical professional cannot remove uncertainty surrounding eligibility. One of the reasons for appeal that some claimants give is that the opinion of the examining medical practitioner was based upon a 'good day' of claimants and therefore was neither a typical nor accurate representation of their conditions and impairments.

3.4 Implications for the take-up measure and feasibility of its estimation

3.4.1 Implications for the choice of the take-up measure

The description of claiming and decision-making processes suggests that any take-up measure has to be based on the assumptions about the treatment of uncertainty and subjectivity surrounding eligibility. Table 3.1 presents the potentially eligible population by their benefit receipt and 'true' eligibility status. Since the truly eligible population (A+B+C+D) is difficult to define, identification of those who wrongly receive (E) or wrongly do not receive (B) the benefit is also difficult. However, even if it was possible to define non-eligible receivers (E) and eligible non-receivers (B), a take-up measure that excludes the former group and includes the latter group would not reflect existing decision-making practices. Instead, it would be a theoretical construction of what the take-up rate should be.

In order to reflect existing claiming and decision-making practices, the take-up measure should reflect subjectivity and uncertainty present in both of them and refer to the probably eligible population, the notion defined in the previous chapters. In Table 3.1 the probably eligible population occupies the boxed area that is comprised of groups A, E, C and G. Accordingly, a take-up measure that this study proposes is determined by a ratio of the number of existing benefit recipients to the probable number of those who would receive it if they applied: $(A+E)/(A+E+C+G)$ ¹⁴.

¹⁴ Note that in a situation that disregards legitimate subjectivity and uncertainty in claiming and decision-making processes, B=E=D=G=0.

Table 3.1 The potentially eligible population by their benefit receipt and 'true' eligibility status¹⁵

	Applied for benefit		Not applied for benefit	
	Awarded	Disallowed	Would have been awarded	Would have been disallowed
'Truly' eligible	A	B	C	D
Not 'truly' eligible	E	F	G	H

In addition to reflecting existing claiming and decision-making practices, this measure ensures consistency between the numerator and denominator of the ratio. This is because the denominator identifies those members of the overall population that resemble those who receive the benefits (the numerator) in terms of their characteristics, including their needs.

Importantly, this measure does not question the correctness of award decisions and treats all those who receive the benefits as those eligible, even if some recipients are awarded the benefit in error. This follows from the probabilistic approach to the definition of eligibility and implies that the take-up measure incorporates uncertainty, including that associated with fraud and error. Consequently, this take-up measure does not, strictly speaking, estimate the proportions of those who wrongly receive DLA/AA or who wrongly do not receive it. Nor does it require a clear definition of 'truly eligible' or an estimate of the number in this category.

The approach to estimating take-up therefore should be able to identify those members among the general population who resemble recipients with regard to their needs and would receive the benefit if they applied, regardless of whether they would receive it in error. A numeric example should help the understanding of the definition of the take-up rate. It is built on one of the examples given above, where out of 100 claimants with identical needs meeting the DLA/AA criteria (say, they need help walking safely) 80 claimants were awarded the benefit. Let's assume that only these 100 people applied for the benefit and that there are an extra 200 people who have exactly the same needs (i.e. who also need help walking safely) but who did not apply.

The probability of being eligible applicable to the 100 claimants is, as explained in the previous chapters, 80 per cent. In Figure 1.1 these people would occupy an 80 per cent probability point on the curve. The same probability applies to 200 non-claimants because they have the same needs (help walking safely). However, only 100 applied and given their probability of being eligible, 80 ($100 * 0.8$) were awarded, i.e. were considered eligible. 200 people did not claim but had they claimed, given the same probability of receipt, 160 ($200 * 0.8$) of them would have received, i.e. would have been considered eligible. Being the ratio of the number

¹⁵ With acknowledgement and thanks to Jane Parkin.

of recipients to the probable number of eligible, the take-up rate for this group of people (that need help walking safely) is 33 per cent $\left(\frac{80}{160+80} * 100\% \right)$

It should be noted that since the measure of take-up reflects existing decision-making practices it is valid only under the rules existing at the point of estimation. If decision-making practices are expected to change in a way that would alter the existing award rates, or the eligibility criteria, or the relationship between them, these changes should be anticipated and incorporated into the approach to estimating take-up at its development stage. Any changes to decision-making practices that impact on the probability of being eligible, unless incorporated into the approach to estimating the take-up, are likely to invalidate the estimated rate.

In the light of this, the approach to estimating take-up should account for the introduction of a new claim form following the CCM pilot; for the changes, if expected, following the implementation of PIDMA; and for any other innovations in the decision-making practices that are anticipated prior to the time of take-up estimation. At the same time, since the take-up rate is an aggregate estimate it may be more sensitive to some changes (e.g. an introduction of means-testing) than to others (e.g. an increase in the number of disabling conditions to be accounted for in award decisions).

The measure of take-up is sensitive not only to changes in decision-making practices but also to changes in the needs that a disabled person may experience over time (e.g. as a result of surgery). Since such changes in needs are difficult to predict, the take-up measure recommended by this study is a point in time estimate and does not account for possible changes in needs in the future. This is consistent with the reference of the take-up estimate to existing (at a point in time) decision-making practices. Nevertheless, it is desirable to develop an approach that is able to shed light on the dynamic of changes in care and mobility needs of the population.

3.4.2 Implications for the feasibility of take-up estimation

Complexities of claiming and decision-making processes have a number of implications for the feasibility of take-up estimation. The analysis of claim packs and interviews with decision makers demonstrate that in order to assess the probability of being eligible among the members of the potentially eligible population, first of all the population of the potentially eligible (i.e. regardless of whether they are claiming or not) should be identified. Second, the data on the members of this population should match the data that decision makers use when arriving at award decisions. These requirements have a number of implications:

- the reasons for non-claiming should be examined in order to enable an accurate identification of the potentially eligible population, i.e. including those reluctant to claim¹⁶;
- the data should reflect information contained in the claim pack that is relevant to the entitlement criteria. This includes the nature of disabling conditions (e.g. eye disease), impairments caused by these conditions (e.g. blindness) and, defined according to the entitlement criteria, needs arising from the impairments (e.g. help with day and night care). This information should be available with regard to all the potentially eligible (i.e. claimants as well as non-claimants) in order to account for cases where the potentially eligible are not in a position to accurately assess their needs;
- the content of supporting evidence also has to be reflected in the data;
- the information on the needs of the potentially eligible may have to be collected from a variety of sources, including a medical professional and a third party;
- the data collection process may need to take place in stages as this is the case when decision makers seek additional evidence in order to arrive at a decision.

3.5 Summary

This chapter describes the claiming and decision-making processes and analyses their complexities in terms of their implications for the take-up measure and feasibility of its estimation. It demonstrates that in order to reflect existing decision-making practices, the take-up rate should be measured as a ratio of the number of existing recipients to the probable number of those who would receive the benefit if they applied. This is a point-in-time measure and as such it does not account for possible changes in needs of the potentially eligible person over time. It is sensitive to changes in decision making rules and practices and therefore, any anticipated changes to these have to be incorporated into the approach to estimating take-up at its development stage.

The review of claiming and decision-making processes points out that in order to assess the probability of being eligible, first of all the population of the potentially eligible should be identified and second, the data required for the take-up estimation should be available with regard to all members of this population of the potentially eligible. The results of analyses relating to the reasons for non-claiming and to the ability of existing data to provide the required information are the subject of the following two chapters.

¹⁶ Moreover, if a survey approach to estimating take-up is chosen, understanding why some potentially eligible people are reluctant to claim will enable the briefing of the interviewers to overcome the respondents' reluctance to be interviewed.

4 Understanding non-claiming and the complementary study

4.1 Introduction

This chapter reviews the current understanding of why some people with apparently qualifying needs do not apply for Disability Living Allowance (DLA)/ Attendance Allowance (AA). For example, informed opinion among welfare rights organisations interviewed for this study supported a figure of about a third to a half of eligible people in their respective client groups failing to claim benefit. The analysis draws on research carried out on the non-take-up of means-tested benefits and on information and views provided especially for this feasibility study by interviews with Department for Work and Pensions (DWP) staff, a number of welfare rights organisations and social workers. The chapter also sheds light on the complementary study that is expected to provide new understanding of why potentially eligible people may fail to apply for DLA/AA.

4.2 Models of non-claiming

This study does not aim to provide a thorough analysis of the likely causes of non-claiming of DLA/AA. Inevitably though, some consideration of the main explanations for non-claiming is necessary because people's barriers to claiming are also barriers to measurement. A better understanding of what is known of such barriers and investigating how these barriers appear to apply in the case of DLA/AA, is an important step in designing an approach to the estimation of take-up. The analysis conducted for this study suggests the following eight main models of non-claiming.

4.2.1 Delay

The most frequent observation among informants was that many disabled people who claim DLA and especially AA, have usually coped with their problems for a long time. Indeed, a short element of 'delay' is anyway built into the qualifying conditions since claimants have to be respectively three and six months beyond some point of disability onset before they can claim. Thus, in any cross-sectional sample of potential applicants there are those who will later go on to make a claim.

Delayed claims are said to add a lot to the non-claimant count in the case of DLA/AA. Such delay is inevitable and will always place limits on the take-up rate among eligible people found in surveys like the FRS when they are used to estimate the take-up rate of means-tested benefits and tax credits. More so than other benefits, it is unrealistic to expect everyone who moves into eligibility to claim DLA/AA very promptly. There comes a point, however, when chronic delay shows little sign of crossing the threshold towards take-up. In the case of DLA/AA this is more serious because, unlike some means-tested benefits whose eligible non-claimants can improve their circumstances and move away from eligibility sooner or later, the majority of eligible disabled people are likely to remain eligible for longer. For a different reason, in the case of the terminally ill, even a short delay is a serious concern.

Delay is also caused by variability in potential claimants' conditions, as windows of greater need are interspersed with periods of lesser need, which is a complication peculiar to DLA/AA, though analogous to the way recipients of tax credits see their income fluctuate over quite short periods of time.

4.2.2 Awareness and comprehension

It is axiomatic that disabled people must be aware of the availability of benefits before they can claim them. Or, often in the case of those with severe mental incapacity, illness or dementia, someone else has to become aware of their likely entitlement on their behalf. Informants are confident that there is a generalised awareness of the availability of 'more money' for disabled people, though many confused DLA with Incapacity Benefit (IB), for example. It is acknowledged that The Pension Service takes steps to make pensioners aware of the availability of AA but informants draw attention to a lack of aggressive marketing of DLA. Some say that at the heart of the non-take-up problem is an expectation among potential claimants to wait and be told what benefits they might claim. This posture is felt to challenge the whole basis of self-assessment, by which is meant that an application form that asks applicants to give, in free-form, a clear and adequate description of their needs and shortcomings in self-care and mobility, assumes a spontaneous willingness to report their problems. It demands quite a lot of insight and objectivity about their personal circumstances and capacities.

There is a special problem of comprehension attached to applications made on behalf of disabled children since it is often hard, even for parents, to judge how

far their child's capacity falls short of what might reasonably be expected of a child of similar age.

4.2.3 Identity and acceptance

A problem deeper than cognitive awareness is one of acceptance and identity. Whatever the extent of their problem, there are people with severe impairments leading to care and mobility needs who are still reluctant to accept the status of 'disabled person'. Many elderly people accept incapacity as a penalty of ageing – elderly couples often support one another in their complementary needs, propping each other up '*...like a pair of bookends*' as one adviser puts it. They are a generation trained all their lives not to grumble and have an instinct to 'play down' their difficulties. In contrast, though, there are working disabled people who would for quite different reasons be reluctant to identify themselves as disabled in the sense defined in the qualifications for DLA.

People with chronic mental health conditions are sometimes almost completely unable to look after themselves at home, reliant solely on help and encouragement in order to self-care or go out, yet feel that making an application for DLA would be an admission of disability that would mark a new phase of dependency, one they might never recover from. It would, in their view, alter the way their carers and medical advisers see them, as hopeless cases that no longer merit special efforts to treat them, or as candidates for institutionalisation.

Those told they are terminally ill can be faced with a dilemma. In order to claim DLA under Special Rules they have to accept that they are terminally ill and likely to die within six months; they can be, understandably, reluctant to sign a form accepting such a poor prognosis. Their financial position is rarely their first thought anyway.

4.2.4 Skill transfer

The point often made by the informants to this study is that claiming DLA/AA is a skill-based activity. Those lacking experience and skill at claiming benefits either give up on the forms altogether or they, in a sense, **under-claim** by giving an inadequate or wrong assessment of their needs.

There is agreement that the claim form, completed by proxy as often as by own-account claimants, makes considerable cognitive and interpretative demands, taking self-assessment to its likely limits. Often elderly people approach welfare rights advisers asking for help to complete a few last details on a form that, on inspection, has been completed in ways almost guaranteed to invite rejection by decision makers. Such claimants tend to answer questions by saying what they can do rather than what they cannot do. For example, an elderly woman said she had 'no problems' with getting up in the morning because after about an hour of painful effort and manoeuvres she could, in fact, get up unaided. She began by writing:

'...I have no problems getting out of bed...I have to hold onto a frame to stand...I have to wait a few minutes as I get dizzy and have a lot of pain and stiffness in my legs...but I cope...'

Her adviser re-wrote this account giving the undeniable description of need that it in fact was.

Another example cited a woman who said that, yes, she could wash herself but, it turned out, only when someone else had brought a chair into her bathroom and gave her considerable other assistance. People who can self-care or go out only with the assistance of others, but who reliably get such assistance, are often not aware that their need alone qualifies them for benefit.

Part of the difficulty is that disability discriminates little by education or social class. People become entitled to disability benefits who have never contacted the benefits system before. They have no friends or relatives with such experience. They have no individual or pooled skills to bring to the task of claiming benefit. Often the most capable have no such skills and the least capable had them once but have forgotten them.

4.2.5 Critical mass and social networks

It follows from the above that social location can be the main factor determining whether or not people become aware of the availability of benefit or have the skills to initiate and carry through a claim. Hard-to-reach groups are usually perceived as young poorly educated, foreign-born and living in social or privately rented accommodation. Available evidence, however, suggests that, from the point of view of the benefit system, the hardest-to-reach clients might be older native middle-class home-owning couples living in reduced circumstances in small provincial towns. Outreach programmes to improve benefit take-up in the London Borough of Newham, for example, can claim success (increasing benefit receipt by £9.1m, they estimate) built on the extraordinarily rich local networks of welfare and charitable organisations (LBN, 2005).

The interviewees also point out that people with sensory handicaps have special problems of social isolation that are not eased by being members of an identifiable group.

4.2.6 Threshold or 'trigger event'

Early models of non-take-up relied quite a lot on ideas of thresholds or trigger events that spark people into first awareness of benefits and then into actions to claim. Informants agree that these ideas are still helpful in the case of DLAA because, as discussed above, readiness to claim involves stages of awareness and acceptance more severe than is typical of income replacement benefits.

Typical triggers are financial – the arrival of large bills, even for heating, laundry and so on, that may also be associated with the extra costs of disability – or are care-related, especially first contact with service providers.

Other triggers to claim can be inappropriate, such as receiving a diagnosis for a chronic condition such as multiple sclerosis. Quite a large number of such first sufferers interpret diagnosis, rather than care and mobility needs, as entitlement to benefit. Unfortunately, being declined at this stage can then delay a new claim long past the point when their condition has advanced beyond the point of eligibility.

4.2.7 Risk aversion and the costs of claiming

It may seem strange to point out that submitting a claim for benefits designed to compensate people for the financial effects of disability should impose costs that discourage eligible people from claiming. However, this is a widespread view.

Some people with chronic mental health conditions, for example, are said to calculate the likely effects that the claim process might have on their health and prospects for recovery. Such patients are said to be 'terrified' of the forms and often feel that staff will judge them harshly, or that their application will be received with mistrust. Such mistrust is exacerbated by the variability of their condition and the common anxiety they suffer anyway. Others, in contrast, fear that the process of investigation for benefit will result in a judgement about their condition such that it would be better to '*have them put them away...*' A cancer patient is quoted as saying that the claim process in her case was more stressful to her than the diagnosis that prompted it (MCR, 2004).

More widely, people, especially elderly people, are fearful of exposure to a state process that, as discussed above, they have no experience of. Worse, they have read of public indignation toward benefit fraud and are afraid they may make a mistake in claiming, be exposed as benefit cheats and punished. Many are fearful of the stigma and intrusion they feel attaches to claiming benefits. 'Sheer pride' is a persistent barrier to claiming, especially if it involves admitting to strangers that they need help with toileting, for example.

Others do not understand that DLA/AA are not counted as income against means-tested benefits and fear they will lose other support, particularly their Housing Benefit (HB). Moreover, they fear that they will be paid a benefit that, through error, will later be revoked and leave them in unmanageable debt, as in the case of Tax Credit overpayments. This fear may be reinforced by the practice of some local authorities of taking DLA into account in means testing the cost of social care.

