

Department for Work and Pensions

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Sharing and matching local and national data on adults of working age facing multiple barriers to employment: Administrative Datasets for Measuring Impacts on Disadvantage

Nicholas Pleace and Joanne Bretherton

A report of research carried out by the Centre for Housing Policy, University of York on behalf of the Department for Work and Pensions

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Abbreviations

ADMID	Administrative Datasets for Measuring Impacts on Disadvantage
CHP	Centre for Housing Policy, University of York
DPA	Data Protection Act
DWP	Department for Work and Pensions
ETE	Education, Training and Employment
GIS	Geographic Information Systems. Computer-aided mapping and analysis which can employ demographic and socioeconomic data
HMRC	Her Majesty's Revenue and Customs
HRA	Human Rights Act
ICO	Information Commissioner's Office
JCP	Jobcentre Plus

Summary

Background to the research

People facing multiple barriers to work

- Government maintains that employment represents the most effective route out of poverty. The New Deal and the Tax Credit system have delivered improvements in employment levels. However, problems remain in securing work for individuals who can work, but who face multiple barriers to employment.
- Adults who face multiple barriers to employment may experience sustained social exclusion. Alongside the concern for the well-being of people in this situation, there is evidence of high 'lifetime' costs to the Exchequer because benefits are claimed for sustained periods and people tend to make high use of publicly-funded services.

Sharing data to improve information on people facing multiple barriers to work

- National level data tend not to provide sufficient detail on workless adults who could work, but who face multiple barriers to employment. There is also an absence of detailed, longitudinal, statistical information on this group at local authority level.
- A detailed longitudinal dataset would allow specific individuals and localities to be more accurately targeted with services. Services and programmes could also be evaluated longitudinally. The life courses of people in the target group could be better understood and services tailored accordingly.
- DWP can share data with service providing agencies working at local authority level, or across individual cities, to improve information on workless adults facing multiple barriers to employment.

- Many agencies, such as those working with homeless people and larger housing associations, are increasingly concerned with promoting the economic and social inclusion of their service users. This means that a wide range of agencies hold relevant data, alongside those services providing education, training and employment services to people facing multiple barriers to work.
- The transfer or sharing of personal information is governed by legislation. A free and informed consent, compatible with the eight principles of the Data Protection Act, must be secured before personal information can be shared between local agencies and DWP.

The research

- The research was designed to explore the possible advantages of linking project level, local authority level and city-level datasets with DWP datasets as a means to improve the range and extent of data available on 'hard to help' groups who are able to work.
- The research explored the views of local service providers, service commissioners and services users on the practicality, desirability and legality of possible data sharing.
- Fieldwork took place in Leeds and London with a range of relevant agencies and with people facing multiple barriers to work who were refugees, homeless people, drug dependent people or who were recently released former offenders.

Current practice in data sharing at local level

Case-by-case sharing of information

- Most information exchange at local authority level involved the case-by-case transfer of, generally, quite limited information on service users between local agencies, usually for the purposes of referral. This process was generally mediated by frontline staff.
- Service users' legal rights were not always well understood by frontline staff. However, these staff generally interpreted the legislation as prohibiting information disclosure without a service user's permission.
- There were some concerns that information was not always shared when it should have been because of misinterpretation of the legislation.

Shared databases

- A small number of shared multi-agency databases were found to be in use within Leeds and across London. These were recent developments, and were designed to be compliant with the data protection legislation.

- These databases provided a rich, longitudinal record of individual service users' interactions with services.
- These systems were web-based and the administrative burden of participating in a shared database fell on each participating agency. To minimise administrative costs these databases tended to record only basic information.
- The shared databases were 'walled gardens'. They allowed appropriate sharing of data on individuals among participating agencies and were used to produce statistical reports, based on aggregate, anonymised data.
- Data on individuals were not shared beyond the agencies participating in these databases.
- Some concerns were raised about the administration and maintenance of shared databases, particularly in respect of securing accurate and timely entries from all participating agencies.

Issues in sharing data locally

- People facing multiple barriers to work were seen by service providers as needing to 'trust' agencies before they would disclose personal information. A central aspect of this 'trust' was that their personal information would not be shared without their knowledge or consent.
- There were concerns that data collection could deter some adults with multiple needs from seeking services. Some service providers thought that data sharing with mainstream agencies such as Jobcentre Plus, or criminal justice services, was not viewed positively by some adults with multiple needs.
- Some local agencies reported frustrations because they lacked a detailed longitudinal dataset on workless adults that could be used for planning and commissioning purposes.

Service providers' and service commissioners' views on sharing service user data with Government

The potential advantages of data sharing with DWP

- Local service providers and service commissioners saw several potential advantages in sharing data with DWP about workless adults, who could work, but who faced multiple barriers to employment.
- There was particular interest in the scope for improving coordination between local agencies and DWP and in the capacity to track individuals (and evaluate service impacts) by linking to the longitudinal datasets on benefit claims by individuals held by DWP. Larger agencies and local authorities had an interest in the ways in which data sharing might enhance their Geographic Information Systems, particularly with respect to monitoring progress in area regeneration.

The Data Protection Act and sharing data with DWP

- Some frontline staff were confused about the legislative framework and how it might limit such sharing of data. Those staff whose knowledge of the law was more limited tended to take the view that it prohibited the sharing of personal data between their agency and DWP.
- Among staff who had an awareness of the legislative framework, there was a broad consensus that data sharing with DWP could take place with the appropriate free and informed consent.
- Some respondents thought agencies would need to take on an additional administrative burden to support the process of obtaining an informed consent. Without such support, there were concerns that service users might sign a consent without always being entirely aware of what they were being asked to do.
- Some took the view that there would be at least some resistance to signing informed consents to share personal data with DWP among some of their service users.
- Others thought that many of their service users would be prepared to sign informed consents, providing those consents set acceptable conditions from the perspective of those service users, and were carefully explained.
- Only a very few respondents discussed any modification of current law to facilitate greater ease of data sharing. None argued that the current protection was excessive.

Concerns about data sharing

- There were concerns that a 'label' such as 'drug user' or 'homeless person' would elicit prejudice, were data containing such a 'label' to be shared inappropriately. There were particular worries about the consequences were such a label to be an enduring presence in someone's life, particularly after it had ceased to be applicable.
- Risks in inaccuracy within shared data were also raised as a possibility. Some respondents were concerned about over-simplification, as categorisations like 'drug user', for example, covered people with a very wide range of needs and characteristics.
- While many respondents saw advantages in the capacity to track individuals longitudinally, they found it difficult to reconcile this with some concerns about the implications for service users centred around the use of data to monitor individuals.

The views of people facing multiple barriers to work on data collection and sharing

Views on the disclosure of personal information

- Adults facing multiple barriers to work were generally prepared to disclose information if they felt that information was pertinent to the objectives of the service that was seeking it. However, there was often reluctance to hand over personal information if the request was seen as intrusive or unnecessary.
- Respondents were more comfortable with disclosing information when they felt they could 'trust' the person to whom they were revealing information. Part of this sense of trust depended on feeling their needs and situation were properly understood and another part depended on the service user feeling their data were 'safe' and would not be disclosed in an uncontrolled way.
- These often highly marginalised people frequently regarded data collection as a series of deliberately erected 'barriers' that were intended to make accessing services more difficult.
- Some respondents reported deliberately withholding sensitive information, for example on drug use, from some mainstream agencies like Jobcentre Plus. This was because they anticipated negative responses from those services if the information were disclosed.
- Respondents sometimes reported feeling embarrassed and uncomfortable when discussing some more sensitive issues. A sense that the person to whom the information was disclosed would react with understanding was important to them.
- There were sometimes concerns that agencies lost information or misrepresented individuals in the information they recorded.
- Many respondents thought that computerised information was inherently insecure.
- The shared perception of data collection among service users was a quite negative one. As they saw it, some services tried to 'trip them up' and 'stop them from getting services' through questioning, whereas if they were honest about their needs, they might encounter prejudice.

Views on data sharing

- Some respondents reported negative experiences that were associated with the sharing of personal information. For example, if mainstream agencies that tended to work with the general public learned of drug use or a history of offending, this was viewed as often eliciting negative responses from those services.
- If personal information were to be shared between agencies, respondents wanted a sense that they could trust the agency that was doing the sharing and that the act of sharing would not disadvantage them.

- It was important to respondents to have a sense that a 'fair exchange' was occurring when they allowed personal information to be shared. If they were going to disclose information, they wished for a sense that this was likely to be to their benefit, for example, in facilitating access to required services.
- Many adults facing multiple barriers to work regarded themselves as being in a situation of surveillance by an overarching 'state' which processed their personal data in an arbitrary way. Few had any conception of their rights or the legal protection governing the use of their personal data.
- There were concerns among service users that if they were 'labelled' in a certain way this would disadvantage them. Like service providers and service commissioners, individuals feared that a label might remain with them and disadvantage them for a sustained period.
- Views were mixed on whether a free and informed consent would provide sufficient guarantees to feel comfortable about sharing personal information. Some thought that it could offer no guarantee, which was generally linked to the conception of Government as an arbitrary authority and to negative experiences of data processing. Other respondents viewed the use of informed consents more positively, particularly if they had prior experience of signing an informed consent.

Ways forward

- Local service providers and commissioners are interested in engaging in data sharing, but require reassurance in respect of how shared data might be used. Their concerns about data sharing potentially disadvantaging some service users, could be addressed through establishing clear and robustly enforced rules about the conditions under which personal information is shared and examined. Such rules need not undermine the potential advantages of data sharing, but should, instead, reinforce existing good practice.
- There are many questions surrounding the securing of free and informed consent. These centre on distrust of mainstream agencies among people facing multiple barriers to work and their need for a sense of 'fair exchange' when giving consent for information sharing. Smaller agencies were apprehensive that some people would refuse to engage with their service if they were asked to consent to data sharing for these reasons. Larger agencies had some concerns about ensuring consents were free and informed and about resource implications. Further research on this area is required.
- Education about the Data Protection Act (DPA) and associated legislation, among people facing multiple barriers to work and among some frontline staff, is a vital part of ensuring that rights and responsibilities are properly observed. People facing multiple barriers to work often assume they have little or no protection, which contributes to a situation in which they are reluctant to share certain information with agencies. While frontline staff generally err on the side of caution, it is clearly the case that they do not always fully understand the DPA.

- People facing multiple barriers to work need reassurance that data sharing is intended for their benefit. It is not desirable or practical to limit the uses of data sharing to the extent where legitimate use of data to detect benefit fraud, for example, becomes difficult. At the same time, the positive aspects of data sharing could be better explained to people facing multiple barriers to work.
- Additional reassurance might be provided through reference to the Freedom of Information Act principles, which would give an individual the right to review the shared data held on them.
- A combination of better education about the DPA and clear rules that provide reassurance about the uses to which shared data can be put, could facilitate data sharing between people facing multiple barriers to work, local service providers and DWP.