4.2.8 Negative feedback

A problem peculiar to DLA is that half of all applications are disallowed. News of these disallowances is shared widely, especially among candidate populations who are moving into eligibility or whose relatives see them becoming eligible, when they may be seeking advice from friends or advisers. There is a common impression that these benefits are just hard to claim. Whereas the usual thinking is of hard-to-reach customers, many potential customers are said to have a notion of hard-to-reach benefits.

4.3 The complementary study

As the research into the feasibility of estimating take-up passes through its stages, it should improve an understanding of the eligible population who fail to claim DLA/AA. The first stage, this study, assesses the feasibility of developing an approach to estimating take-up in principle. The progress to the second stage, at which the recommended approach is to be tested and refined, should allow the first contact with eligible non-claimants. There may be a sufficient number of them at this point to draw some very broad conclusions about their social location, attitudes to claiming and other characteristics.

These broad conclusions are to be informed by the models of non-claiming described above. Once drawn, they should help to design a method of identifying the potentially eligible population (i.e. both claiming and non-claiming) for the purpose of the three-stage feasibility research. This interdependence between the complementary study and the feasibility research allows the former to be part of the latter. It is reasonable to develop and test the complementary study as part of the development and testing of the approach to estimating take-up.

The complementary study is envisaged as a separate research project into non-claiming. The development of a proposal relating to it is not the aim of the feasibility research. However, the outcomes of the feasibility research should allow preliminary conclusions on the scope, research questions and methods of analysis of the complementary study.

It is difficult to comment on the design of the complementary study at this point, when the results of stage two of the feasibility research are unknown. Depending on the success in identifying a sufficient number of the potentially eligible and not claiming people at that stage, a qualitative analysis and/or a quantitative analysis of characteristics of non-claimants and barriers to claiming among them may be conducted.

A qualitative analysis may take place even if the number of potentially eligible non-claimants precludes any quantitative analysis. In this case, it may still be possible to select representatives of the most important groups by benefit, age or any other characteristic of interest and carry out a number of in-depth interviews. These interviews should add substantially to the knowledge of the barriers to claiming and take-up and inform policy directly.

If the quantitative analysis can be undertaken, this should provide a picture of the social location and characteristics of non-claimants and enable estimates of volume and the relative importance of the barriers identified by the qualitative study. The probability of being eligible may also be assessed demonstrating whether some groups of the non-claiming population are more likely than other groups to be eligible and/or to choose not to claim and/or to be denied the benefits.

The results of the complementary study should inform the policy by suggesting whether the increase in take-up may require better publicity (be it wider or better targeted publicity) and/or better tackling of specific barriers to claiming.

4.4 Summary

This chapter focuses on potentially eligible non-claimants and their possible reasons for non-claiming. It describes eight main models of non-claiming that point to the varied and significant barriers that stand in the way of claiming. Since these barriers to claiming are also barriers to take-up measurement, people's reasons for non-claiming have to be taken into account in the design of approach to measure the take-up rate. They also have to be accounted for in the design of the complementary study that centres on non-claimants and investigates their characteristics, including their social location and attitudes towards claiming. This interrelation between the subjects of the complementary study and this feasibility research allows the complementary study to be developed and tested as part of the development and testing of the approach to estimating take-up. At the same time, the development of an approach to estimating take-up should benefit from the results of the complementary study as they feed information on non-claimants into the main research.

5 Data availability and usefulness

5.1 Introduction

Previous chapters suggest that in order to enable the estimation of take-up, the data should meet the following requirements: they have to match the data used by decision makers when arriving at decisions; and they have to contain this information with regard to the potentially eligible, regardless of whether they are claiming or not. This chapter assesses existing data, both administrative and survey, against these criteria. It is based on interviews with data holders at the Department for Work and Pensions (DWP) and Disability and Carers Service (DCS) and a review of the relevant documentation.

In an ideal case, all the necessary data would come from the same source. Alternatively, the data might come from different sources but merging the data sets into one might be possible. The aim of this chapter is two-fold. First, it is to compile a list of information that would enable the estimation. This list can be used as guidance if a decision to collect the necessary data by administrative means was taken. Second, it is to assess the various data sets against this list in order to investigate whether, and which elements of, these data may be used for estimating take-up.

5.2 Required data

Successful estimation of the take-up rate requires the data on the potentially eligible that enable the identification of its sub-group that resembles Disability Living Allowance (DLA)/Attendance Allowance (AA) recipients in terms of their mobility and care needs. Such identification is only possible if the information used by decision makers in order to arrive at an award decision is available with regard to all potentially eligible people, and information on award outcomes is additionally available with regard to the known claimants.

In order to identify the population of potentially eligible, the data should include information on the incidence of disability, for example on poor health or long-term illness. Information on other disability-related benefits that individuals receive (e.g. Incapacity Benefit (IB) and Industrial Injury) may also be used to identify those who are potentially eligible. Data on the duration of these other benefits as well as on the date of the disability onset may help to determine whether the potentially eligible meet the criteria relating to the DLA/AA qualifying periods.

The data should also enable the identification of care and mobility needs among the potentially eligible. Since these needs arise from impairments that are caused by some disabling conditions, some medical data describing the conditions and the nature of impairments are also required. Information on needs of the potentially eligible should match the entitlement criteria.

Given that the potentially eligible may have more than one disabling condition causing their impairments and determining their needs, the data should provide information on multiple disabilities. Existing administrative data (see below) suggests that a minority of claimants have more than five disabling conditions. Therefore, information on five conditions should suffice. At the same time, a single disabling condition may lead to a number of impairments and variety of needs. This implies that the data should record more than one impairment type¹⁷.

Likewise, although information in the claim form may be sufficient for making an award decision, statistics suggest that, often, an additional piece of evidence (but usually not more than three) is sought by decision makers. This implies that the data should convey information on the content of evidence in addition to the information contained in the claim form. Additionally, since a third party (but not a medical professional) may be best placed to provide information on a disabled person's needs, the instances where such a third party is necessary should be identified and allowed for in the data.

As was explained, this information should be available with regard to all the potentially eligible. But estimation of the take-up rate would be impossible without additional data on claimants. This refers to their award rates (including nil rates). Since some award decisions are revised over time, the data on claimants should point to the type of event (e.g. new claim, reconsideration or appeal) and the records should span a time period sufficient to capture a change in the award decision.

In addition to the data directly relevant to the benefits under consideration, other information is needed in order to accurately match the recipients with those who resemble them among the potentially eligible. By definition, this information should refer to all potentially eligible, i.e. regardless of their claiming status. These data have to include variables on the demographic profile of individuals (including

¹⁷ Lack of research on the impairments reported by claimants makes a more precise estimation of the number of impairments difficult.

their age, gender, household size and composition); type of their accommodation (e.g. residential), housing tenure, type of dwelling (e.g. flat, bungalow) and their housing conditions (e.g. accessibility of toilet); their socio-economic status (including self-employment, Standard Occupational Classification (SOC), Standard Industrial Classification (SIC)); and geographical location. Some of these variables (e.g. gender, socio-economic status, location) are needed if the take-up rates are to be estimated across different subgroups of the population (e.g. by gender, region, etc.).

Table 5.1 provides a summary of the data required for estimation of DLA/AA eligibility and the take-up rates. This information may be collected administratively and/or via a survey. The following sections describe the existing administrative and survey data in terms of their usefulness for estimating take-up.

Table 5.1 Summary of the required data

Data	Population coverage	Additional information
Receipt of any disability related benefits	All the potentially eligible, including claimants	Benefit types and length of spells
Demographic characteristics	All the potentially eligible, including claimants	Age, gender, household size and composition, etc.
Socio-economic status	All the potentially eligible, including claimants	SOC, SIC, unemployment, self-employment, etc.
Need for involvement of the third party	All the potentially eligible, including claimants	Relationship with the claimant
Characteristics of accommodation	All the potentially eligible, including claimants	Tenure, type of dwelling, housing conditions, etc.
Geographical location	All the potentially eligible, including claimants	Ward, postcode or similar
Dates of disability onset	All the potentially eligible, including claimants	Up to five disabling conditions
Medical condition(s)	All the potentially eligible, including claimants	Up to five disabling conditions
Impairment(s)	All the potentially eligible, including claimants	More than one impairment type
Need for additional evidence and its content	All the potentially eligible, including claimants	Up to three pieces in addition to the claim form
Needs in accordance with the entitlement criteria	All the potentially eligible, including claimants	Mobility and care needs
Dates of placing the new claim, applying for reconsideration, appeal	Claimants	
Award rate (including nil rate)	Claimants	Mobility and care components
Type of benefit	Claimants	DLA Adult, AA, Special Rules, etc.
Type of event	Claimants	New claim, appeal, reconsideration, etc.

5.3 Available data

There are two types of data that contain information relating to the disabled population: administrative and survey.

5.3.1 Administrative data

The available administrative data typically record claim processes and contain information mainly about recipients. Moreover, DCS, while basing decisions on the (multiple) **impairment(s)** reported by claimants, only records the main **disabling condition** on their computer system. To that end the existing administrative data are quite limited in their value to this research. Nevertheless, the main potential uses of administrative data are as follows:

- help understand the relationships between different pieces of information used in decision making and the way this information is numerically coded;
- help identify clusters of claimants who are very likely and who are very unlikely to be successful in their claim;
- verify the proposed method of estimating take-up.

There are two sources of administrative data, which result in different types of datasets. The first is the Management Information (MI) data and the second source provides data on claimants.

Aggregate Management Information data on claimants

The MI data contains aggregated information on some key measures of DLA/AA activity and operations. These data provide the timeliest information on registered claims, appeals, etc. and are mostly used for forecasting expenditure and workloads. For this reason the data are supplied at an aggregated level and cannot be used for assessing the take-up rate of DLA/AA.

Data on claimants

This source of data provides information at an individual level and in its original form includes the data on all claims (whether successful or not). However, the most widely used sub-sets that are derived from this data source only cover successful claimants, or recipients. These data sub-sets include Work and Pensions Longitudinal Study (WPLS) and five per cent data.

WPLS and five per cent data on recipients

Both are point-in-time data available on a quarterly basis, the difference between them being that the five per cent data includes a larger collection of variables than the WPLS data but WPLS covers a wider population of recipients. There are

problems with the accuracy of some of the additional variables recorded in the five per cent data¹⁸ and there are plans to discontinue it.

The WPLS covers the total population of benefit recipients. It can be linked to other benefits data making it possible to identify whether DLA/AA claimants were previously, or are currently, in receipt of other benefits. Furthermore, these data can be linked to Her Majesty's Revenue and Customs (HMRC) data on jobs to identify whether claimants were also in work. The data also has information on claimants' National Insurance numbers, one of the disabling conditions, different benefit components (mobility and care), amounts paid, geographical dimension and information on benefit spells.

However, neither WPLS, nor the five per cent sample data can be used at any stage of estimation mainly because they do not provide details on impairment and all medical conditions.

There are three other data sets that include details of both successful and unsuccessful claimants. One originates from a one-off three-day data collection exercise that was conducted by DWP in February 2005 in order to test the feasibility of Customer Case Management (CCM) pilots. Another data set contains information collected during the CCM pilots. And the third data set represents a sample of DCS customers selected for the Customer Service Survey from the main source of DLA/AA data held by DWP.

The data collected during the DWP three-day data collection exercise

The data collected during the three-day data collection exercise contain information on up to five disabling conditions as well as records of decisions taken on all claims. The data distinguish between Normal and Special Rules, between DLA Child, DLA Adult and AA benefit types and between the type of event (new claim, renewal, etc.). Importantly, the set also contains information on the type of evidence provided (customer contact, letter from GP, etc.) and the number of pieces of evidence for each case. This data set is examined in terms of its capacity to inform the development of a system of numeric codes representing the free text information of the claim pack and to help establish relationships between different pieces of information used in decision making.

The results of the investigation suggest that the data are very prone to error when recording disabling conditions and contain no information on the impairment. They cannot be used for identification of the relationships between pieces of information required to arrive at a decision. The lack of data on some demographic characteristics, socio-economic status and housing conditions is also among its deficiencies. However, these data may still be used when distinguishing sub-

¹⁸ For example, the error rate associated with the record of the 'main' disabling condition of a claimant is said to be at least 20 per cent. There also are questions as to which condition is recorded as the 'main' disabling condition.

groups of disabled people that are very likely and very unlikely to be awarded the benefit, provided that in the two years since these data were collected the award practices have not changed in this respect.

The CCM data on claimants

The CCM database is designed to mirror the decision making process and therefore, unlike all other data sets, it contains information on needs, up to six disabling conditions, sometimes their severity on a three-point scale (mild, moderate and severe)¹⁹ and medical evidence. However, these data have limited coverage:

- information is only available on claimants submitting new claims and the subsequent events;
- the benefit type piloted by CCM is restricted to DLA Adult (of working age);
- the system provides detailed guidance only with regard to ten disabling conditions;
- geographic dimension is represented by only two pilot areas of the country (Bootle and Manchester).

These limitations make CCM data not suitable for distinguishing sub-groups of disabled people with a very high or very low probability of being eligible. However, they may be used for identification of the relationships between some pieces of information required to arrive at a decision in DLA working age cases. Moreover, since in the new claim form more questions are pre-coded than before, the CCM data may help to develop a system of numeric codes that would represent information from the claim pack. Although the results of these tasks may only be applicable to the working age potentially eligible population, their value is explained by the decision to introduce and roll out CCM claim forms. This use of new claim forms by claimants should also be incorporated into an approach to estimating take-up.

Data scans

The main DLA/AA data source referred to above is the DCS liveload system. It contains information on DLA/AA claims that benefit processing staff record and check on a day-to-day basis. Extracts of certain information are taken from this system to feed into WPLS and the five per cent data on recipients (along with other benefit liveload systems, such as Jobcentre Plus and The Pension Service). It is possible to commission a one-off scan from the DCS' liveload system according to a specified set of required variables. (An example of such scans is a sample of claimants that DWP invites to participate in an annual Customer Satisfaction Survey.) However, the original data, and therefore the scans, do not contain all the

¹⁹ It is understood that for a large proportion of the conditions, severity was never established in spite of the detailed medical guidance available in CCM.

variables required in order to estimate the take-up rate. The liveload system holds information only on claimants, only on up to two disabling conditions, only on one piece of evidence and only if it is medical, and has no record of impairment or severity of disability.

To summarise, the analysis of existing administrative data suggests that no set in its present form enables an estimation of the take-up rate. However, some use might be made of the information obtained during the three-day data collection exercise and, especially, CCM. The lack of necessary data implies that the information required for identifying eligible non-claimants and estimating the take-up rate has to be collected.

5.3.2 Surveys

The main potential uses of existing survey data are as follows:

- identify the potential of existing surveys to estimate take-up;
- help design a survey if necessary.

The sources of survey data that are examined in this study include the British Household Panel Survey (BHPS), the Health Survey for England (HSE), the Scottish Health Survey (SHS) and the Welsh Health Survey (WHS), the English Longitudinal Study of Ageing (ELSA), the General Household Survey (GHS), the Labour Force Survey (LFS), the House Conditions Surveys, and the Health Education Monitoring Surveys (HEMS). These surveys are selected into analysis because they provide information on the health status of the population.

The British Household Panel Survey

The BHPS is an annual survey of each adult (aged 16 or more years) member of a nationally representative sample of more than 5,000 households, making a total of approximately 10,000 individual interviews. Starting from 1994 there is also a special survey of 11-15 year old household members. This survey consequently has problems with coverage of the population of interest (i.e. it excludes children) and has only a small sample of disabled people. It must, thus, be excluded from potential sources of data for estimating take-up.

Nevertheless, BHPS uses:

- the General Health Questionnaire to measure mental health (all waves);
- the Activities and Daily Living questionnaire (waves 7-8 and 10-13) to ascertain the activities of elderly people;
- the Short Form 36 (waves 9 and 14) to measure mental and physical health;
- Quality of Life questions (at wave 11 and will also be included in wave 16).

These questionnaires and systems of coding respondents' answers to them as well as the methods of selecting respondents into the survey (i.e. the survey

instrument, the screener and the screening method) adopted in the survey are worth investigating at stage two of the feasibility research if a survey approach to estimating the take-up rate is adopted.

The Health Survey of England

The HSE started in 1991 but until 1995 it excluded people younger than 16. By definition, it excludes people living outside England and therefore cannot be used for the estimation of take-up across Great Britain. People living in residential care are also not covered by the survey. The sample size varied over the years and in 1998 it contained about 16,000 adults and 4,000 children.

The use of this survey is problematic because in addition to the above mentioned shortcomings, each year it focuses on a different demographic group or disabling condition. The health conditions are limited to cardio-vascular disease, physical activity, eating habits, oral health, accidents and asthma. However, the survey has a core module which is repeated for each wave. It includes, among others, questions on general health and psycho-social indicators, questions about the use of health services and prescribed medicines. Therefore, as in the case of the previous survey, while HSE cannot be used for the estimation of take-up, its instrument, the screener and the screening method may be worth examining at stage two of the feasibility research.

The Scottish Health Survey and the Welsh Health Survey

The SHS and the WHS fill the geographic gap of the HSE, but suffer from similar problems in relation to the estimation of DLA/AA take-up. The SHS aims to estimate the prevalence of a range of health conditions and to monitor progress towards Scottish health and dietary targets, but the primary focus is cardio-vascular disease, whilst the WHS covers health service use, medicines, illnesses, general health and well-being, health-related behaviours and personal and demographic information.