1 Introduction

This report describes the results of a study conducted on behalf of the DWP by the Centre for Housing Policy (CHP) at the University of York. The research was undertaken as part of a DWP project entitled 'Administrative Datasets for Measuring Impacts on Disadvantage' (ADMID). The ADMID project seeks to improve the range and extent of data available to DWP on 'hard to help' groups, which are those adults of working age who are capable of work, but who face multiple barriers to employment.

The research project was specifically designed to explore the extent to which it might be possible to combine data from organisations working at local authority and city level with those held by DWP in its administrative datasets. This subject was explored because the data held on workless people with multiple needs at national level have some limitations, in respect of understanding the needs, experiences and characteristics of these groups in more detail. The research explored the many practical, cultural, legal and ethical questions that arise in respect of sharing personal data between local agencies and Government.

The report is divided into five main sections and contains one appendix:

- **Chapter 2** reviews the policy context in which the research took place before moving on to provide an overview of the project.
- **Chapter 3** reviews current practice in information collection and sharing in the case study areas, drawing on the results of the interviews with service providers and commissioners.
- **Chapter 4** describes the responses of local service providers and commissioners towards the possible sharing of personal data on service users with central Government.
- **Chapter 5** explores data collection, processing and sharing from the perspectives of individuals facing multiple barriers to employment.

- **Chapter 6** contains the conclusions to the research and also contains the recommendations for ways forward in improving the data on workless adults facing multiple barriers to employment.
- A list of participating organisations is presented in the **Appendix**.

2 About the research

2.1 Introduction

This first section of the report reviews the policy context in which the research took place before moving on to provide an overview of the project. The difficulties in securing work for adults who face multiple barriers to employment are examined and the reasons for a shortage of detailed aggregate information on this group are discussed.

The legal issues that arise when personal information is shared between agencies are then described. This section concludes with a description of the research and its objectives.

2.2 The background to the research

2.2.1 Securing work for those facing multiple barriers to employment

Government maintains that employment represents the most effective route out of poverty. Major attempts to improve access to work have been undertaken since 1997. The New Deal programme, which provides help and support to people seeking employment through personal advisers, has been combined with the Tax Credit system to make lower-waged employment more attractive. Independent research has described the New Deal and the Tax Credit system as being by far the most systematic and sustained effort to move people into jobs yet attempted in the UK (Hirsh and Millar, 2004).

However, some problems remain in securing work for adults of working age who face multiple barriers to employment. There is evidence of a low rate of economic activity among adults of working age who have support needs, a low degree of formal work experience and low levels of qualifications (Berthoud, 2003). There is also evidence that some individuals with support needs can face difficulties in sustaining employment once it has been secured (Lakey *et al.*, 2001; Furlong and Cartmel, 2004).

Existing research on barriers to employment tends to show that the New Deal and associated programmes tend to be most effective when individuals can be described as being broadly 'work ready'. When support needs are present or someone has characteristics that can deter potential employers, such as a history of drug use, offending or homelessness, attempts at job placement are often less effective (Hirsh and Millar, 2004).

Particular groups also face specific barriers to work. Ex-offenders often have poor skill levels, low self-esteem and can sometimes have behavioural and health problems, which when combined with a lack of recent work experience and the likelihood of employer discrimination, can create significant obstacles to employment (Fletcher *et al.*, 1998). Homeless people and drug and alcohol dependent people face essentially the same barriers (Singh, 2005; Kemp and Neale, 2005; Klee *et al.*, 2002; Lownsborough, 2005). Individuals can also have multiple needs which may compound the disadvantages they face when seeking work (Singh, 2005). Other groups face particular barriers as a result of their circumstances, such as refugees who do not have English as a first language and who may face cultural and racial prejudice (Bloch, 2002).

The present Government has responded by developing specialised programmes of Education, Training and Employment (ETE) services for people facing multiple barriers to work. The Progress2Work programme, for example, aims to help people recovering from drug misuse to make better use of Jobcentre Plus services to help them into jobs. However, there is evidence that these interventions are not always proving effective for some people facing multiple barriers to employment (Hirsch and Millar, 2004; Kemp and Neale, 2005; Singh, 2005).

It has been acknowledged by government that recent labour market improvements have not impacted evenly across the country and that concentrations of worklessness remain (Berthoud, 2003; Green and Owen, 2006). The 65 Jobcentre Plus Action Teams in the UK, focused on specific concentrations of worklessness, provide targeted support to homeless people, ex-offenders and refugees. Local Jobcentre Plus and Learning and Skill Council (LSC) funding also supports a wide range of specifically targeted ETE projects for homeless people, refugees and drug and alcohol users.

People facing multiple barriers to work are a concern for social and employment policy in a number of respects. The first and most obvious concern is for the life chances and well-being of these individuals. In addition, there are concerns about the wider cost to society, as although people facing multiple barriers to work are not especially numerous, each individual may have a high 'lifetime' cost to the Exchequer, as they use public services and claim benefits throughout their lives. Socioeconomically excluded people may also be more likely to become involved in criminal activity which, again, has high costs for the Exchequer (Scott *et al.*, 2001).