In the 2003 SHS (the third in the series started in 1995) there were no age limits and children from zero upwards and adults aged 16 and over were included. The survey involved an interview and a nurse visit. Nurses collected information about prescribed medicines, vitamins and gastro-enteritis.

A total of 8,148 adults and 3,324 children were interviewed, of whom 5,444 adults and 2,224 children saw a nurse. The overall response rate was estimated to be 60 per cent among all adults, with 40 per cent of all those eligible seeing a nurse. The corresponding figures for children were 72 per cent and 48 per cent.

The 2003/04 WHS (also the third in the series started in 1995) comprised a 15 minute face-to-face household interview and a 16-page self-completion questionnaire for each household member aged 16 or over. The target sample size was 30,000 adults and 7,500 children.

Similarly to the HSE, the instrument, the screener and the screening methods of these surveys may be worth examining at the next stage of the feasibility research.

The English Longitudinal Study of Ageing

The ELSA is a multi-topic longitudinal survey of people aged 50 and over and their partners, even if these are under 50. It includes a wide range of information on the health, leisure and social activities, well-being and financial circumstances of the older population – the information that may have the potential to provide an indication of respondents' care and mobility needs. The survey has been conducted twice so far – in 2002/03 and in 2004/05. The sample size at wave one consisted of around 12,000 people drawn from households that had responded to the HSE in 1998, 1999 and 2001. An interesting feature of this survey is that a qualified nurse visits study members and asks to take some measurements (height, weight, etc.) and a small sample of blood. As previously, the survey does not provide all the necessary information required to assess DLA/AA entitlement; does not cover the whole of Great Britain; and does not include younger age groups. It cannot be used for the purposes of estimating take-up, even among those who may potentially be entitled to AA. However, the screening method, the screener and the survey instrument are worth investigating, if a survey route to estimating take-up is taken.

The General Household Survey

The GHS collects information on a range of topics, including health and use of health services. However, it only covers 13,000 people living in private households (i.e. excluding those in residential care). Potentially useful to the estimation of take-up, details of the illness are coded and aggregated into groups which approximate to the chapter headings of the International Classification of Diseases (ICD9). Also potentially valuable to the purpose of this study may be the questions on the use of health services. This is because respondents are asked whether they have seen a medical professional in the recent past.

The Labour Force Survey

The LFS is a quarterly sample survey of 60,000 households living at private addresses in Great Britain, with an equivalent survey for Northern Ireland. People living in NHS accommodation are sampled using a separate list of such accommodation. The survey seeks information on respondents' personal circumstances and their labour market status during a specific reference period, normally a period of one week or four weeks (depending on the topic) immediately prior to the interview. Questions on disability are limited and not suited to estimating DLA/AA take-up.

The House Conditions Surveys

The English House Conditions Survey (EHCS) is a national survey of housing in England. Parallel surveys are also conducted in Scotland, Wales and Northern Ireland. They cover all tenures. The information obtained through the survey provides an accurate picture of the type and condition of housing, the people living there and their views on housing and their neighbourhoods.

There are a number of component surveys that make up the overall EHCS. An interview is first conducted with the householder that covers household characteristics, satisfaction with the home and the area, disability in relation to housing needs (and as such is limited in use for estimating take-up of DLA/AA) and adaptations to the home, work done to the property and income details.

Headline results from the 2005 survey were published in January 2007. From April 2008 the EHCS will be integrated with the Survey of English Housing. It will become part of the new Integrated Household Survey (IHS) which the Office of National Statistics (ONS) are launching in January 2008²⁰. Within the IHS the EHS sample size will comprise around 17,000 household interviews.

The Health Education Monitoring Surveys

The HEMS in 1998 was the fourth and final survey in an annual series. It was carried out to monitor the health promotion indicators relating to health-related knowledge, attitudes and behaviour, and to investigate the links between social inequality, social support, social capital, health and health behaviours.

Topics covered include household characteristics, socio-demographic characteristics of respondents, general health, social support and social capital, activities of daily living for those aged 65 and over, behaviour in the sun, smoking and drinking, physical activity, diet and sexual health.

The 1998 survey covered 5,800 interviews with adults aged 16 years and over living in private households in England, with a response rate of 71 per cent. The survey is now ten years old and as such is not well-suited for this research.

To summarise, the analysis demonstrates that none of these surveys can be used for estimating the DLA/AA take-up rate because none of them has all the data required. Moreover, these surveys do not fully cover the population of interest. Some of them have limited geographical coverage, some exclude children, some focus on people aged 50 and over, some do not include those living in residential care, and so on. None of these surveys, therefore, can be used as a vehicle for estimating the take-up rate.

²⁰ This new survey brings together the Labour Force Survey, the GHS, the Expenditure and Food Survey, and the Omnibus Survey. There will be a core module that all respondents answer, and then a module for each of the previous surveys.

5.4 Summary

This chapter describes the requirements of the data necessary for the identification of eligibility and estimation of the take-up rate. It provides a list of data that meet these requirements, noting that the information should relate to all potentially eligible (both claiming and non-claiming).

The analysis of existing administrative data against these requirements suggests that it can only be used to determine the number of claimants, the number of recipients and their award rates. However, two data sets may help to develop some elements of an approach to estimating take-up. The data collected during the three-day data exercise may be used to identify those with a very high and those with a very low probability of being eligible among the general population. The data collected during the CCM pilots may be used in an analytical exercise of establishing the relationships between various pieces of information required to arrive at a decision and developing a system of numeric codes that would represent the information from the claim pack.

The existing social surveys that provide information on the health status of the population are also examined in terms of their potential to estimate take-up or to inform the design of a survey if this was chosen as a means of collecting the data. The analysis demonstrates that none of these surveys can be used for estimating the DLA/AA take-up rate because none of them fully covers the population of interest. However, the methods of selecting respondents into these surveys, their questionnaires and systems of coding respondents' answers should be investigated at stage two of the research if a survey approach to estimating take-up is adopted.

Since none of the existing surveys or administrative data sets can be used to estimate the take-up rate, some survey-based approach to collecting the data and estimating take-up should be developed. Prior to developing such an approach, however, consideration should be given to the existing experience and research relating to survey-based methods of collecting the disability-related data and estimating the DLA/AA take-up rate.

6 Disability-related surveys and potential approaches

6.1 Introduction

A number of surveys relating to various aspects of disability have been conducted in Britain in the past 20 years. Most aimed at establishing the distribution of impairment and the additional costs associated with disability but one (the Family Resources Survey (FRS) Disability Follow-up Survey) was directed specifically at determining eligibility and the take-up rate of Disability Living Allowance (DLA)/ Attendance Allowance (AA). Recently a study by Purdon *et al.* (2005) suggested two survey-based approaches to assessing the take-up rate: an approach based on submitting the completed claim forms to decision makers for an assessment and a more conventional survey approach.

This chapter reviews the methods adopted in the past disability-related surveys and those put forward by Purdon *et al.* (2005). The methods and measurements of the past surveys are assessed in terms of their usefulness to a potential survey; and suggestions of Purdon *et al.* (2005) are reviewed in terms of their suitability for the estimation of the take-up rate.

6.2 Disability-related surveys

6.2.1 **The Office of Population Censuses and Surveys (now ONS) Disability Surveys**

Between 1985 and 1988 the Office of Population Censuses and Surveys (OPCS) carried out a series of surveys of disabled people to estimate the distribution of impairment and disability in Britain. Separate surveys were conducted of adults and children, and of both in residential care, and so, uniquely, the sample was representative of the population of disabled people (or, using the terminology of this report, of all potentially eligible). Surveys also included special studies of the financial impact of disability on the disabled (Walker, 1991).

The surveys established who in the population were disabled, their level of disability and their need for personal services but not their entitlement to AA or Mobility Allowance, which pre-dated DLA. For the first time attempts were made to use objective criteria for the assessment of disability and its severity. In these surveys, a range of disabling conditions was covered across 13 areas of disability, such as locomotion, reaching and stretching, behaviour and communication. The severity of disability in each area was measured against a specially developed scale and the overall severity score was derived.

Attempts at the development of such scores with the aim of linking them to disabled persons' needs and DLA/AA award rates would note that there is little correlation between the degree of severity and the rate of award. A disabled person could rate 'severe' for 'fits, convulsions or consciousness' but only qualify for a lower AA award rate because even if they needed assistance, they could still physically walk. Although a repeat of these surveys would not provide an estimate of the take-up rate of DLA/AA, the design of OPCS Disability Surveys may inform the development of a screening method, a screener and a survey instrument employed to collect the data.

6.2.2 Daly and Noble survey

Daly and Noble (1996) conducted their own survey of 486 individuals living in low-income households. The authors aimed to examine the extent to which individuals' apparent eligibility for DLA/AA was matched by their receipt of the benefit, following the introduction of DLA in 1992. In this survey, they used questions from the OPCS Disability Survey and others relating to an individual's mobility. The authors also applied an OPCS disability scale to arrive at an overall measure of severity. Similarities between this and OPCS Disability Surveys in their methods imply that a repeat of such a survey could not deliver the take-up estimate.

6.2.3 FRS Disability Follow-up Survey

Between July 1996 and March 1997, the Disability Follow-up to the 1996/97 FRS survey took place. Around 8,800 disabled adults living in private households in Great Britain were invited to participate in the Disability Follow-up Survey as they met certain disability-related criteria or were aged 75 years or over. Of these 7,300 people responded and 6,200 long interviews and 1,100 short interviews were conducted. The long interviews were with those respondents who indicated that they had some difficulty in the short part of the interview (Craig and Greenslade, 1998).

This was the only survey specifically designed for the purpose of estimating the DLA/AA take-up rate. Consequently, its questions were closer to the entitlement criteria for DLA/AA than the questions in the earlier OPCS Disability Surveys. They did not exactly match those in the claim form and the data lacked information on medical evidence. Nevertheless, the questionnaire developed for this survey should be thoroughly investigated at stage two of the feasibility research.

As was already mentioned, despite the attempts to produce the take-up estimates, the results could not be considered robust. The rate was defined as a ratio of the number of recipients to the total entitled population. The population of recipients included those who may have been in receipt of an inappropriate award. The population of those entitled may or may not have been in receipt of an award. Using the terminology of Table 3.1, the rate was defined as $(A+E)/(A+B+C+D)$.

This definition of eligibility and hence, the measure of take-up, do not reflect the existing decision-making practices and differ from the ones proposed by this study. This means that the two take-up rates, if one is produced following this feasibility research, will not be comparable. Another reason for the two rates to differ is that the FRS Disability Follow-up Survey excluded people in residential care.

The description of this survey demonstrates that although a repeat of the FRS Disability Follow-up Survey would not produce a measure of take-up defined by this study, the experience, the screening method, the screener and the instrument of that survey are likely to be useful to any survey-based approach to estimating take-up and should be examined at stage two of the feasibility of research. This analysis should take into account changes in decision-making practices that took place since the survey was conducted. These included changes to DLA entitlement rules (mainly those applicable to children), an increase in the number of disabling conditions covered by DLA/AA and the introduction of some administrative measures in order to improve the quality of award decisions (Morgan, 2002).

6.3 Potential approaches

Both approaches to estimating entitlement to DLA/AA suggested by Purdon *et al.* (2005) consist of a number of phases and involve identifying the potentially eligible population using some methods. The approaches differ in their treatment of complexities of claiming and decision-making processes, such as the possibility that potentially eligible people may choose not to claim, the need for additional evidence and the complexity and open-ended nature of the claim form. The claims-based approach requires respondents (or someone else on their behalf) to claim the benefit and a more 'survey-friendly' approach recommends recording respondents' observed characteristics and estimating the take-up rate by means of statistical modelling. These proposals are now considered in detail.

6.3.1 Claims-based approach

This approach replicates the application process and consists of four phases:

- 1 select a sample of potentially eligible people;
- 2 among these, select those currently not claiming and with their permission, fill in DLA/AA claim forms on their behalf;
- 3 submit the forms to decision makers for an assessment;
- 4 determine eligibility according to the decisions made with regard to these claims.

The claims-based approach recommends conducting a survey where respondents (the population of non-claiming potentially eligible people) fill in the claim forms and agree to these being submitted to decision makers for an assessment. Decision makers then may seek and obtain additional evidence, if this is required. Their decision determines the respondents' eligibility. This must be probable eligibility, as the term is defined in this study, because there is no guarantee that the decision would be the same if the claim was considered by a different decision maker.

This approach addresses the problems of complexity and the open-ended nature of the claim form and the need for evidence. Another advantage of this approach is that it avoids difficulties relating to the development of a statistical model of eligibility. However, as the authors themselves point out, there are also a number of disadvantages.

According to the authors, these include ethical problems raised among those who would be denied the benefit. From the methodological point of view too, the authors believe that there are problems associated with the possibility that respondents would not answer the survey questions in the same way as they would answer the questions in the claim form. Likewise, claim forms filled in by interviewers may differ in a consistent way from those filled in by claimants (or a third party on their behalf) in, say, how the needs are presented. Decision makers may be able to distinguish these claims from the ones they usually deal with and this may affect their judgement. In this case the estimated eligibility may not accurately reflect existing practices.

There are additional problems with this approach that render it unfit for the purpose: First, the authors' recommendation seems to stop at phase four rather than go on to replicate appeals to be lodged by those at first deemed ineligible. Given subjectivity and uncertainty surrounding the process, success at appeal is possible and it would alter the size of the eligible population determined by the first round of decisions.

Second, the ethical position of the interviewers would also be compromised because they would be charged with persuading disabled people to enter into a relationship with the authorities that these people might prefer to avoid.²¹ Moreover, in order to obtain a robust take-up estimate under this approach, some people who have a relatively low probability of success would need to be persuaded to claim. However, it is difficult to envisage a conversation with a respondent where they are told that they are unlikely to be entitled to benefit, but need to fill out all the forms anyway just to check.

Third, since respondents would be aware that the assessment of their claims would attract a clear yes or no answer, there is an ethical issue of acting on the decision makers' decision. If the answer is yes, it seems reasonable to abide by it.

²¹ Social workers are said to quite often get themselves into such difficulty, this being one reason why they tend to avoid giving benefits advice unless they have to.

If the answer is no, it also seems reasonable that respondents whose claims were disallowed were informed that another decision maker might have reached an opposite decision on their case. No one, however, would be in a position to assess the probability of reaching that opposite decision. Moreover, this would aggravate an ethical problem of raising hopes unnecessarily.

Fourth, even if all the above disadvantages were overcome, there is a fundamental flaw in this proposal which hinders accurate estimation. The main methodological objection to this approach is that it assumes that having their claims assessed represents a 'carrot' for disabled people. It, therefore, ignores those categories of the potentially eligible that know about the benefit but have no intention of applying for it for the reasons described in previous chapters (see also Goldstone *et al.*, forthcoming). Examples of these types of potentially eligible people include those who do not want to admit, even to themselves, that they have the needs that make them eligible for DLA/AA, or those who are afraid of having their other benefits withdrawn. They are all likely to refuse to submit a claim for an assessment.

In the absence of their claims this approach does not allow even for a probabilistic assessment of their eligibility. At 100 per cent, the non-response rate of those who chose not to submit a claim would be much higher than the non-response of the rest of the potentially eligible population. But there would be no data to determine which subgroups of the potentially disabled they resemble in terms of their DLA/AA relevant needs in order to assess their eligibility by means of statistical modelling. Therefore, a sample of respondents is likely to be biased and the estimated entitlement flawed if an approach to estimating take-up is based on the agreement of the potentially eligible to submit actual claims.

Although Purdon *et al.* (2005) do not suggest this, the claims-based approach may be disguised as a survey if the information necessary for reaching an award decision was obtained using a survey questionnaire. Applying decision makers' judgement as the criteria of eligibility would require this information to be transferred into the claim form before being submitted to the decision makers. However, this would raise an ethical issue of respondents' eligibility being assessed without their consent. And even if respondents were not informed about the subsequent submission of their answers to decision makers, this approach is unlikely to deliver because decision makers will probably be able to recognise the artificial claims. Their decisions would, therefore, not be reliable. In order to avoid these claims being instantly recognised, they would have to include names and signatures; the practical difficulties of arranging this would be huge. Moreover, in order to estimate take-up, these artificial claims would have to be taken out of the system. That would also represent a difficulty at the practical level.

Finally, the employment of decision makers on a large scale has high resource implications. It does not seem to be cost-effective to invest such effort into collecting data that can only be used for the purposes of the take-up estimation and that do not provide any additional information on the potentially eligible population to the data contained in the claim pack. However, if attempts are made

at collecting any additional information, the more conventional survey approach seems reasonable.

6.3.2 Modelling-based approach

This approach consists of four phases:

- 1 take a sample of actual claims and develop a questionnaire, including the coding system, that replicates the claim form;
- 2 build a statistical model of probability of award based on these coded claims;
- 3 pilot the survey by asking the survey questions of either:
 - a) a sample of recent claimants; or
 - b) a sample of disabled non-claimants;and verify the model;
- 4 select a sample of potentially eligible disabled people, conduct the survey and apply the statistical model to determine the eligibility.

This approach is less charged with ethical issues than replicating the application process. Purdon *et al.* (2005) see challenges in this approach in its requirement for a survey instrument that captures all the information contained in the claims, and in the feasibility of the development of a statistical model that would estimate the entitlement. However, there are a number of other problems that remain unsolved under this approach.

The approach, as outlined by Purdon *et al.* (2005), does not allow for verification of the survey instrument separately from verification of the model. At the piloting phase, respondents are supposed to submit actual claims shortly after they responded to the survey questionnaire in the pilot. It is suggested that the award decisions on the actual claims be used for verification of the model that uses their coded responses. However, it is not clear how the coded responses are made to reflect the actual claim information fully and accurately. This means that if mistakes are made at the first phase, the development of a survey instrument, they are likely to feed into the second phase, the development of a statistical model. In this case, at the third, piloting, phase, it would be difficult to refine the statistical model without being able to distinguish the source of the problem.

However, the third phase of the approach is unlikely to achieve robust verification of the model, regardless of the success of the previous two phases:

- First, neither option A (involving a sample of recent claimants), nor option B (involving a sample of non-claimants) allow for robust verification of the model because each of them covers only a subgroup of population of potentially eligible. A model that is built on the basis of a sample of claimants and is piloted on a sample of recent claimants (option A) is likely to suffer from a sample selection bias. Verification of the model built on the basis of a sample of **claimants** using a sample of **non-claimants** (option B) does not seem possible.

- Second, the use of a sample of recent claimants (option A) may additionally lead to a bias in responses. This will happen if claimants respond to the survey questionnaire differently from how they responded to the questions in the actual claim forms.
- Third, the viability of option B (using a sample of disabled non-claimants) depends on the willingness of respondents to participate in the pilot and shortly after that to place actual claims. This revives some of the ethical problems associated with the claims-based approach.
- Fourth, even if there are a sufficient number of disabled people that have never claimed and are willing to respond to the survey and shortly after that fill in an actual claim form and submit it, in line with the argument given above, there are no reasons to believe that their sample will be representative.

Finally, the survey approach, again as outlined, does not account for the possibility that not all information may be available at once during the interview. It is plausible that some (e.g. medical) evidence may be required in order to support the answers of a respondent. In this case, either an interview has to have a break or an interviewer has to be trained to collect such evidence on the spot. Therefore, there may be circumstances when the authors' suggestion that this approach does not require specially trained interviewers would not hold.

To conclude, the two approaches suggested by Purdon *et al.* (2005) have advantages and disadvantages, though the first probably rules itself out on methodological grounds. Neither of them meets all challenges presented by the task of estimating entitlement and the take-up rate.

6.4 Summary

This chapter describes the disability-related surveys conducted in the past and the approaches to estimating DLA/AA take-up that are put forward recently. It shows that a repeat of none of the surveys would produce a required take-up estimate. Compared with this research, the OPCS Disability Surveys had a different aim and the FRS Disability Follow-up Survey differed in its definition of eligibility and a measure of the take-up rate. Moreover, the FRS Disability Follow-up Survey excluded people living in residential accommodation.

However, detailed analyses of certain elements of these surveys are likely to inform this research at stage two of the project, if a decision to progress to it is taken. For example, methods of selecting respondents into a survey and the design of the OPCS Disability Surveys may inform the development of an approach to identifying the potentially eligible population. The questionnaire and the coding systems developed for the FRS Disability Follow-up Survey are likely to facilitate the design of any survey-based approach to estimating the DLA/AA take-up rate. A review of the methods of dealing with under-reporting in the FRS Disability Follow-up Survey would be especially valuable to this research.

The analysis of two more recent research proposals put forward by Purdon *et al.* (2005) suggests that one of them (a claims-based approach) is unlikely to achieve the desired result on methodological, ethical and practical grounds. Another (modelling-based) approach should be modified in order to avoid spurious results. The analysis of this approach suggests that the estimation of take-up should be conducted in phases and the achievements of each phase have to be verified before progressing to the subsequent phase. The next chapter puts forward the recommended approach to estimating take-up.

7 Recommended approach

7.1 Introduction

This chapter describes a survey-based approach to estimating take-up of Disability Living Allowance (DLA)/Attendance Allowance (AA) that is recommended by this study. The approach is multi-phased, with progress to each subsequent phase depending on the successful completion of the previous phase. It is based on the assessment of people's probability of being eligible and the chapter starts with an explanation of how the take-up rate would be calculated and interpreted. The chapter then provides a detailed description of the tasks to be completed at each phase.

7.2 Measuring the take-up rate

The probabilistic approach is consistent with the definition of eligibility adopted in this study, whereby potentially eligible disabled people become (probably) eligible on receiving the DLA/AA award if they applied. The previous chapters explained how people with identical needs may receive different award decisions and how this introduces an element of probability into the concept of eligibility. An example was given showing that 100 people with identical needs may have an 80 per cent chance of being eligible, according to this definition of eligibility.

This was the concept adopted by Purdon *et al.* (2005), more explicitly so in their modelling approach. This study also recommends determining the association between respondents' stated needs and their probability of being eligible by means of statistical modelling. The most obvious advantage of this approach is its ability to avoid the problem of refusal to claim. If the reasons for non-claiming are accounted for when selecting respondents into the sample, the presence of all the potentially eligible in the sample ensures that the probability of being eligible is assessed with regard to everyone in it, regardless of whether they applied for the benefit. This is possible under the assumption that the probability of being eligible depends on respondents' needs and not on their propensity to claim. This is a safe assumption because even if claimants differ from non-claimants in their DLA/AA

relevant needs, the association between the needs and award rates is determined only by the eligibility criteria and does not depend on the claimants' status.

The detail on statistical modelling is provided below. At the moment, it is sufficient to say that for each member of the sample of the potentially eligible, the model will produce a number, a probability, which will show the chance of success that person would have if they applied. Once the probability is determined, a simple formula can be used to estimate the take-up rate:

$$TUR = \frac{R}{\sum_{i=1}^n P_i} \quad , \text{ where}$$

TUR – the take-up rate

R – the number of recipients

P_i – the probability of receiving DLA/AA by respondent *i*.

In numerical terms, suppose there are 384 potentially eligible people, of whom, 120 people are in receipt of DLA. (These are not people with identical needs as in the previous examples.) Suppose that the statistical model produced the following estimates: 200 people have a 20 per cent chance of being eligible, 100 people have a 50 per cent chance and 84 people have an 80 per cent chance. In this example, the take-up rate is 76 per cent.

$$\frac{120}{(0.2 * 200) + (0.5 * 100) + (0.8 * 84)} = 0.76$$

If this rate were to be the estimated figure, it would mean that given current decision-making practices, there are 3.68 (2.8/0.76) million people in total who are eligible for DLA (including those with low probability of receipt). Under current decision-making practices, 2.8 million of them receive the benefit and 0.88 million do not receive, either because they did not apply or due to error.

It has already been stressed in the previous chapters that this measure incorporates any fraud and error existing in the current decision-making practices and does not distinguish the proportions of those potentially eligible who receive or who do not receive the benefit due to these factors. However, indirectly, this approach to estimating take-up enables the analysis of instances where people receive the benefit despite having a low probability of being eligible and vice versa – instances where people do not receive the benefit despite having a high probability of being eligible. This provides a perspective on the extent of error, but not of fraud whereby needs might have been misrepresented.

The probability of receiving a certain award rate may also serve as a proxy indicator of the degree of a person's care and/or mobility needs. For example, a person whose probability of receiving high rate DLA care award is estimated to be 90 per cent, could be expected to have greater care needs than a person with a

probability of 60 per cent. Availability of such data over a number of points in time may demonstrate the dynamic of changes in care and/or mobility needs of the potentially eligible population.

Another advantage of this take-up measure is that the outcome of statistical modelling is a probability of being eligible, rather than a clear yes or no answer. Therefore, one could argue that there is no sense in informing the survey respondents of the likely outcome of their application, if they applied.

7.3 Phases of the approach

A five-phase approach to establishing the feasibility of estimating take-up is recommended, the aims of the five phases being as follows:

- A** Development of a screening method, a screener and a survey instrument. Development of the complementary study.
- B** Validation of the survey instrument using the data on claimants.
- C** Piloting the survey instrument on the potentially eligible (i.e. both claimants and non-claimants). Piloting the complementary study.
- D** Development of a statistical model using the data on claimants.
- E** Piloting the survey and verification of the statistical model on the potentially eligible (i.e. both claimants and non-claimants).

Given the complexity of the task, progress to each subsequent phase should depend on the successful completion of the previous phase. The suggested sequence ensures this by verifying the results of each phase before moving to the next. Each phase consists of a number of tasks described in the sections below.

7.3.1 Phase A: Development of a screening method, a screener and a survey instrument. Development of the complementary study

In order to select a nationally representative sample of the potentially eligible population, those disabled people who have at least some care and/or mobility needs have to be identified among the general population. This is done by means of a screening method and a screening questionnaire, i.e. a shortlist of questions offered to a representative sample of the general population through various means of communication, such as telephone and/or post. Methods for maximising the response rate to the screening questionnaire (or the screener) should be employed in order to avoid the problems of bias in selection for the survey.

Those whose answers to the screener indicate that they may be potentially eligible should be invited to take part in the main survey and the next task is to conduct this survey among the potentially eligible. As is the case with the screener, it is necessary to maximise the response rate to the main survey. The main survey has to collect data (preferably in a numeric format) about the respondents' needs that

are equivalent to the information they would provide if submitting a claim. This is done by means of the survey instrument, which includes a main questionnaire and a system of (preferably numeric) codes (or coding frames) that allow the data to be represented in some more structured form than the free text.

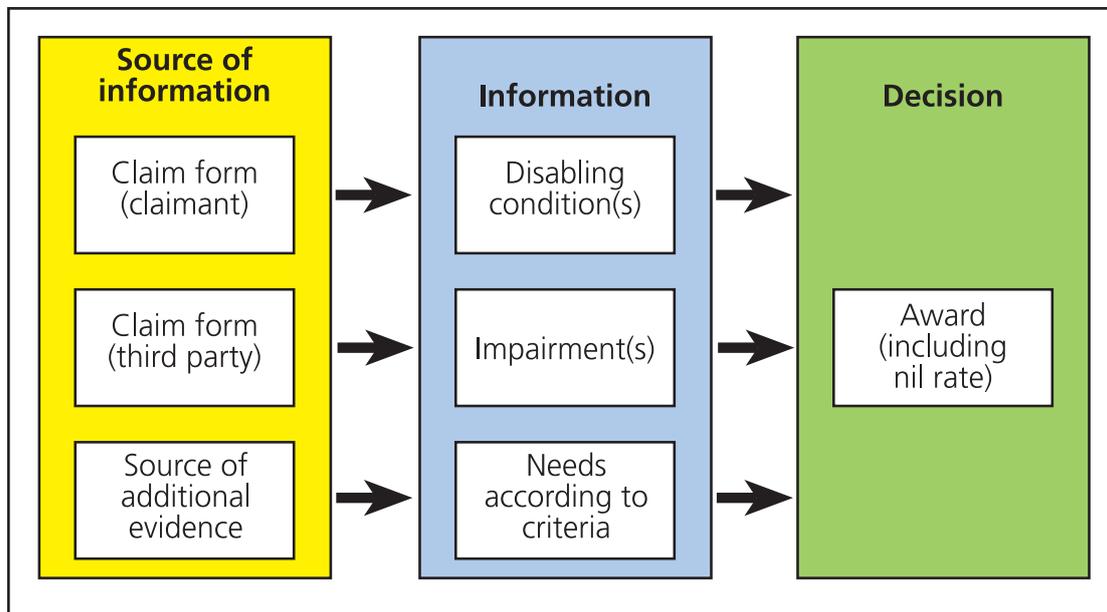
At phase A, a screening method, a screener and a survey instrument have to be developed. The development of a screening method and a screener should be based on the analysis of social surveys providing information on the health status of the population. These surveys were described in the previous chapters. Their more detailed analysis should be undertaken at stage two if the recommendation of this study is accepted.

The development of the main questionnaire and the coding system should be based on the analysis of claim documentation. The roll out of Customer Case Management (CCM)-based claim forms implies that they have to be used in the exercise if the estimated take-up rate is to reflect the existing decision-making practices. Any other anticipated changes to these practices should also be accounted for at this phase.

The information contained in the claim packs is to be used in order to identify the logical associations between various pieces of data necessary for making an award decision. Therefore, the variety of claim packs to be used in the analysis should capture all possible benefit types (DLA Child, DLA Adult, AA, Special Rules, etc.), benefit rates (including nil rate), types of needs (mobility, care), types of disabling conditions and impairments and types of evidence (GP factual report, Examining Medical Practitioner (EMP) report, etc.). Figure 7.1 demonstrates the pieces of information and their sources that have to be analysed using the claim documentation.

The first two blocks (yellow and blue) show the elements between which the logical associations should be identified and numerically coded. Existing combinations between the types of care and mobility needs, impairments and disabling conditions (blue block) should be established and a system of numeric codes that takes account of these combinations should be developed. This system of relationships has to be linked with the information on sources and types of evidence (yellow block). The analysis of claim forms and supporting documentation should help to understand what evidence, and from which source, decision makers seek for a given combination of disabling conditions, impairments and needs. For example, a medical professional might need to be approached when deciding on the needs of someone unable to walk, while a family member may be best placed to provide evidence of someone's needs associated with their inability to assess danger. This exercise should also help to identify instances where a proxy/third party is best placed to provide information required by the claim form.

Figure 7.1 Claiming and decision-making processes



The importance of establishing associations between the pieces of information contained in these two blocks cannot be overestimated. The data collected during the three-day data collection exercise and CCM pilots can help in this task. Its successful completion lays the groundwork for obtaining complete information on the case and this, according to decision makers, is paramount to their confidence in the award decisions.

On the basis of this information, and using the wording of questions in the claim forms as additional guidance, the main questionnaire is to be built. The questionnaire and the coding system should enable the numerically coded information on needs and other characteristics provided by respondents during the survey to represent the claim packs information as closely as possible.

The analysis of associations between the second (blue) and the third (green) blocks presented in Figure 7.1 should illustrate whether certain combinations of care and mobility needs, types of impairments and disabling conditions are very likely, or very unlikely, to be associated with certain award decisions. This information should inform the development of a screening questionnaire that is to be used to identify those potentially eligible.

The combinations of the elements of the second block that are strongly associated with disallowance can be used to identify those members of the general population who are not potentially eligible; they should not be invited to participate in the survey (i.e. they should be screened out). The combinations that are strongly associated with positive award decisions can be used to identify the potentially disabled (i.e. those who should be screened into the survey) who do not need to answer the detailed survey questions.

To enable this task, the claim packs used in the analysis should include CCM documentation relating to the claims that are already decided upon, including by appeals panels where this was the case. Another requirement of these claim packs is that they should be representative of all types of information, its sources and award rates, including nil rates.

In order to obtain a representative sample of all the potentially eligible, including those, for example, who would not admit having a disabling condition, the reasons for non-claiming described in the previous chapters should be accounted for when developing a screening method, a screener and a survey instrument. The way the claimants (or the third parties on their behalf) describe their conditions, impairments and needs may help in the design of the instrument that captures the categories of the potentially eligible that do not tend to apply. Additional questions on respondents' attitudes, reasons for not claiming, needs other than those relevant to DLA/AA may also be envisaged to provide information that may be useful for any study into disability. This task of phase A does not only belong to the feasibility research but is also part of the complementary study development, even though the complementary study itself represents a separate research project.

To summarise, phase A should include the following tasks:

- select a sample of claim packs that captures a variety of benefit types, benefit rates (including nil rate), types of needs, types of disabling conditions and impairments, and types of evidence;
- code the information contained in the claim packs, including additional evidence, so that it was presented in some more structured (preferably, numerically coded) way rather than the free text;
- determine the associations between the award decisions and claimants' needs, their other characteristics relevant to the entitlement criteria and additional evidence;
- identify instances where a proxy/third party is best placed to provide information required by the claim form;
- design and develop a survey instrument;
- develop a screening method and a screener;
- identify possible reasons for not claiming and develop a questionnaire and coding frames relating to these reasons (as part of the complementary study development).

By the end of phase A, a screening method, a screener and a survey instrument would be developed. The complex relationships between the needs, disabling conditions and impairments, the lack of necessary evidence (from the claimant or from additional sources) and the presence of conflicting evidence imply that it may be difficult to establish robust associations between the three blocks in

Figure 7.1. The complexity of this task requires its results to be verified. This is the aim of phase B.

7.3.2 Phase B: Validation of the survey instrument using the data on claimants

At phase B the survey instrument developed at phase A should be validated and the importance of evidence submitted in addition to the information in the claim form should be assessed. Since the survey instrument was developed using a sample of actual claim packs, this same sample cannot be used for verification purposes. A new sample of actual claim packs with a representative set of characteristics (such as benefit type, award rate) and known award decisions, including disallowed, should be selected for the verification of the survey instrument. Its size should be large enough to use for statistical modelling (see below).