2.2.2 The need for better information

The effectiveness of responses designed to help people facing multiple barriers to work is undermined by some limitations in data held at national level. The main issue is the quality and range of large scale longitudinal statistical data available on workless individuals at local authority, regional, and national level. Supply-side interventions, focused on improving individuals employability and demand-side interventions, designed to encourage employers into areas characterised by worklessness, both depend on high quality data because they need to be precisely targeted to be effective.

DWP collect data on characteristics like homelessness and drug use but these data are limited in two key respects: First, the data depend on self-reporting, which claimants are not always prepared to do (see Chapter 5) and second, the information that is collected is not very detailed.

A description of someone as a 'drug user' or as 'homeless' cannot really convey what the needs, characteristics and experiences of an individual are, nor what **specific** barriers to employment they may be facing. A series of studies have pointed to the complex interplay of factors that are associated with sustained worklessness (Fletcher *et al.*, 1998; Lakey *et al.*, 2001; Klee *et al.*, 2002; Furlong and Cartmel, 2004; Kemp and Neale, 2005). As one example, an individual may be simultaneously homeless, a former offender, a drug user and have mental health problems.

DWP's datasets provide a longitudinal record of benefit claims. However, these data are insufficiently detailed in respect of people who are able to work but who face multiple barriers to employment. This makes it difficult to understand more about the life course of workless people with multiple needs, which might allow the development of new preventative services.

In turn, data limitations may undermine accurate judgement about whether the right type of services are being provided. If it is difficult to be entirely confident about what the numbers of a population are, how they are distributed and what their needs are, it is consequently difficult to know, precisely, whether appropriate ETE commissioning is taking place.

Presently, these potential risks are managed in two ways: First, specialised ETE services are based within or alongside other services for people in the target groups, such as former offenders or homeless people, via joint working arrangements. Second, enough geodemographic data are available on relative rates of worklessness and benefit claims to enable the focusing of ETE services on both local authority areas, and smaller localities, where worklessness levels are known to be high.

However, the first approach does not guarantee access to specialised ETE services, as it depends on whether other services are well used by target groups and can be relied on to make timely referrals. The second approach is also limited, because it can only be broadly aimed at areas where people facing multiple barriers to employment are concentrated. Thus, ETE services are placed in the localities where worklessness

is high, but without necessarily knowing the exact extent and nature of that worklessness.

It would be quite wrong to suggest that specialised ETE services are casting around in the dark when seeking employable adults facing multiple barriers to work. However, it is the case that gaps in the data could mean they are not as accurately targeted as they could be.

Data limitations create particular problems in assessing programme and service effectiveness. ETE projects provide data about their engagement with people facing multiple barriers to employment. But these are confined to the contacts and short-term outcomes for each individual project.

It is often not possible to examine the impact of interventions over time. For example, it can be difficult to determine whether someone who had entered employment via an ETE service has been able to sustain that employment for a given period after their contact with that ETE service ceased.

Equally, the extent to which some individuals may be characterised by repeated experiences of unsuccessful ETE interventions cannot be entirely determined. If it is the case that individuals are sometimes experiencing one failed episode of service use after another, the potential costs for those individuals and for wider society are unacceptable. However, it is currently difficult to accurately determine the extent to which this may be the case.

In summary, current limitations in the statistical and client data available mean that:

- it is difficult to **entirely accurately** count, map and describe the needs, characteristics and experiences of all the adults who can work, but who face multiple barriers to employment, at local authority, regional and national level;
- the life paths of workless adults facing multiple barriers to employment are not as well understood as they could be. This may forestall the development of appropriate preventative services and other interventions to some degree. There are particular concerns about the possible nature and extent of any population which is characterised by repeated contacts with ETE services which continually fail to deliver a satisfactory outcome;
- there are difficulties in ensuring all adults facing multiple barriers to work are being **accurately** and appropriately targeted by the right sorts of ETE services, both in terms of locating the individuals who are likely to benefit, but also in ensuring those ETE services are appropriate to their needs;
- there are difficulties in producing accurate maps of the distribution and nature of need within areas characterised by high levels of worklessness. It is known where these areas are, but a detailed breakdown of need for the purpose of service planning and commissioning is not always available;

- there are problems in **accurately** judging service and programme effectiveness on a local, regional and national scale. This applies both in terms of whether these services are undertaking the correct role in the most appropriate localities and in respect of accurate longitudinal evaluation of outcomes for service users.

If a richer longitudinal dataset could be established, it would bring a number of theoretical advantages. These would include:

- the capacity to accurately map need by locality which would enhance local, regional and national level strategy and service commissioning;
- the capacity to target individuals according to their specific needs, characteristics and experiences, matching the person with the programme or service that is most likely to enable them to access employment;
- the capacity to undertake longitudinal research, learning about the nature of economic exclusion among specific groups and within specific localities and modifying service delivery accordingly;
- enabling longitudinal service and programme evaluation, determining which interventions are effective and which are ineffective and informing resource allocation. This could help prevent inappropriate use of services by those who do not require specific assistance to secure work and stop the commissioning of any services that are limited in effectiveness.

2.2.3 The sharing and matching of local and national data

There are some limits to the extent to which DWP can directly collect all the information it needs from its customers. If more detailed questions were asked of its customers this would add to the already complex bureaucracy of DWP and Jobcentre Plus (National Audit Office, 2005). There are also some constraints in terms of DWP's engagement with its customers. Research has raised concerns that interaction with DWP can be a difficult experience for some claimants with multiple needs (National Audit Office, 2005). Adding to the demands made upon claimants by DWP might create problems in successful engagement with some vulnerable workless groups.