The main questionnaire and the coding system developed at phase A should be applied to this new sample of claim packs in order to produce coded claims containing information that replicates the actual claims information. These coded claims should be given to decision makers for the award assessment. The purpose of involving decision makers is to ensure that the coded claims convey information equivalent to that in the actual claim documentation.

However, different decision makers may arrive at different decisions due to differences in their judgement rather than due to a poor reflection by coded claims of their actual prototypes. In order to exclude the deviation in decisions caused by the difference in judgement among decision makers, it is suggested that the same decision maker that decided on the actual claim was asked to decide on its coded version. Under these conditions, the success in developing the survey instrument is determined by the degree of similarity between the decisions based on actual and coded claims.

Medical or other evidence that is usually sought by decision makers in addition to the information collected through the claim form may play a crucial role in award decisions. Since some of this information may be impossible to collect during the survey it is important to establish its importance. It is suggested that this is achieved by asking decision makers to decide on the coded claims twice: first using the coded claims from which information on the additional evidence is removed. These claims would consist of coded DLA/AA claim forms containing information provided by claimants and/or third parties on their behalf. The second time decision makers should be using the coded claims with full information, i.e. the claims that contain additional evidence. These claims would consist of all coded information from the claim pack except the decision taken on the case. The real-life decision itself may be the initial decision taken on an original claim, the one taken after reconsideration, or the one arrived at by the appeals panels. The most important condition for the success of verification at phase B is that the coded information available to decision makers participating in verification was equivalent to the free-text information they used when arriving at the real-life

decision. Obviously, the proportion of the sample of coded claims that does not contain additional evidence only needs to be assessed once.

The comparison of the two decisions, one taking into account additional evidence and another without it, would indicate the importance of that evidence in reaching the decision on the actual claim. This information on the importance of evidence could guide the development of a training programme for interviewers so that they were able to collect some evidence on the spot. The questionnaire and the coding system should also be adjusted depending on whether the decisions taken on the basis of coded claims differ from the decisions taken on the basis of actual claims.

In order to be confident of the results of verification a number of requirements should be met: First, decision makers participating at this phase should have different degrees of experience, representing as closely as possible the current variation in experience of staff in the country. This is to ensure that the recommended approach reflects decision-making practices at the time of the survey. This requirement implies that any initiatives and measures that are expected to change decision-making practices should be considered when selecting a sample of claim packs for coding and inviting decision makers to participate in the verification. The impact of CCM claim forms, accreditation according to the Professionalism in Decision Making and Appeals (PIDMA) programme or any other anticipated change should be analysed with regard to their possible impact on decision-making practices.

For example, if accreditation is rolled out across the country and is expected to change the decision-making practices so that, for example, the level of fraud and error in the system will significantly differ from their current level, then only PIDMA-accredited decision makers should participate in phase B. Likewise, if the introduction of new claim forms is expected to have a consistent impact on decision-making practices in the country, only those decision makers who participated in CCM pilots should be asked to verify the coded claims. However, if the impact of the changes is not consistent across the country, the take-up measure, being an aggregate estimate, will be relatively robust to them.

Second, the sample should consist of claim packs on which the decisions were taken relatively recently. This is to reduce the possibility that over time less experienced decision makers gain experience and subsequently, despite being provided with the same information, arrive at a different decision from the one they took in the past. At the same time, some measures might need to be taken in order to avoid the situations where decision makers reach the same decisions simply because they remember the case rather than because the coded claim reflects the actual claim fully and accurately. However, it is possible that the recall itself, of the actual case, by decision makers, may serve as the proof of the quality of the coding system, because the recall suggests that the coded version enabled decision makers to reconstruct the actual case in their memories.

Third, the sample of claim packs should be chosen from various District Business Units/Centres in order to account for regional variations in decision-making practices.

Fourth, as will be shown below, this sample of coded claim packs is to be used in statistical modelling at later phases. This gives rise to a requirement relating to the size and the composition of this sample of claim packs. The sample should be representative of all claims in the country and sufficiently large to allow a robust estimate (see following chapters for detail). If the analysis of take-up is to be carried out across the subgroups of population (say, separately for men and women), the sample has to be greater, in order to ensure that the number of cases in each subgroup is sufficiently large. This means that the types of subgroup analysis should be determined at this phase in order to allow the sample of claim packs to contain a sufficient number of cases representing each subgroup.

To summarise, the tasks of phase B should include:

- selecting a new sample of claim packs that were decided upon over a recent period and applying the coding approach developed at phase A;
- removing additional evidence from the coded claims that contain it and asking the decision makers who decided on this sample of actual claims to reassess them (i.e. working from the coded data that excludes additional evidence);
- in those cases where the additional evidence was removed, reinstating it in the coded claims and ask decision makers to reassess the claims again (i.e. working from the coded data that includes additional evidence);
- establishing the importance of additional evidence by analysing the extent to which decision makers give the same or different answers when working from coded claims with evidence versus coded claims without it;
- refining the survey instrument by analysing the extent to which decision makers give the same or different answers when working from actual versus coded claims;
- developing a draft guide to a training programme for interviewers.

7.3.3 Phase C: Piloting the survey instrument on a sample of the potentially eligible, i.e. both claimants and non-claimants. Piloting the complementary study

Successful completion of phase B would mean that the information contained in the coded claim packs accurately reflects information available through the actual claim packs. The next task is to verify that the survey instrument is capable of collecting the data from respondents that is equivalent to the information they would provide if submitting actual claims. For example, the wording of questions has to ensure that they are not interpreted differently from how they would be interpreted if respondents were filling in the actual claim forms. The answers respondents offer to the questions should fit into the coding system developed on

the basis of claim packs. The screening method and the screener should ensure that all groups of the potentially eligible are represented among those selected into the survey.

The validation of the survey instrument is achieved through piloting it in the field. The representatives of the potentially eligible (i.e. claimants as well as non-claimants) should be identified, invited into the pilot and asked questions of the main questionnaire. Their answers should be recorded using the coding system. The screening method, the screening questionnaire, the main questionnaire and the coding system should be adjusted in accordance with the findings of the pilot.

A set of questions that are not relevant to the eligibility criteria but aim at identifying the triggers and barriers to claiming are also to be piloted at phase C. Although these are the aims of the complementary study, the value of the information on these issues to the design of the screener and the survey instrument is such that this part of the complementary study has to take place during phase C. A number of face-to-face qualitative interviews may follow the pilot if this was felt to be needed to improve the design of the screening method, the screener, the coding frames and a section of the questionnaire that aims to directly tackle barriers to claiming among eligible non-claimants. This task would also be part of the complementary study that takes place during the feasibility research. The inclusion of questions that are not directly related to DLA/AA (i.e. on people's needs other than those of mobility and care) in the pilot would help to ensure success in obtaining the disability-related information during any survey of disability among the general population.

During the pilot, the data collection methods also have to be tested. This task is especially important in the case of the benefit in question for such reasons as the sensitivity of some data (e.g. on children), the need for a proxy to provide information (e.g. in some cases of mental health condition patients) and the need for evidence. For example, a break may be needed if the claimant is unable to submit the required evidence and/or the interviewer has to approach a third party to collect it. In these cases, the consent to approach the third party should be obtained and this raises a need to deal with some ethical issues. The break may also be needed due to respondents' fatigue. This would have implications for the length of the questionnaire and therefore the interview. The findings of the pilot should inform the research about how best to collect the required information.

To summarise, the tasks that belong to phase C should include:

- using the screening method and the screening questionnaire developed at phase A, to select a sample of the potentially eligible (both claimants and non-claimants) into the pilot;
- using the survey instrument developed at phase A and verified at phase B, interview those potentially eligible covering the information used by decision makers to arrive at an award decision;

- asking additional questions on respondents' attitudes to claiming and reasons for not claiming (as part of the complementary study pilot);
- conducting a few face-to-face interviews with non-claimants;
- refine the screening method, the screener and the survey instrument accounting for both claimants' and non-claimants' responses;
- refining the data collection methods and the guide to a training programme for interviewers.

7.3.4 Phase D: Development of a statistical model using the data on claimants

Once the questionnaire and the coding system are developed and verified, statistical modelling may take place. The aim of the modelling is to establish associations between the award decisions and the characteristics of the disabled people. For example, the model may suggest that, other things held constant, disabled people without a limb have a 30 per cent higher chance of being awarded than disabled people who have all limbs. Once the associations between the award decisions and the characteristics of the disabled people are established (or, in other words, once the parameters of the model are identified), they can be applied to the characteristics of respondents in the survey in order to obtain the probability of being eligible for each respondent. The example given at the beginning of this chapter demonstrated how the outcome of the model, i.e. the probability of being eligible identified for each respondent, will be used to calculate the take-up rate.

It appears sensible to model care and mobility components separately because they cover different types of needs. A discrete choice statistical model assigning the probability of award (yes or no) to each respondent will be easiest to build. This model would show the chance of receiving the benefit (or a component in the case of DLA) that each respondent has, without providing a detail on the likely rate of award on the case. The resulting take-up estimate would also only distinguish between the type of benefits overall. A statistical model that distinguishes between the rates of award is more difficult to develop but, if successful, it would provide a take-up estimate for each award rate. At present, it is difficult to judge the feasibility of statistical modelling. However, it seems reasonable to start with a more complicated task, i.e. with modelling award rates, and if this proves impossible, to revert to a simpler task.

The sample of coded claim packs verified at phase B should be used in modelling. The size of this sample depends on the desired degree of precision of the estimate, the type of modelling and the type of subgroup analysis. Detailed requirements of the sample size are described in the following chapter. Looking ahead, it will show that 618 DLA coded claim packs and 568 AA coded claim packs should be made available for statistical modelling if the take-up rates are to be estimated for each DLA/AA award rate at 95 per cent confidence level and 0.05 confidence interval. These estimates will be applicable to the overall population of the country. If the

analysis is to be carried out across the subgroups of population (say, separately for men and women) or across the regions of Great Britain the sample size should be larger. The increase in the sample size is proportionate to the number of subgroups. This explains why the types of subgroup analysis should be defined at phase B, i.e. when the sample of coded claim packs is produced and verified.

To summarise, phase D tasks are as follows:

- take the coded claim packs that were verified at phase B;
- develop a statistical model predicting the outcomes of claims, using the coded data.

7.3.5 Phase E: Piloting of the survey and verification of the statistical model on a sample of the potentially eligible

The aim of this phase is to pilot a survey and to verify the statistical model. Since the statistical model is being developed using the information on claimants only, the model has to be verified by piloting it on a sample of the potentially eligible population, i.e. both claimants and non-claimants.

Similarly to phase C, a sample of pilot participants should be selected from the general population using the screening method and the screening questionnaire developed and validated at the previous phases. A similarity with phase B consists of the participation of decision makers in the verification of modelling results. However, at phase E, their involvement raises an ethical issue of receiving respondents' consent to being assessed by decision makers and not being told of the outcome of the assessment.

It is suggested, therefore, that only those who agree to participate in it under these conditions are selected into the pilot. A subsequent sample selection bias would not distort the results of modelling. As was explained, it is assumed that the propensity of the potentially eligible to claim is independent of the relationship between their mobility and care needs and the award outcomes. At the same time, the consent may not be very difficult to obtain if respondents know that they are asked to participate in a statistical exercise conducted by an independent research organisation.

Nevertheless, it is likely that despite all the effort to collect the data, not all the necessary information would be obtainable for each respondent of the pilot. If, for example, respondents are unable to provide evidence themselves or object to the interviewer approaching the third party, some information on the respondent will be missing. However, it is hoped that the model developed at previous phases would be equipped to deal with the problems associated with the missing data because it would be built on the basis of actual claim packs that may also lack evidence.

During the pilot, all the available information should be obtained from respondents and their responses should be coded. These coded responses would enter the

statistical model that was built at the previous phase. The model should produce the estimates of the probability of being eligible with regard to each respondent of the pilot. In order to verify the model, decision makers should also be asked to decide on the award on the basis of the coded responses. It may be practical to draw on the same decision makers who were asked to decide on the coded claims at the previous phase. Since the survey instrument has already been verified, the comparison of estimated probabilities of eligibility with decisions made by decision makers should help to verify the statistical model and adjust it accordingly.

Looking ahead into the main survey, it is possible that the number of benefit recipients derived from the survey will be lower than the administrative estimate. The problem of under-reporting the receipt of the benefit is not uncommon to many surveys. In the case of DLA/AA, claimants may report they are in receipt of one benefit but not another, or they may confuse different benefits (e.g. Incapacity Benefit (IB) and DLA). A survey-based approach to estimating take-up should envisage the possibility of using administrative data on the number of recipients or, better still, linking the survey and administrative data on respondents' DLA/AA award status. In the former case, it should be possible to derive the weights that would gross up the number of recipients into the survey to administrative estimates. The Family Resources Survey (FRS) researchers, for example, used the grossed number of recipients in their take-up equation. The latter case would produce the most accurate individual level data on the potentially eligible population.

To summarise, the tasks of phase E should include:

- using the screening method and the screening questionnaire to select into the pilot those potentially eligible who give their consent for being assessed by a decision maker and not being told of the assessment outcome;
- using the main questionnaire and the coding system, to interview the potentially eligible selected into the pilot;
- apply the parameters of the model developed at phase D to this sample and determining the probability of being eligible associated with each respondent;
- asking decision makers to decide on these cases;
- recalibrating the model;
- investigating approaches to the linking of the survey data to administrative estimates of recipients.

7.4 Summary

This chapter provides an explanation of how the take-up rate would be calculated and interpreted and recommends an approach to estimating take-up. The approach consists of five phases, each subsequent phase taking place only if the goals of the previous phase were achieved. The tasks of each phase are as follows:

- A** Development of a screening method, a screener and a survey instrument. Development of the complementary study:
- select a sample of claim packs that captures a variety of benefit types, award rates (including nil rate), types of needs, types of disabling conditions and impairments and types of evidence;
 - code the information contained in the claim packs, including additional evidence, so that it was presented in some more structured (preferably, numerically coded) way rather than the free text;
 - determine the associations between the award decisions and claimants' needs, their other characteristics relevant to the entitlement criteria and additional evidence;
 - identify instances where a proxy/third party is best placed to provide information required by the claim form;
 - design and develop a survey instrument;
 - develop a screening method and a screener;
 - identify possible reasons for not claiming and develop a questionnaire and coding frames relating to these reasons (as part of the complementary study development).
- B** Validation of the survey instrument using the data on claimants:
- select a new sample of claim packs that were decided upon over a recent period and apply the coding approach developed at phase A;
 - remove additional evidence from the coded claims that contain it and ask the decision makers who decided on this sample of actual claims to reassess them (i.e. working from the coded data that excludes additional evidence);
 - in those cases where the additional evidence was removed, reinstate it in the coded claims and ask decision makers to reassess the claims again (i.e. working from the coded data that includes additional evidence);
 - establish the importance of additional evidence by analysing the extent to which decision makers give the same or different answers when working from coded claims with evidence versus coded claims without it;
 - refine the survey instrument by analysing the extent to which decision makers give the same or different answers when working from actual versus coded claims;
 - develop a draft guide to a training programme for interviewers.
- C** Piloting the survey instrument on the potentially eligible, i.e. both claimants and non-claimants. Piloting the complementary study:
- use the screening method and the screening questionnaire developed at phase A, to select a sample of the potentially eligible (both claimants and non-claimants) into the pilot;

- use the survey instrument developed at phase A and verified at phase B, to interview those potentially eligible covering the information used by decision makers to arrive at an award decision;
- ask additional questions on respondents' attitudes to claiming and reasons for not claiming (as part of the complementary study pilot);
- conduct a few face-to-face interviews with non-claimants;
- refine the screening method, the screener and the survey instrument accounting for both claimants' and non-claimants' responses;
- refine the data collection methods and the guide to a training programme for interviewers.

D Development of a statistical model using the data on claimants:

- take the coded claim packs that were verified at phase B;
- develop a statistical model predicting the outcomes of claims, using the coded data.

E Piloting the survey and verification of the statistical model on the potentially eligible, i.e. both claimants and non-claimants:

- use the screening method and the screening questionnaire to select into the pilot those potentially eligible who give their consent for being assessed by a decision maker and not being told of the assessment outcome;
- use the main questionnaire and the coding system to interview the potentially eligible selected into the pilot;
- apply the parameters of the model developed at phase D to this sample and determine the probability of being eligible associated with each respondent;
- ask decision makers to decide on these cases;
- recalibrate the model;
- investigate approaches to the linking of the survey data to administrative estimates of recipients.

The successful completion of all five phases will allow a positive conclusion on the feasibility of estimating the DLA/AA take-up rate by the three-stage project. Given that this study represents the first stage of the project, the five phases of the recommended approach are distributed across the stages of the project as follows: phases A to C belong to its second stage and phases D and E belong to its third stage. Therefore, the main survey only takes place if all three stages of the project suggest that the task is feasible. If stages two or three prove not to be feasible, only the complementary study can be conducted. (The main survey and the complementary study are two separate projects.) The following chapter describes advantages of, and challenges to, the recommended approach.