However, a fuller dataset on people facing multiple barriers to work can be established by sharing, merging and matching data held across different services and agencies. Work in this field is being undertaken at national level. For example, there are current experiments in linking DWP and Her Majesty's Revenue and Customs data. DWP is also sharing data with the Home Office on former offenders at the time of writing, using a system of informed consent.

It is also theoretically possible to match and share data with agencies working at local level. Potentially detailed information on the needs, characteristics and experiences of workless populations may be held by individual projects, services and agencies working within one city or one local authority area. It is not just ETE services that may hold such data. Supporting People services, which provide low intensity

support through supported housing and floating support services, collect data that is relevant to understanding barriers to work among their service users. It is increasingly the case that these services seek to promote access to employment for their service users (Pleace and Quilgars, 2003). In addition, social landlords often have as much concern with regeneration, with helping households into employment and with social cohesion as with housing management and they may hold pertinent data on their tenants (Pleace and Quilgars, 2002). Local authorities themselves also hold pertinent information, for example, on Housing Benefit claimants and through the statistics they collect for Supporting People commissioning, regeneration strategies and ETE service commissioning.

2.2.4 The legislation on data protection and privacy

Data sharing is governed by a legislative framework. The law is designed to protect individual privacy and also ensure that personal information is not abused by agencies that hold it. Alongside the intention to prevent unethical use of personal information, the law is also intended to protect individual rights. The law forms a very important part of the context in which data sharing may take place and it is necessary to understand the reasons for this before proceeding to the description of the current study.

Most of the data collected by local services on adults who face multiple barriers to work are potentially sensitive. An ETE service can hold information someone would not want disclosed. As many services are highly specialised, not just in ETE, but also in respect of Supporting People or social housing services, the simple disclosure that an individual is in contact with a given service would mean that personal information had been disclosed.

Legal and ethical questions arise when contemplating sharing this sort of information. Data sharing must be compatible with the legal protections afforded to individuals in respect of their right to privacy. Data sharing must also respect individuals' rights in respect of not having their personal information abused by those agencies which hold it.

There is no single piece of legislation that governs the collection, storage and sharing or matching of data. The key legislation includes:

- the Data Protection Act (1998);
- the Human Rights Act (1998);
- the Freedom of Information Act (2000).

The DPA requires that eight principles are followed in 'data processing'. Data processing is a wide term, which includes all aspects of collection, storage and use. The eight principles to be followed in data processing are that the data must be:

- 1** fairly and lawfully processed;
- 2** processed for limited purposes;

- 3 adequate, relevant and not excessive;
- 4 accurate;
- 5 not kept for longer than is necessary;
- 6 processed in line with an individual's rights;
- 7 secure;
- 8 not transferred to other countries (outside the European Economic Area) without adequate protection.

The processing of data that takes place must be demonstrably compatible with the eight principles. Data cannot be used for purposes other than those for which they were collected and must be fairly and lawfully processed (Department for Constitutional Affairs, 2003).

Highly personal information, for example, on health and support needs or ethnicity, may be pertinent to understanding why someone is facing multiple barriers to employment. The DPA places controls on the use of such 'personal data' which includes information on:

- physical and mental health;
- sexual life;
- race or ethnic origin;
- religious or political beliefs;
- trade union membership;
- criminal proceedings or prosecutions.

In order to collect and process this sort of personal information, agencies must seek a **free and informed consent** from the person from whom they are requesting the information. Free and informed consent is defined as '*any freely given, specific and informed indication of his wishes by which the data subject signifies his agreement to the personal data relating to him being processed*' (Data Protection Directive, 95/46EC, use of masculine pronoun in original).

Consent must be in writing and it must be demonstrable that it is freely given, in that there should be no pressure to sign a consent form. The consent must also relate to the specific purposes for which personal information is going to be used. No relevant information about data processing can be withheld from the person from whom consent is being sought. Individuals must also be able to **withdraw** their consent at any time (Department for Constitutional Affairs, 2003).

It is an obvious point, but one worth making, that a free and informed consent allows processing within the terms of the DPA. In other words, someone cannot be asked to sign a free and informed consent that breaks the principles of the DPA. A signed consent from an individual is not a *carte blanche* that allows an agency to process personal information in any way it sees fit.

The DPA must be followed in respect of the sharing, merging or matching of personal information held across different Government departments at national level. There may also be issues in respect of merging or matching separately held datasets within a single department such as DWP.

Any merging of data from services or service commissioners at local authority level with DWP data also needs to be compatible with the DPA. If DWP were to request data from local agencies, it would need to be confident that those data were not being supplied by those agencies to DWP in breach of the DPA. DWP would also need to be confident that it was not in breach of the DPA in retaining and processing any data supplied to it by local agencies.

The Human Rights Act (HRA) places Article 8 of the European Convention on Human Rights into UK law. Article 8 provides individuals with the right to respect for their private and family life. Data collection is usually held to be a potential interference with this right, but it can be undertaken for a 'legitimate' aim and if 'necessary' within a democratic society. Again, there is an emphasis on keeping individuals informed about how the data collected on them will be used. For data collection and processing to be deemed 'necessary', the broad consensus of interpretation is that the greater the intrusion into someone's privacy, the stronger the case for that intrusion needs to be (Department for Constitutional Affairs, 2003). There are also some other aspects of common law and European Union law relating to privacy that are potentially applicable to data processing (Department for Constitutional Affairs, 2003).

The Freedom of Information Act (2000) gives individuals a general right of access to information held by or on behalf of public bodies. The legislation is intended to contribute to developing a 'culture' of openness and accountability across the public sector. The right to request disclosure of information, which came into force in January 2005, allows an individual to review the information held on them and dispute any incorrect or misleading information. This includes incorrect information that might disadvantage them, create a false impression or lead to inappropriate service referrals or responses.

Government has no authority to compel agencies working at local level to supply it with personal data on identifiable individuals. This includes those situations in which there is a lawful way to disclose the data within the terms of the DPA, HRA and other relevant law.

These legal protections are not universally applied in all circumstances in the UK. Exceptions exist in respect of data sharing and matching when benefit fraud is being investigated. The Social Security Administration (Fraud) Act (1997) allows data matching to detect benefit fraud, with these powers being strengthened in the Social Security (Fraud) Act (2001). Every two years, the Audit Commission conducts a large data matching exercise under the National Fraud Initiative, for which Housing Benefit is the main target. In 2002/03, this exercise involved 1,150 agencies sharing data with one another, including NHS data on its employees, local authority data

and data from other bodies. This data matching reportedly detected some £83 million in fraud and overpayments (Audit Commission, 2004). Such exercises in benefit fraud detection are complex and relatively resource intensive, data often having to be specifically collected to check for fraud.

Data sharing and matching can also occur when criminal investigations are being undertaken focused on a specific individual. There are also provisions that allow the sharing of information on individual former offenders who represent a potential risk to the public. When information is being sought on national security matters, this can also override elements of the legislative framework.

The Information Commissioner's Office (ICO) is the independent supervisory authority reporting directly to Parliament which regulates the DPA and the freedom of information legislation. It responds to complaints about breaches of this legislation and provides advice on the legislation. Parliamentary scrutiny on DPA and HRA is provided through the Joint Committee on Human Rights.

2.3 The research

2.3.1 The objective of the research

The research was designed to explore the possible advantages of linking local authority-level and city-level data to DWP datasets as a mechanism to improve data quality on workless adults facing multiple barriers to employment. The research was undertaken as part of the DWP ADMID project.

The ADMID project seeks to improve the range and extent of data available on the 'hard to help' groups within the DWP administrative datasets, both for the purposes of improving the data held on individuals, but also for aggregate analysis. There is also an interest in how data that would allow better mapping of need, including possible applications in Geographic Information Systems (GIS), can be brought together. Agencies are also interested in the longitudinal analysis of ETE service outcomes that might take place via data sharing.

2.3.2 Research design

The research was a relatively small scale exploratory study, involving the equivalent of one full-time University of York researcher over the course of 15 months. The intention was to gain an overview of the key issues in relation to data sharing by conducting fieldwork that would provide a good illustration, though not a full representation, of current practice in information use. The research was equally concerned with exploring experiences of data sharing and the views of service commissioners, providers and adults facing multiple barriers to work on sharing personal data with Government.

Fieldwork was concentrated around four groups of people:

- homeless people;
- people who are drug users or alcohol dependent;
- refugee households;
- ex-offenders.

The four groups were selected as **exemplars** of groups of people who faced multiple barriers to employment. The selection of these groups should not, in any sense, be seen as downplaying the barriers faced by other groups people who find it difficult to secure work. People recovering from mental health problems and disabled people, for example, face particular obstacles in securing employment. In addition, it must be noted that there are localities in the UK which are characterised by poorer labour markets than the rest of the country. Geographical location, rather than someone's characteristics, needs or experiences, can be important in explaining economic exclusion (Berthoud, 2003; Green and Owen, 2006).

Fieldwork was focused in two areas: Leeds and the London Borough of Hammersmith and Fulham (see the Appendix). A range of ETE agencies, social landlords, social care providers, social landlords and Supporting People service providers were interviewed for the research. The local authorities in each locality also provided interviewees, as did Jobcentre Plus district offices. These localities were chosen because they were service-rich environments in which many agencies worked for the benefit of the four groups being examined. A number of agencies working in London Borough of Hammersmith and Fulham had a London-wide remit and they were asked to comment on their work in general as well as within the Hammersmith and Fulham area. A small amount of fieldwork was also conducted in Liverpool, Manchester and York with regional and national level agencies who worked in the Leeds area. Fieldwork took place from the summer of 2005 into early 2006.

3 Current practice in local information sharing

3.1 Introduction

This section of the report reviews current practice in information sharing between agencies in Leeds and in the London Borough of Hammersmith and Fulham. It is based on in-depth interviews with 37 individuals from a range of relevant agencies (see the Appendix). The range of local information sharing practice is discussed first, before each of the three main types are reviewed in detail. Some of the limitations and problems in local information sharing that were described by respondents are then considered. This chapter concludes with a summary of the main findings.

3.2 An overview of current information sharing

There was little variation in information sharing practices found in Leeds and Hammersmith and Fulham, nor were there significant differences between different sectors of service commissioning or service provision. Information sharing could be classified as falling into one of three types:

- 1** Case-by-case information disclosure about individuals, usually mediated by frontline workers.
- 2** The creation and use of shared databases accessible to a group of agencies involved in joint working, usually centred on one specific area of activity, or on one interagency project.
- 3** Attempts to link existing datasets to enhance strategic planning at local authority level, involving Jobcentre Plus and local authorities.