8 Advantages and challenges of the approach

8.1 Introduction

The recommended approach to the estimation of Disability Living Allowance (DLA)/ Attendance Allowance (AA) take-up is multi-phase, each phase being complex and consisting of a number of tasks. Such a breakdown is explained by the features of benefits, complexities of (non)-claiming and decision making, the sensitive nature of information required for estimating and the practical difficulties of collecting it. This chapter explains the advantages of the recommended approach in how it deals with these issues and warns against potential difficulties that would have to be dealt with in the course of its implementation.

8.2 Advantages

The probabilistic measure of take-up that is to be estimated using the recommended approach accounts for the complexities of claiming and decision-making processes. It reflects existing decision-making practices by showing how many people would receive the benefit if they applied, given the level of uncertainty, judgement, fraud, error and other characteristics of the decision making process at the time of estimation.

The consistency with current practices among decision makers is achieved by employing decision makers when verifying the survey instrument and the statistical model, and by ensuring that the degree of their experience reflects that of decision makers in the country. The participation of decision makers in the verification of the survey instrument allows the coded claims to reflect information from actual claims as closely as possible. It also enables the importance of medical or other evidence to the award decisions to be established. At phase E, when the statistical

model is verified, their decisions help to recalibrate the model taking into account the data on non-claimants.

The information on non-claimants is also incorporated into the screener and the survey instrument. The participation of non-claimants in their validation at phase C allows for the establishment of whether consistent differences between claimants and non-claimants exist with regard to their needs and/or the ways they present these needs. Accounting for these differences enables the sample of respondents in the main survey to be representative of all the potentially eligible and the information relevant to the DLA/AA criteria to be obtained with regard to all respondents, including those who would choose not to claim.

This ensures that the take-up estimate is not distorted due to the refusal to apply for the benefit by some groups of the potentially eligible population. The deployment of statistical modelling (rather than, for example, decision makers) in order to assess the eligibility for DLA/AA among the survey respondents provides not only an accurate take-up estimate but also an estimation of the probability of being eligible with regard to each respondent. Since the probability of being eligible is different from a clear yes or no answer given by a decision maker on the case, the approach reduces the ethical problem of acting on the decision maker's decision, which might have been different had another decision maker considered the case.

The data on the probability of being eligible will allow the potential rates of award among the non-claiming eligible population to be estimated. These rates of award may serve as a proxy indicator of the degree of a person's severity of care and/or mobility needs. Consequently, even if changes to decision making policies and/or practices do not allow re-estimation of the take-up rate, at some point in time in the future, the repeat of the survey may generate data that shed light on the dynamic of changes in care and/or mobility needs of the population. The probabilistic approach to eligibility will also provide an indication of circumstances when awards may be granted in error. This may be achieved through the analysis of instances where respondents report receiving an award despite having a low probability of being eligible and, vice versa, where respondents do not report receiving an award despite having a high probability of being eligible.

Approaching the estimation by means of a survey allows the presentation of information used in the decision making process in a more structured form than free text. This may be used in the future if a decision is taken to modify the claim form. Another implication of using a survey is the availability of additional information on the potentially eligible population, such as the data on their other needs, their demographic profile, social location and attitudes to claiming. The identification of eligible non-claimants will also provide a first indication of triggers and barriers to claiming among them. Additionally, if the survey questionnaire is not excessively long, the direct questions about awareness of benefits and attitudes may be asked in order to better understand the reasons for non-take-up. In the future, this information should help develop an approach to in-depth qualitative analysis of

non-claimants' experiences. The scope and questions for such qualitative research may also be shaped by the results obtained during the survey.

The approach deals with ethical concerns raised by the involvement of decision makers in the assessment of information provided by the pilot participants at phase E. The issues of consent and of raising hopes unnecessarily are being addressed by selecting into the pilot only those who agree to being assessed for their eligibility and not being told of the outcome. With respect to the first issue, it is assumed that those who agree to be assessed at phase E may differ in their propensity to claim but not in how their needs are related to the potential award decisions. Therefore, although the sample of the pilot will not be representative of the potentially eligible population with regard to the propensity to claim, the bias should not affect the relations of interest. With respect to the second issue, it should be explained to the potential participants of the pilot that the outcomes of the pilot will not be a clear yes or no assessment of DLA/AA eligibility, of which anyone could be informed.

The inclusion of some elements of the complementary study into the main feasibility research also represents an advantage of this approach. The two projects are interconnected both methodologically and substantively. The development of the approach to estimation requires the findings of the complementary study on non-claimants, while the complementary study employs the screening method, the screener and the survey instrument that are developed, verified and piloted within the main feasibility research. Such a synergy makes the approach not only methodologically sound but also cost-effective. Even greater efficiency would be achieved if the main survey was used to collect the data for the complementary study.

The multi-phase nature of the approach also has implications for saving public resources. It ensures that all elements required for the estimation of take-up are verified and piloted prior to the conduct of the survey. This provides an opportunity to assess the feasibility of the approach before it is applied and stop at any phase that presents a challenge impossible to address. In the latter case, the research will be able to provide a clear exposition of the reasons why the recommended approach to the estimation of take-up is not feasible.

8.3 Challenges

The necessity of implementing the approach in phases is explained by the challenges it presents. Ultimately, the feasibility of the approach depends on the ability of research to meet these challenges. They are to be explored at the subsequent stages of research.

The establishment of associations between different pieces of information, including evidence, used in the decision making process is the most immediate challenge. Developing a system of numeric codes that represents these relationships is another task of phase A, the feasibility of which should be tested. The work conducted by

the Department for Work and Pensions (DWP)/Disability and Carers Service (DCS) as part of the Customer Case Management (CCM) pilot (including the three-day data collection exercise) may help the research to meet this challenge. The need for a proxy – instances where the potentially eligible may not be in a position to accurately assess their needs – and their relations to the potentially eligible should also be analysed and accounted for in the development of the survey instrument.

The development of a screening method and a screener that allow for representation of all groups of the potentially eligible, regardless of their social attributes, demographic profile or geographical location, is another challenge that should be addressed at phase A. A thorough analysis of screening methods and screening questionnaires used by the other health and disability related surveys should inform this task.

The employment of decision makers for verification of the survey instrument gives rise to an issue of recall among decision makers because they are asked to decide on the coded claims, having recently decided on their real-life versions. On the one hand, situations where decision makers arrive at the same decisions due to their recall of actual cases rather than because the coded claims reflect the information contained in the actual claims fully and accurately should be avoided. On the other hand, the recall itself may serve as the proof of the quality of the coding system because it suggests that the coded version enabled decision makers to reconstruct the actual case in their memories. At phase B, the research examines the ways of dealing with the recall problem.

The ability to determine the importance of medical or other evidence is also to be tested at phase B. This may result in recommendations about the training programme that would enable interviewers to collect as much information as possible on the spot. Another challenge of phase B is to predict the types of subgroup analyses that would need to be conducted following the main survey. Since the set of claim packs to be used for modelling purposes is coded at phase B, the decision on the types of subgroup analyses should be taken at this phase.

A number of issues relating to the data collection methods will have to be addressed at phase C. The first challenge is to ensure an acceptable response rate to the survey. Existing methods for maximising participation of the disabled people in the surveys have to be tested at this phase. The second task is to collect all the required information during the interviews. This is because not all the required evidence may be available at once during an interview: interviewees may ask for a break to obtain the required pieces of evidence or they may refuse to provide the required evidence due to its sensitivity or they may refuse permission to approach the third party for evidence. At phase C research has to find ways of collecting as much information as possible on the spot and without breaks, especially because interviewees may find (long lasting) interviews tiring. It is a challenge to control the length of the questionnaire and therefore, of the interview with respondents whose tolerance may be below average. Phase C has to assess whether and

how well the employment of trained interviewers can meet the data collection challenges.

At phases D and E, the issues to be addressed are related to statistical modelling and piloting of the survey. At the model development phase, an appropriate econometric technique, functional form and sample size have to be chosen in order to arrive at a robust take-up estimate. The types of subgroup analysis and modelling outcomes are also to be tested at this phase. A problem of underestimating the take-up due to under-reporting the receipt of the benefit will also have to be dealt with. Administrative data on the number of recipients may need to be used for this purpose. A potential solution may lie in designing the weights and using them to gross up the survey estimates to the administrative data on benefit recipients. At phase E, the survey piloting phase, an ethical issue of obtaining respondents' consent to being assessed by decision makers will have to be resolved.

The participation of decision makers at phases B and E and the employment of trained interviewers at phases C and E require resources additional to that of the research team. In order to increase the participation rate, financial incentives to respondents may have to be provided and this would also increase the costs associated with the approach.

Finally, although the take-up rate is an aggregate estimate and therefore, is relatively robust to fluctuations in decision-making practices across the country, it is sensitive to changes that will impact on these practices in some consistent way. This poses a challenge of anticipating such changes and incorporating them into the development of the approach. For this reason, if it is anticipated that the implementation of the Professionalism in Decision Making and Appeals (PIDMA) programme, or the move to CCM claim forms, or the revision of the Disability Handbook, or any other change to the decision making process will impact on decision-making practices in some consistent way, these changes should be accounted for when developing an approach to estimating take-up.

8.4 Summary

This chapter presents advantages of and challenges to the recommended approach. The advantages of this approach over the other methods of estimating take-up are:

- a probabilistic measure of take-up that makes the estimate consistent with existing decision-making practices;
- provision of an accurate take-up estimate, including the potential rates of award among the non-claiming eligible population;
- ability to indicate circumstances when awards may be granted in error;
- presentation of information used in the decision making process in a more structured form than free text;

- ability to collect the data on the sample of respondents that is representative of all the potentially eligible, including those who would choose not to claim;
- identification of consistent differences between claimants and non-claimants with regard to their needs and/or the ways they present these needs;
- ability to provide a first indication of the characteristics of eligible non-claimants and triggers and barriers to claiming among them;
- availability of additional information on the potentially eligible population that may be relevant to any analysis of disability in the country;
- ability to exploit the synergy between the complementary study and the main feasibility research and to do it in a cost effective way;
- integration of the complementary study into the main survey allows for exploiting the synergy to the full extent;
- opportunity to assess the feasibility of the approach to meet its challenges and deliver a robust take-up estimate before it is applied and thus, save public resource;
- ability to shed light on the dynamics of changes in care and/or mobility needs of the population, if the survey is repeated.

The adoption of the approach depends on the ability of research and policy makers to meet its challenges that include:

- development of a screening method and a screener that ensure a representative sample of the potentially eligible;
- identification of methods for maximising the response rate to the screener and to the survey among disabled people;
- establishment of associations between different pieces of information used in decision making and development of a survey instrument;
- ability to control the length of the questionnaire and, therefore, of the interview;
- establishment of the importance of medical or other evidence to the award decisions;
- an issue of recall where decision makers arrive at the same decisions due to their recall of actual cases rather than due to an accurate reflection of actual claims by their coded versions;
- development of the data collection methods that deal with circumstances where the potentially eligible people are not in a position, or are unwilling, to accurately assess their needs and/or present the required evidence and/or give permission to approach a third party for evidence;
- development of a training programme that would enable interviewers to collect as much information as possible on the spot;

- anticipation of the types of subgroup analyses that would need to be conducted following the main survey;
- development and application of an appropriate econometric technique when modelling the take-up rate;
- exploration of approaches to linking the survey estimates to administrative data on recipients;
- anticipation of changes that will impact on these practices in some consistent way;
- ethical issues, especially those relating to getting consent to approach the third party and to collecting sensitive data;
- availability of resources to employ decision makers at phases B and E; to train interviewers; to provide incentives to respondents; and to obtain a relatively large sample of claim packs, especially if analysis of subgroups is desirable.

The next chapter presents some initial calculations relating to the required sample size.

9 Requirements of sample and sub-samples

This chapter outlines the requirements of a sample and sub-sample sizes, to be used in verification of the survey instrument at phase B and statistical modelling at phase D of the recommended approach. It starts with a description of the parameters that determine the sample size in general and suggests an option that would enable the statistical modelling of take-up rates, distinguishing between the award rates. It then explains how a division of the sample into subgroups will influence these sample size estimates, thus allowing the Department for Work and Pensions (DWP) to make an informed choice about the types of subgroup analyses.

9.1 Sample size

A survey is a two-step process with an initial short screening survey followed by a more detailed survey. The screening survey would be applied to a sample of the general population and will be designed to exclude people who are clearly not eligible for Disability Living Allowance (DLA)/Attendance Allowance (AA). The resulting sample is a sample of the potentially eligible population. The more detailed questionnaire will seek to provide a robust identification of (probable) eligibility for people selected into the more detailed, main take-up survey.

The required sample sizes at each step of the survey can be calculated in order to estimate DLA/AA take-up with a chosen degree of confidence. The formula to calculate such a sample size is as follows:

$$N = \frac{t^2 * p * (1 - p)}{c^2}, \text{ where:}$$

- N – is the required sample size;
- t – is the t-value for a given confidence level (in most research a 95 per cent confidence level is used and this convention is followed here, so the value of t throughout this discussion is 1.96);
- p – is the proportion of people with the required characteristic (in this case it is the proportion of people who go from the screening survey into the main survey and the proportion of people in the main survey eligible for DLA/AA);
- c – is the confidence interval, the range within which the estimate of p should fall with 95 per cent confidence.

The formula is based on a range of assumptions including: that a random sampling methodology is used; and a binary choice model is used to estimate take-up.

A 95 per cent confidence level means that if 100 different population samples of a given size were surveyed, the resultant estimates of the proportion of people eligible for DLA/AA would fall with a chosen confidence interval in 95 out of the 100 samples. The confidence interval selects the desired range within which the estimates from a single survey should fall with 95 per cent confidence. Thus, the required sample size would be bigger if the confidence level is higher and/or if the confidence interval is smaller.

From the above one, can choose the confidence interval and proportions to produce the required sample size for each survey step.

Thinking about the second step survey first; Table 9.1 gives the required sample for different values of p and c . The required sample size is highest when p is 0.5, so in order to make conservative estimates of the required sample size, the focus is on these numbers. For a confidence interval of 0.1 one would need a sample size of 96. This means that with this sample size, if one produced an estimate of the proportion of people eligible for DLA/AA of 0.5, they would be 95 per cent sure that the true proportion in the population that was eligible for DLA/AA would fall between 0.4 and 0.6.

Moving along the rows of the table shows that increasing the precision of that estimate (or reducing the confidence interval) requires a bigger sample. Thus, with a sample of 385 and an estimate of 0.5 one would be 95 per cent sure that the true proportion in the population that was eligible for DLA/AA would fall between 0.45 and 0.55 (confidence interval 0.05). Reducing the confidence interval further to 0.025 increases the required sample size to 1,537.

Table 9.1 Required sample size by confidence interval and estimated proportion eligible for DLA/AA: binary outcome

	Confidence interval (c) = 0.10	Confidence interval (c) = 0.05	Confidence interval (c) = 0.025
Proportion eligible for DLA/AA (p)			
0.5	96	385	1,537
0.4	92	369	1,475
0.3	81	323	1,291
0.2	64	246	983

Similar estimates can be produced for the screening survey, but here the required sample size relies much more heavily on the proportion that would go on to the second survey step. If half of the sample went to the second survey step then the numbers reported in Table 9.1 would need to be doubled.

In reality, the purpose of the screening survey is to filter out as much of the sample as possible, so one would expect the proportion of people who reach the second survey step to be much lower than 0.5. Piloting the survey at phase C and then at phase E of the recommended approach will give a much better idea of this proportion. However, for an indication of the required sample size, if the screening survey filtered out 80 per cent of the sample, one would need 1,920 people to produce the required sample of 385 people at the second survey step (assuming a 95 per cent confidence level and a 0.05 confidence interval for the main survey). Estimates of the sample size required at the second survey step relate to the number of coded claim packs that should be available to analysis at phase B and phase D.

All of the above discussion is concerned with a single estimate of DLA/AA take-up for the whole population. As discussed above DLA/AA is not so straightforward. Since DLA and AA benefits have (between them) two components and may be awarded at different rates, a simple yes or no outcome will not capture the diversity of possible award decisions. If estimates for different rates of award are required, a sample of 385 people is not large enough. This sample size would only suffice if the outcome of interest was the probability of receiving a benefit, regardless of the type, rate or component.

If each of the mobility and care components is modelled separately and within each component a distinction across the rates is made, the outcomes to be modelled are:

- DLA Mobility component with three award outcomes: High/Low/Nil;
- DLA Care component with four award outcomes: High/Middle/Low/Nil;
- AA Care award with three award outcomes: High/Low/Nil.

Detailed calculations of sample sizes for non-binary categorical data are provided in Bromaghin (1993). Table 9.2 presents the results relating to the sample sizes necessary for modelling the above outcomes assuming 95 per cent confidence level and a 0.05 confidence interval. They suggest that 618 DLA claim packs and 568 AA claim packs should be coded and verified at phase B in order to obtain a robust estimate of the take-up of these benefits at different award rates.