3.3 Case-by-case information sharing between services

3.3.1 The culture of joint working

Welfare services are now centred on the provision of multi-agency packages of care and support, arranged through joint working, that are tailored to individual needs. To take a theoretical example, it is quite possible that someone who is sleeping rough (i.e. is without any form of accommodation) will have a combination of needs that require interventions from several agencies. Beyond access to suitable accommodation, someone who is a rough sleeper is disproportionately likely to have mental health problems, be a drug user and/or have an alcohol dependency, poor physical health, low educational attainment and to have experienced sustained periods of worklessness as well as lacking basic skills (Anderson *et al.*, 1993; Pleace, 1998; Fitzpatrick *et al.*, 2005).

A coordinated intervention involving many agencies should simultaneously meet a given combination of needs. Packages of interagency support both increase the chances of success for an individual, but also enhance the chances that each service will not fail because of a lack of support in another area. For example, an attempt at rehousing might fail if drug use is not addressed, or an ETE intervention might fail because someone does not have suitable accommodation. It should be noted that failures in coordination and difficulties in securing some services can mean that attempts to provide packages of support can sometimes fail in practice (Jones and Pleace, 2005).

Agencies that provide social housing, care or low intensity support are increasingly concerned with social and economic exclusion among their service users. This reflects the objectives of these agencies in respect of securing stable futures for their service users and in promoting community cohesion. In many instances, such services have either moved directly into ETE service provision or they have increased links with ETE services in their locality. ETE services are themselves increasingly integrated within the packages of housing, care and support provided, through joint working to people with multiple needs. This tendency is perhaps most pronounced in respect of homeless people and ex-offenders and perhaps at its most developed within London (Jones and Pleace, 2005).

3.3.2 Typical practice in case-by-case information exchange

Case-by-case information exchange was the mechanism by which service providers coordinated joint working. This kind of exchange, involving information disclosure about one individual service user, normally took place between frontline staff. For most of the service providers, the amount of information exchanged on each individual tended to be quite restricted. It was uncommon for service providers to share detailed files about an individual with one another.

Information exchange tended to have what might be termed a 'referral bias', in that information was most likely to change hands when an individual was being referred

from one service to another. This meant that the details exchanged were often minimal and that any personal information disclosed was confined to potential risks that a service user posed to themselves or to others. However, sometimes the mere act of referral, for example to a drugs service or ETE service for former offenders, involved the disclosure of personal information.

Most frontline staff emphasised the role of 'trust' in their relationships with service users. Staff described some adults facing multiple barriers to work as being highly alienated individuals who would sometimes only disclose information once a sense of trust had been established:

'There is an issue that sometimes people will tell you what they think you want to hear and then as the relationship develops, then more information will be shared. When someone is first asked about their substance misuse, they may not give you that information. However what you will then find is that maybe sometime down the line, once they have that trust, they have that relationship, then they're able to give you a lot more information.'

(Frontline worker, ETE service)

Building up this trust was generally viewed as being dependent on the service user feeling that no information would be disclosed to third parties without their permission. Frontline staff, therefore, took the view that successful engagement with service users was often dependent on appropriate management of information sharing with other agencies.

Frontline staff reported that they thought that service users could cease to disclose information to their service if they felt that information was to be shared without their permission. There was also a concern that some might disengage with that service:

'As a rule, I'd say, unless there is a really clear risk, we don't pass any information on, unless we'd talked to the service user first.'

(Frontline worker, homelessness service)

'It's so difficult to get people to turn up to a treatment agency in the first place. If you say to them "you can come here, you can talk, it's completely confidential, nobody will know you're here", then that's important to people. And I think treatment agencies will do everything in their power to avoid undermining that and they feel very uneasy about [other agencies] coming in and asking for some of this information, they don't feel that's right.'

(Manager, drugs service)

Those agencies working with some of the most alienated and marginalised individuals, such as people sleeping rough and people who are drug users, had particular concerns in managing information exchange. These services tended to be working with people who were described as often being involved in some form of petty crime and as having a general distrust of specific agencies. The agencies some

people facing multiple barriers to work distrusted included Jobcentre Plus (see Chapter 5) and the Police (although frontline staff were prepared to release information to the Police to support a criminal investigation):

'We just take the approach that as long as someone acts like an adult and behaves themselves...I don't know what they do when they are not here, fiddling the dole...or whatever they are doing, but I'm not aware of it...it's not hiding from any of it, it's just acknowledging that the people we work with, they're really hard get at people. If they think you're telling the employment service that they're not actually looking for work, they won't come back.'

(Frontline worker, drugs service)

'...the reality is that Jobcentre Plus have an enforcement role, people will not go near them, you know, sometimes they will come to us but they will not go near Jobcentre Plus and tell them the things they tell us. That also needs to happen, people need the freedom to tell agencies things and then know there's going to be no comeback, because sometimes you just need to air these things and discuss them, with an independent advisor you know is on your side and know it will not affect your benefits...if there's a risk you may not ever talk about it and you may not ever solve the problem.'

(Manager, ETE service)

A few small services tended not to share any information with other agencies for fear of service user disengagement. This minority of services also tended not to attempt to record particularly detailed information about their service users, nor did they check the information that they did collect:

'...they'll tell you what part of X they live in, but not which street, and phone numbers can be difficult. Especially if people are living with parents, they don't want someone from the drugs project banging on the door, so you do get a bit of resistance and some people may be making it all up...but they're usually quite happy to tell us, providing they think it's relevant.'