Table 9.2 Required sample size for non-binary categorical data at $p=0.5$, $c=0.05$, $t=0.95$

Benefit type	Sample size
DLA Mobility component	568 DLA claim packs
DLA Care component	618 DLA claim packs
AA Care	568 AA claim packs

The assumption of random sampling methodology on which the calculations presented in this section are based requires a sample of claim packs available for the analysis to be nationally representative. If the decision to estimate take-up for each award rate is taken, this requirement means that the claim packs with various rates of award (including nil rate), benefit types, etc. are present in the sample in the proportions that are found in the claimants' population. These proportions may be identified via the DLA/AA caseload statistics.

9.2 Subgroup analysis

The sample sizes provided in the previous section would not be sufficient if within these categories of respondents further subgroup estimates were needed. These will require a larger sample to produce estimates of the same precision. Any subgroup analysis will require an increase in the sample size x -fold where x is the number of sub-groups along one dimension (such as age, gender and region). For example, if separate analyses of DLA outcomes are required for men and women, the sample size would increase two-fold, bringing the total to 1,236 DLA claim packs, and consist of 618 DLA claims made by women and 618 DLA claims made by men.

If the subgroup division along a combination of dimensions is required (e.g. by gender and by age), the calculation of sample sizes becomes more complicated because it will have to account for proportions of population in each subgroup (e.g. younger men, older men, younger women and older women).

Subgroup analyses will differ from the analysis of the overall population in the focus of examination and hence, results. The factors (such as gender, region, and age) that potentially determine the division into subgroups are likely to be present in the model for the population as a whole. This would allow for conclusions about the associations between the probability of an award and these factors. In the case of gender, for example, the overall model would show how the association

between the award and gender varies between men and women, all other things (e.g. age) held equal. The interpretation of results would be that at the same age level, men are more (or less) likely than women to be awarded the benefit. Modelling two subgroups (men and women) separately allows the relationship between the award and other factors (e.g. age) to vary between men and women. For example, the subgroup analysis by gender may show that reaching a certain age band is likely to be associated with an award among women but not among men.

9.3 Summary

This chapter demonstrates that the choice of the outcomes of modelling and of the types of subgroup analysis should be made at phase B of the feasibility research in order to provide a sufficient number of cases for statistical modelling at phase D. The indications of the required sample sizes are given with regard to modelling the receipt of benefit overall and with regard to modelling the receipt of various award rates, both for the overall population of Great Britain. It is then explained that the increase in the respective sample size will be x -fold, where x is the number of subgroups along one dimension. In order to provide an estimate of sample sizes required for the subgroup analysis, the types of subgroups have to be decided upon. This chapter should help to inform such a decision.

10 Conclusions

10.1 Introduction

It is believed that not all the disabled people whose needs qualify them for Disability Living Allowance (DLA) and Attendance Allowance (AA) are receiving these benefits. But it is not known how many people have such needs. An attempt to solve the problem in the past suggested that the task may not be feasible. This study is undertaken as part of the wider research project into the feasibility of estimating the take-up rate of DLA/AA.

This report presents the findings relating to the first stage of the potentially three-stage research project, which aims to produce a detailed proposal on the estimation of take-up. A complementary study to this research is also envisaged, its focus being on non-claimants and their reasons for not claiming. The aim of the present study is to recommend an approach to estimation that can be refined and tested at the subsequent stages of the research. This is a methodological piece of research that does not question the current level of fraud and error. Nor does it aim to suggest whether or how DLA/AA policies and/or practices should change.

The recommended approach to estimating take-up should account for the complexities of claiming and decision-making processes, the usefulness of existing data in estimating the take-up and a stock of existing experience and knowledge relating to the subject of research. In order to achieve this, the study employs the following methods:

- a desk-based review of documentation relating to claiming;
- interviews with key stakeholders involving decision makers, key personnel in the Department for Work and Pensions (DWP), medical professionals, social workers, welfare rights organisations and data holders;
- investigation of existing data relevant to claiming and decision-making processes;
- analysis of potential approaches to estimating take-up of DLA/AA suggested by previous research and disability-related surveys.

The outputs presented in this study include:

- a description of the process from claiming to decision making and analysis of its complexities in terms of implications for estimating take-up;
- an assessment of the availability of existing data and its usefulness in representing the process and allowing the estimation of the take-up rate;
- an examination of potential approaches to estimating take-up;
- recommendation of an approach to estimating take-up;
- a description of requirements of a sample and sub-samples;
- recommendations regarding the next steps of feasibility estimation.

10.2 Findings

The interviews with decision makers and the analysis of claiming and decision-making processes lead to the development of a probabilistic measure of the take-up rate. By incorporating the degree of uncertainty, judgement, fraud and error existing in the system it reflects existing practices in decision making. It is a point-in-time measure and it defines the take-up rate as a ratio of the number of existing recipients to the probable number of those who would receive the benefit if they applied.

This definition implies that the estimated take-up rate is only valid under the rules and practices that were taken into account when developing an approach to its estimation. Thus it is sensitive to changes that have a consistent impact on decision-making practices, unless these changes are incorporated into the estimation at its development stage. This definition of take-up also accepts that the truly eligible population may be impossible to define and refers to the probably eligible population whenever the term eligibility is used.

In order to assess the probability of being eligible, first of all the population of the potentially eligible should be identified. This is the population of disabled people with at least some care and/or mobility needs, regardless of whether they are claiming or not. Second, the data on the members of this population should match the data that decision makers use when arriving at award decisions. The list of the necessary data is compiled in order to enable the analysis of existing data in terms of its ability to provide such information. This list can also be used as guidance if a decision is taken to collect the data on the potentially eligible by administrative means.

The accurate identification of the potentially eligible population requires understanding of the possible reasons for non-claiming by some of its subgroups. Information and views provided by interviews with DWP staff, a number of welfare rights organisations and social workers suggest eight main models of non-claiming pointing to significant barriers that stand in the way of claiming. They should

be accounted for at the subsequent stages of the feasibility research when the approach to the estimation of take-up is to be tested and refined.

An analysis of barriers to claiming is also the subject of the complementary study. However, the first contact with non-claimants is likely to take place within the feasibility research as it progresses to developing a method of identifying the potentially eligible. This link between the complementary study and the feasibility research allows the complementary study to be developed and tested as part of the development and testing of the approach to estimating take-up. In turn, the preliminary findings of the complementary study can feed back into the feasibility research and help in the development of methods of identifying the potentially eligible population.

The analysis of the existing data in terms of their usefulness in assessing the eligibility of the potentially eligible population and estimating the take-up rate, suggests that neither administrative data nor existing social surveys containing information on the health status of the population, are able to provide all the information required for the estimation. The administrative data, however, provide information on the number of claimants, the number of recipients and their award rates. Additionally, the data collected during the three-day data collection exercise and the data collected during the Customer Case Management (CCM) pilots may be used when developing a survey instrument. The analysis of currently on-going social surveys that contain information on the health status of the population suggests that their methods of selecting respondents into the surveys and their questionnaires and systems of coding respondents' answers should be examined at subsequent stages of the feasibility research if a survey approach to estimating take-up is adopted.

The lack of necessary data among existing sources implies that the information required for identifying eligible non-claimants and estimating the take-up rate has to be collected by means of a dedicated survey. In order to inform this task, the study examines the disability-related surveys conducted in the past and the approaches to estimating take-up that were put forward recently.

The analysis suggests that a repeat of the previous disability-related surveys would not produce a required take-up estimate, although certain elements of these surveys should be examined in order to inform the feasibility research at its subsequent stages. The experience accumulated during the Family Resources Survey (FRS) Disability Follow-up Survey, including the ways it dealt with under-reporting, would be especially valuable to this research.

The two more recent research proposals on the survey-based approach to estimating take-up illuminate the challenges of the task. The first, a claims-based approach, is impaired by the difficulty of identifying the potentially eligible population and the inability of collecting any additional data on disability nationally. The second, a modelling-based approach, points to the danger of obtaining spurious results if estimation does not take place in phases so that the progress to each subsequent phase depends on the achievements of the preceding phase.

10.3 The recommended approach

The recommended approach consists of five phases allowing each subsequent phase to take place once the results of the previous phase are tested and verified. This saves public resources by ensuring that the approach is able to meet the challenges of estimation and deliver a robust take-up estimate before it is applied. The phases are as follows:

- A** Development of a screening method and a screener that allow all the potentially eligible to be represented in the survey. Development of a survey instrument that allows respondents' answers to a survey questionnaire to replicate the claim form information as closely as possible. Development of the complementary study.
- B** Validation of the survey instrument using the data on claimants.
- C** Piloting the survey instrument on a sample of the potentially eligible, i.e. both claimants and non-claimants. Piloting the complementary study.
- D** Development of a statistical model using the data on claimants.
- E** Piloting the survey and verification of the statistical model on a sample of the potentially eligible, i.e. both claimants and non-claimants.

The successful completion of all five phases will lead to a positive conclusion on the feasibility of estimating the DLVAA take-up rate by the three-stage project. In this case, the main survey can take place, as separate from the feasibility research project. The five phases of the recommended approach are distributed across the remaining stages of the feasibility project as follows: phases A to C belong to its second stage and phases D and E belong to its third stage.

Since the complementary study is developed and piloted in the course of the feasibility project, it may take place after stage two regardless of its conclusion on the feasibility of estimating take-up. It may even involve the design and conduct of a survey if this is judged to be reasonable by the outcomes of stage two. Quantitative analysis will provide an overall picture of the non-claiming eligible population and enable the analysis of characteristics of the eligible non-claimants and their reasons for not claiming. An understanding of these issues will inform policy makers trying to tackle the barriers to claiming and to increase the take-up rate. The complementary study may additionally employ more focused qualitative analysis of certain case studies. The scope of case study analyses will also be informed by the results of the stage two research and, if a survey is feasible, also by the outcomes of the quantitative analysis of the survey data. If the main take-up survey takes place, the complementary study may further be integrated into it. Remaining separate from the main survey project, it may use the take-up survey as a vehicle for collecting the data it requires. This is possible because the screening method, the screener and the survey instrument to be used in the complementary study are to be developed and verified during stage two of the feasibility research.

This synergy and cost effectiveness are not the only advantages of the recommended approach. The others include:

- consistency of the take-up measure with existing decision-making practices;
- provision of accurate estimates of the take-up rates, including the potential rates of award among the non-claiming eligible population;
- indication of circumstances when awards may be granted in error;
- presentation of information used in the decision making process in a more structured form than free text;
- ability to collect the data on a sample of respondents that is representative of all the potentially eligible, including those who would choose not to claim;
- identification of consistent differences between claimants and non-claimants with regard to their needs and/or the ways they present these needs;
- ability to provide a first indication of the characteristics of eligible non-claimants and triggers and barriers to claiming among them;
- availability of additional information on the potentially eligible population that may be relevant to any analysis of disability in the country;
- ability to shed light on the dynamics of changes in care and mobility needs of the population, if the survey is repeated.

However, the challenges of the task are also numerous and the adoption of the approach depends on its ability to meet them. The challenges are related to the tasks of each phase and Table 10.1 demonstrates how the phases of the approach are related to the stages of the feasibility research and which challenges are to be met at each stage.

Table 10.1 Next steps of the research on feasibility of take-up estimate and their challenges

Stage of the feasibility project	Phase of the recommended approach	Challenge
Stage two	<p>A: Development of a screening method, a screener and a survey instrument, including the coding system. Development of the complementary study</p> <p>B: Validation of the survey instrument, including the coding system, using the data on claimants</p> <p>C: Piloting the survey instrument on the potentially eligible. Piloting the complementary study</p>	<ul style="list-style-type: none"> • Establishing relationships between the award decisions and types of information required for reaching them, including the variety of evidence • Identifying the need for, and the type of, proxy • Establishing the importance of medical and other evidence • Developing a survey instrument • Developing a screener • Developing a screening method • Identifying methods for maximising the response rate to the screener and to the survey • Developing the data collection methods • Minimising the problem of recall among decision makers • Identifying the types of subgroup analysis • Developing a guide to the training programme for interviewers • Accounting for possible changes in decision-making practices in the future • Ethical issues of getting consent to approach the third party and collect sensitive data • Costs of providing a sample of claim packs • Costs of involving trained interviewers • Costs of involving decision makers • Costs of providing incentives to the pilot respondents

Continued

Table 10.1 Continued

Stage of the feasibility project	Phase of the recommended approach	Challenge
Stage three	D: Development of a statistical model, using the data on claimants E: Piloting the survey and verification of the statistical model on the potentially eligible	<ul style="list-style-type: none"> • Choosing an appropriate econometric technique, functional form and sample size • Ensuring robustness of modelling outcomes • Linking the survey estimates to administrative data on benefit recipients • Ethical issues of getting consent to approach the third party, collect sensitive data and being assessed by decision makers • Costs of providing incentives to the pilot respondents • Costs of involving trained interviewers • Costs of involving decision makers

10.4 Next steps

The next stage, stage two, of the project aims to test and refine the recommended approach by suggesting solutions to the challenges associated with this stage. This is to be achieved through the successful completion of tasks that belong to phases A to C of the recommended approach. These tasks should ensure that the survey instrument when used during the survey is able to deliver information that respondents would have submitted if applying for the benefit. At phase A the screening method, the screener and the survey instrument are to be developed, at phase B the survey instrument should be verified and at phase C piloted. Another task of stage two includes the development and piloting of the complementary study. It is developed at phase A and piloted at phase C.

In order to reflect the decision-making practices existing at the time of the survey, the main questionnaire and the coding system should be developed taking into account the introduction of CCM claim forms in the country. Professionalism in Decision Making and Appeals (PIDMA)-accreditation of decision makers should also be accounted for if the accreditation is anticipated to change decision-making practices in the country in some consistent way. In this case only those decision makers who are accredited by PIDMA and/or who participated in CCM pilots should be employed at phase B, when the instrument is verified.

In general terms, the following tasks should be completed during phases A to C.

Phase A – Development of a screening method, a screener and a survey instrument.

Development of the complementary study:

- select a sample of CCM-based claim packs, including those disallowed, and develop a system of numeric codes that represents the information contained in the claim packs, including the evidence and award decision;
- design and develop a survey instrument accounting for the needs of the complementary study;
- identify instances where a proxy/third party is best placed to provide information;
- develop a screening method and a screening questionnaire.

Phase B – Verification of the survey instrument:

- select a new representative sample of CCM-based claim packs that were decided upon over a recent period and apply the coding approach developed at phase A;
- ask the decision makers who decided on the sample of actual claims to reassess them, working from the coded data: the first time without information on evidence and (where it is available) the second time with it;
- refine the survey instrument by analysing the extent to which decision makers give the same or different answers when working from actual versus coded claims and when working from coded claims with evidence versus those without evidence;
- develop a draft guide to a training programme for interviewers.

Phase C – Piloting the survey instrument and piloting the complementary study:

- select a sample of the potentially eligible (both claimants and non-claimants) into the pilot;
- interview them, asking additional questions relevant to the complementary study;
- conduct a few face-to-face interviews with non-claimants;
- refine the screening method, the screener and the survey instrument;
- refine the data collection methods and the guide to a training programme for interviewers.

The tasks of phases A to C are the tasks that this study puts forward for the second stage of research assessing the feasibility of estimating the take-up rate of DLA/AA.

Appendix A

DLA and AA: Rules and eligibility criteria

Disability Living Allowance and Attendance Allowance rules

Disability Living Allowance

Disability Living Allowance (DLA) is payable to people under 65 years of age (and also to people aged 65 and over who claimed and qualified before they reached age 65 and continue to satisfy the entitlement conditions) who are so severely disabled that they require personal care, have walking difficulties or both. DLA has two components:

- a care component for people who require personal care;
- a mobility component for people who have walking difficulties.

The care component is paid at one of three rates depending on the extent of the need for personal care. In addition, people who do not have personal care needs, but are so severely disabled that they cannot prepare a cooked main meal for themselves, can qualify for the lowest rate care component.

The mobility component is paid at one of two rates; a higher rate for people who are physically unable or virtually unable, to walk; a lower rate for people who can walk but are so severely disabled that they require guidance or supervision from another person when walking out of doors on unfamiliar routes.

To qualify for DLA, a person must have satisfied the entitlement conditions for at least three months (the qualifying period) and be likely to continue to satisfy them for a least a further six months (the prospective test).

Attendance Allowance

Attendance Allowance (AA) is payable to people aged 65 and over who are so severely disabled that they require personal care. AA is paid at one of two rates depending on the extent of the need for personal care.

To qualify for AA, a person must have satisfied the entitlement conditions for at least six months (the qualifying period). There is no prospective test.

Special Rules

People with a progressive disease from which death can reasonably be expected within six months can make a claim for DLA or AA under the Special Rules. A claim under special rules has to be made expressly under those rules, i.e. the person making the claim is asked to make this clear on the claim form.

People who qualify under the Special Rules will get the highest rate of the care component of DLA or the higher rate of AA without having to meet the usual qualifying period requirement (three months for DLA and six months for AA) or having to show that they have care needs (as required under the normal rules). Claims are dealt with very quickly – within five or six days (to a target of eight days, as opposed to the target of 39 days for normal DLA claims and 19 days for AA claims).

A person's GP (or consultant) can fill in a DS1500 form which gives the decision maker extra information about the person's diagnosis and treatment, although the GP is not asked to say how long they think the person has to live. Doctors who provide medical services for the Disability and Carers Service (DCS) are contracted to check each Special Rules claim within 24 hours in order to give the decision maker advice about the likely life expectancy of the customer.

In most cases the claimant will know that they have a short time to live, and will make the claim themselves. But a third party can make a claim on behalf of someone else and without their knowledge. The DCS will deal with the third party as far as possible. This means that people who have not been told that they only have a short time to live can still be paid DLA/AA on the grounds of Special Rules.

Entitlement conditions

The claimant must be so severely disabled physically or mentally that they require:

During the day

- 1** Frequent attention throughout the day in connection with bodily functions.
- 2** Continual supervision throughout the day in order to avoid substantial danger to themselves or others.

At night

- 3 Prolonged or repeated attention in connection with their bodily function.
- 4 In order to avoid substantial danger to themselves or others they require another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over them.

Part-time care

- 5 In connection with their bodily functions attention from another person for a significant portion of the day (whether during a single period or a number of periods).
- 6 To prepare a cooked meal for themselves if they have the ingredients.

There are two rates DLA mobility component:

- High: To qualify for the higher rate mobility component, the main conditions are that the claimant must be unable or virtually unable to walk.
- Low: To qualify for the lower rate mobility component it doesn't matter that the claimant is able to walk but they must be *'so severely disabled physically or mentally that, disregarding any ability (they) may have to use routes which are familiar to them on their own, they cannot take advantage of the faculty out of doors without guidance or supervision from another person most of the time'*.

There are three rates of DLA care component:

- High: recipients need to satisfy either or both of 1 and 2 day time tests **and** either or both of 3 and 4 night time tests.
- Middle: recipients need to satisfy either or both of 1 and 2 day time tests **or** either or both of the 3 and 4 night time tests.
- Low: recipients need to satisfy either or both 5 or 6 part-time day care tests.

There are two rates of AA benefit:

- High: recipients need to satisfy either or both of 1 and 2 day time tests **and** either or both of 3 and 4 night time tests.
- Low: recipients need to satisfy either or both of 1 and 2 day time tests **or** either or both of 3 and 4 night time tests.

Appendix B

Topic guides

Topic guide for welfare rights organisations and social workers

Introduction

The Policy Studies Institute (PSI) is an independent research institute. We have been commissioned by the Department for Work and Pensions (DWP) to consider the feasibility of developing a model for research that will reliably estimate the take-up rate of Disability Living Allowance (DLA) and Attendance Allowance (AA) among eligible people. So we are seeking a method, or a whole suite of methods, that will estimate how many people are eligible non-claimants of these benefits, who they are, and how long they remain eligible without claiming or having a claim submitted on their behalf.

General questions

Do you have any general sense of the numbers of people who might succeed in a claim for DLA or AA but have yet to claim (a) in the population as a whole and (b) among the group your organisation represents?

What do you think is the level of awareness of DLA/AA among the group of people you represent?

How in your experience do people become aware of these benefits?

To what extent does your organisation get directly involved with claims for DLA and AA – prompting and assisting claims, or providing DWP with additional information?

Do you have an outreach programme to prompt claiming among your interest group? If so, have you evaluated how effective this might be?

When involved, do you find some clients resistant or reluctant to claim? Do some of the claimants you assist become discouraged and drop out and if so do you know why this is?

Is there, broadly speaking, some kind of threshold model of claiming DLA and AA: various stages of awareness, prompting and increased incapacity that prompts claiming?

To what extent do you think it might be possible for a research team to devise a face-to-face field questionnaire that will identify people who appear eligible for DLA or AA but have made no claim yet? What in your view are the main problems we face?

Specific topics

- 1 To what extent, in your experience, is diagnosis rather than the claimants'/ proxies' account of incapacity and their need for care instrumental in decisions whether to claim or not?
- 2 How do people in your area of interest with similar diagnosis and severity differ in their reported incapacity?
- 3 Among your interest group, is there one particular incapacity that will typically prompt a claim or is there a range of triggers that have similar importance?
 - a Receipt of diagnosis.
 - b Onset of incapacity – are there recognisable stages?
 - c Prompting by family or friends, especially those involved in care.
 - d Prompting by professionals (social worker, existing home helps).
 - e Availability of care.
 - f Any other?
- 4 How much of non-take-up is:
 - a Simply delay among people who claim eventually; or
 - b Disregard among people who will never claim unless their condition deteriorates to a point when others will intervene on their behalf?
 - c If delay: how long do people remain eligible before submitting a claim and how does this vary between cases?
- 5 What are the main inhibitors delaying a claim?
 - a Demographics: certain kinds of people in particular circumstances who, though probably eligible for benefit, typically do not begin a claim?
 - b Substitution: those typically with devoted relatives who think it is their job to care (especially parents?)

- c** Lack of skill-transfer: people not used to claiming anything?
 - d** Lack of information?
 - e** Complexity of forms and the claiming process?
 - f** Poor advice?
 - g** Lack of suitable proxy?
 - h** Distaste for getting involved with the benefits system or fear of being unjustly accused of misrepresentation?
 - i** Knowledge of rejection of claims other people who seem to have similar problems and needs?
 - j** Previous negative experiences with disability benefit or other benefit application?
 - k** Others?
- 6** Is there any part of the claiming process you identify as more difficult or even unfair compared to others, such that might deter applicants?
- 7** What can you say about the difficulties of cases where the claim for benefit arises mainly from mental health condition? Or when an otherwise mild or low level physical incapacity might be carried over the threshold for eligibility by the onset of mental confusion or by rising anxiety or depression, or compounded by learning difficulties?
- 8** Are some claims prompted more by carers first discovering Carer's Allowance than by claimants discovering DLA or AA?
- 9** Are there any particular problems for claimants in residential care?

Topic guide for interviews with decision makers

Thank you for agreeing to participate in a research project exploring the feasibility of estimating DLA/AA take-up rates. An interview with you will help us to understand claiming and decision-making processes and acquire awareness of potential problems associated with them. We will be asking for your views on four broad topics: a) how you arrive at the award decision; b) what information you use in the process; c) how adequate to claiming and decision making the claim forms are; and d) what usually triggers a claim or delay in claiming.

The length of interview should not exceed two hours. Since it is very difficult to take full notes during an interview, it would greatly help us if our talk was recorded. We will ask for your consent to recording prior to an interview and would greatly appreciate your agreement. The interviews will not be heard by anyone outside the research team; the records will be stored securely and destroyed at the end of the project. Anything you tell us is confidential and we reassure you that your anonymity will be protected in any ensuing reports. If you have any questions relating to research or the interview, please do not hesitate to ask them at any time.

Decision making process

We would like to know how you arrive at the award decision in order to assess whether this can be pre-coded into a questionnaire. Please distinguish between DLA and AA where the answer would differ depending on the benefit.

- 1** Can you tell me what kinds of cases are easier to decide (e.g. if claimants are in residential care, or have a certain type of illness, or are represented by a welfare right organisation)? Are there any particular issues in Special Rules cases? How important is it that all parts of the form are filled in (e.g. what happens if a statement from a person who knows the claimant is missing)?
- 2** How do you deal with instances where claimants do not fill in their forms fully (e.g. describing the illness in their own words but not ticking the box relating to this illness)? How successful is this in resolving the problem?
- 3** Do you see any patterns in terms of the people who have problems completing the form (e.g. by type of illness/disability, region of country, age, gender, ethnicity etc.)
- 4** Where are difficulties in the process likely to arise?
- 5** If there is an 'inconsistency' between the medical diagnosis and the claimant's description of the effects of illness on them (e.g. the claimant says they can cope with an illness on their own but the diagnosis indicates that the illness would require much help in the near future), how would you arrive at a decision?

- 6 How do you assess the degree of need – whether it is a mobility or care need (for example, at which level and frequency of attention during the day would you decide to grant a middle rate DLA care component)? Is there a guide to ‘quantifying’ different care and mobility needs that you could use when determining the eligibility? If yes, how useful do you find it? If not, how useful do you think such a guide would be?
- 7 Which elements of the claiming and decision processes do you think can be pre-coded, if at all?

Role of evidence

We would like you to tell us about the importance of medical assessment and information you receive from other parties to arriving at the award decision.

- 1 What kinds of things influence whether a medical assessment is sought or not? Could you give me an example? What importance is attached to it when it is sought? Would claimants be informed as to whether it was sought or not?
- 2 What determines the choice of an expert to approach for evidence (e.g. a hospital consultant or a GP)?
- 3 How do you decide on the ‘degree’ of illness/disability where medical assessments do not address all the questions asked of them (e.g. on prognosis)?
- 4 In those instances where more than one medical assessment is sought (e.g. from a hospital consultant and from a GP), how do you treat conflicting evidence (e.g. one assessing the degree of illness as moderate and another as severe)?
- 5 If there is a conflict between the type of evidence submitted by the claimant, a social worker and a medical expert (e.g. one reporting back pain and another chest pain), how do you treat the case?
- 6 What importance is attached to the evidence given by a person recommended by the claimant (i.e. the person who knows the claimant and whom the claimant asked to provide evidence)?

Adequacy of claim packs

We would like to know how adequate you think the claim documentation is to claiming and decision-making processes²².

- 1 If it was up to you, which parts of the claim forms would you modify, why and how, if at all?
- 2 Are there ways in which you would like to standardise the completion of claim forms? Why?

²² Previous research has suggested that complexity of forms may be one of the reasons for non-claiming. Indeed, in some instances, detailed questions in the claim form do not seem to correspond to the issues stated in the title (e.g. part 23 of the DLA1A).

- 3 Which forms are used for which claim type (e.g. when are forms DLA434, DS2 and DBD138 used)?
- 4 Why do the forms containing medical evidence differ from each other (e.g. DBD378(N) CPN/MH, EMP (DLA140), DBD378(N) GPFR)? How useful would you find to have one standard form for medical assessment? How feasible do you think is codification of answers recorded in medical forms? What do you see as the advantages and problems of doing this?
- 5 The forms ask about other benefits and tax credits that claimants and their families are receiving or expecting to receive. Is there a linked system of benefit records that you can consult with if you want to validate the information submitted by the claimant?
- 6 Why are the forms used to record a decision different (e.g. DBD810 differs between Feb 2006 and October 2003)?

Triggers of claiming

Lastly, we would like you to comment on triggers and timing of claiming and decision making.

- 1 In your experience what usually triggers a new claim for AA/DLA?
- 2 What types of reasons do people usually give when explaining the delay in placing a new claim or reporting a change in circumstances?
- 3 How and by whom may consideration of change in circumstances be initiated?
- 4 Are there limits placed on the time between an appeal and a decision on the appeal?

Topic guides for interviews with data holders

Thank you for agreeing to participate in a research project exploring the feasibility of estimating DLA/AA take-up rates. An interview with you will help us to assess the availability of existing data and its usefulness in representing the process and may make the estimation of the take-up rate feasible. We will be asking for your views on two broad topics: a) the possibility of transferring the information contained in claim packs into an electronic format; and b) the ability of existing data to capture each stage of claiming and decision making and to estimate the take-up rate.

The length of interview should not exceed two hours. Since it is very difficult to take full notes during an interview, it would greatly help us if our talk was recorded. We will ask for your consent to recording prior to an interview and would greatly appreciate your agreement. The interviews will not be heard by anyone outside the research team; the records will be stored securely and destroyed at the end of the project. Anything you tell us is confidential and we reassure you that your anonymity will be protected in any ensuing reports. If you have any questions relating to research or the interview, please do not hesitate to ask them at any time.

Presentation of information

We would like to hear your views on presenting the information relating to claiming and decision making in a format that can be pre-coded into a questionnaire.

- 1** Could you start by explaining how information is coded in decision making forms (e.g. codes for disability type, reason for decision, evidence codes) and in medical assessment forms at present?
- 2** Is the coding system identical across the forms (e.g. in part 2 of EMP reports and in claim forms)?
- 3** How complicated are these coding systems (e.g. variations depending on the benefit type)? Please could we see some examples?
- 4** How suitable do you think are the existing coding systems for pre-coding of claim forms into questionnaires? What would be advantages of this? What sort of problems would you foresee?
- 5** What is Customer Information System, what is it used for and is it available in an electronic format?
- 6** Is Social Services Care Plan available in an electronic format?

Existing data sets

We would like to familiarise ourselves with existing data sets and would appreciate a brief on existing data.

- 1** Please could you provide us with a description of variables (including their coded values) and where available, with the samples (of about 300 cases each) of the following data sets:
- 2** The five per cent extract of the administrative benefit data.
- 3** Work and Pensions Longitudinal Study (WPLS).
- 4** The Customer Case Management (CCM) pilot data base.
- 5** The latest data dump on all DLA and AA claimants.
- 6** Are there other data sets that you think may contain information on DLA/AA claimants?
- 7** Which of these data sets have a common variable that may be used to merge the data?
- 8** How have the existing data sets changed over time in terms of the variables they contain (e.g. if some variables are not available across all years)?
- 9** How have the existing data sets changed over time in terms of their representativeness of the overall population of Great Britain (e.g. if some sections of population are not represented in all years)?
- 10** How well do you think the existing data represent claiming and decision making? Why do you think so (please give some examples if you can)?

Topic guides for interviews with medical professionals

The PSI is an independent research institute. We have been commissioned by DWP to consider the feasibility of developing a model for research that will reliably estimate the take-up rate of DLA and AA among eligible people. So we are seeking a method that will estimate how many people are eligible non-claimants of these benefits and who they are.

We appreciate your assistance with this research project – thank you for agreeing to participate in it. An interview with you will help us to understand who is likely to be awarded a DLA or AA benefit. The length of interview should not exceed two hours. Since it is very difficult to take full notes during an interview, it would greatly help us if our talk was recorded. We will ask for your consent to recording prior to an interview and would greatly appreciate your agreement. The interviews will not be heard by anyone outside the research team; the records will be stored securely and destroyed at the end of the project. Anything you tell us is confidential and we reassure you that your anonymity will be protected in any ensuing reports. If you have any questions relating to research or the interview, please do not hesitate to ask them at any time.

General questions

- 1** What role does ATOS play in the decision making process with regard to DLA and AA benefits (e.g. visiting claimants, offering advice to decision makers on claimants' impairments and needs, reporting a possible change in claimants' circumstances)?
- 2** In what cases might it be necessary to visit the claimant for assessment? What is your experience of these visits? Does it vary across the claimants depending on their illness types, demographic characteristics, type of benefit claimed, etc.?
- 3** How consistent do you think practices across the ATOS doctors are?
- 4** If the results of medical assessment or advice given by an ATOS doctor differ from those given by other medical professionals, why would this be?
- 5** In what instances, if any, you would expect the claimant to be granted an award. For example, would the claimant's demographic or other characteristics, or their geographical area, or something else indicate to you that this claimant is likely to be awarded? If yes, does this differ between DLA and AA claimants?
- 6** In the same way, is there one particular incapacity or a range of impairments that would typically prompt an award? If yes, does this differ between DLA and AA claimants?
- 7** To what extent do you think it might be possible for a research team to devise a face-to-face field questionnaire that will identify people who appear eligible for DLA or AA? What in your view are the main problems we face? What do you see as advantages and problems of doing this?

Specific questions

- 1 What are the case types (DLA or AA, new claims or reconsiderations, etc.) that you deal with most often? What are the types of illness that you deal with most often? How does the sort of help you provide vary across decision makers, case types and illness types? How do you deal with cases that you are not sure about?
- 2 To what extent, in your experience, is diagnosis rather than the claimants' account of their needs instrumental in decisions whether to grant DLA or AA or not? If there is an 'inconsistency' between the medical diagnosis and the claimant's description of the effects of illness on them, how would you treat claimants' accounts?
- 3 How do people with similar diagnoses and severity differ in their reported incapacity? How do people with similar diagnoses and severity differ in their needs?
- 4 Given that the award decision is based on claimants' needs, how sufficient is the information contained in Examining Medical Practitioner (EMP) for identifying these? Which additional evidence would you usually seek, if any?
- 5 Where (non-ATOS) medical assessments do not address all the questions asked of them, why do you think this would happen? Are there time/resource pressures on medical professionals completing the assessment forms? Are some questions more difficult to answer than other?
- 6 In those instances where (non-ATOS) medical assessments received by decision makers differ (e.g. a hospital consultant assesses the degree of illness as moderate and a GP assesses it as severe) or when the medical assessment is incomplete (e.g. it lacks information on prognosis), what is the basis for your advice to decision makers?
- 7 Are there any particular issues for claimants in residential care? For 'Special Rules' claimants? What can you say about cases where the claim for benefit arises mainly from mental health condition? Or when an otherwise mild or low level physical incapacity might be compounded by mental health problems?
- 8 At present, the forms containing medical evidence differ from each other (e.g. DBD378(N) CPN/MH, EMP (DLA140), DBD378(N) GPFR)? How useful would you find one standard form for medical assessment? How feasible do you think is codification of answers recorded in medical forms? What do you see as advantages and problems of doing this?

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