(Frontline worker)

Compliance with the DPA was not frequently referred to in respect of case-by-case information sharing. Nevertheless, there were concerns among some frontline staff related to uncertainty about the requirements of the law. This included some anxiety about their own position if they were found to have broken the DPA.

'I think there's a real tension because sometimes you can see the value in releasing information but actually if it's not formally agreed within your organisation, you are leaving yourself open, aren't you? If that person then turns round and says "well, I didn't want you to tell them that".'

(Frontline worker, ex-offender ETE service)

Similar concerns were sometimes expressed by managers about case-by-case data sharing and the DPA. These concerns related to the amount of decision making that rested with individual frontline staff and with a degree of informality in some case-by-case data sharing:

'Although, in many cases, there still aren't the sort of official information sharing agreements in place, people just get on with it. In fact there is quite a lot of worry at strategic or managerial level about information sharing problems, but on the ground the practitioners they don't worry too much about those issues, they just get on with it. They all understand confidentiality and they all understand the sensitivities...but beyond that they more or less do what they want.'

(Service manager)

3.3.3 Information sharing in relation to risk

Formalised, probation-led, procedures were in place for risk disclosure for ex-offenders who had committed certain types of offence. Multi-Agency Public Protection Arrangements (MAPPA) covered those offenders who might pose a risk on release, e.g. sex offenders, who are also sometimes referred to as 'Schedule 1 offenders'. Probation took decisions on what other agencies need to know on a case-by-case basis, including the Police, social landlords and so forth. Information release could include sharing information with potential employers, but this would only cover pertinent information for public protection. Such information was only ever released on a case-by-case basis.

Once such information was in other agencies' hands, however, the informal control exercised by frontline staff over case-by-case information disclosure reasserted itself. Staff often relied on their sense of the 'best interests' of the service user:

'If a housing provider said to me "Right, you're referring this person, I'd like a history of their offences", then my first question is "Why? What do you need it for?", if they then come back and say "Well, we need to know if they are a Schedule 1 offender or if they are known for violence", we can then be a lot more specific...so it's all about relevance really, we're happy to share information as long as it's relevant.'

(Frontline worker, Ex-offender service)

In general terms, the frontline staff erred on the side of caution. They tended to confine information disclosure on potential risk to what they deemed it necessary for other agencies to know. For example, they would convey that there was a risk of self-harm or violence, but not always think it necessary to disclose the details on why this risk existed:

'If we are referring someone to an employer, for work placements and work trials and the deal is that the service user has to agree anything that seems important, so if somebody had a criminal record we would have to tell the employer about it, but we would only do so with the explicit permission of the service user. So that would be explained to the individual as part of organising the placement. But it would be very wrong of us to volunteer information, that would be sticking our noses in too far, so if someone gets a job, the arrangement is between them and the employer.'

(Frontline worker, ETE service)

3.4 Shared databases

3.4.1 An overview of shared databases

Shared databases tended to be employed at local level for services that were specifically designed as interagency projects. In the case study areas, these shared databases were all recent developments and were fairly unusual, in that only quite a small number of agencies were involved in such an arrangement.

Three examples of shared databases were found in interagency collaborative services for drug users, former offenders and homeless people. For example, an initiative such as the Leeds Drug Intervention Project (DIP), which involved the Police, The Probation Service, the NHS, social services departments, voluntary sector drug services, Jobcentre Plus and the Prison Service, possessed a purpose-built shared database on service users. Shared databases were also employed by service commissioners as a way of allowing coordination between projects with a shared focus and as a means by which to generate statistical information for service and programme monitoring.

These shared databases were designed to contain an agreed minimum dataset. They did not constitute a collection of all the data held by participating agencies on their clients, but were instead a resource built around the data that each agency was prepared to share with the others. Thus, Police participation in a DIP database was confined to supplying data for a small number of fields (piece of information) and did not give the other agencies access to Police databases. Other agencies participated on the same basis.

The databases were established with procedures that were designed to secure free and informed consent from service users prior to any information being entered onto the system. Typically, these informed consents were documents stating how the data on the shared database would be used and which agencies would have access to it. These informed consents were in line with local interpretations of compliance with the DPA.

'...when we get the client's consent for storing that information, we make it clear that we will share that information within a partnership following certain rules and service users seem very happy to sign that. Because while they wouldn't want that information in the public domain, they seem to broadly trust the mainstream providers in London.'

(Database administrator, shared database)

Each database was accessed via a user name and password system which conferred different levels of privilege on each agency and individual user. Generally speaking, a service provider could only look at the records held on its own service users. The systems all used a web-based interface that allowed data entry and review of records through a browser.

3.4.2 The information recorded on shared databases

The participating agencies often had limited resources available for administration and lacked the capacity to enter extensive records onto a shared database. These systems were generally 'sold' to participating agencies on the basis that they would only record minimal pertinent information. This provided reassurance in terms of DPA compliance (that data were relevant and not excessive) and in respect of minimising additional administrative workload. These shared databases were also of direct use to agencies which added a further incentive to participate.

Shared databases were record keeping systems that were also designed to function as administrative tools. The main attraction to participating agencies was that they held full records of interventions with service users, allowing the construction of longitudinal datasets that monitored service use over time. This information could also sometimes be shared for the purposes of interagency referral:

'[Database] has first of all got all the obvious stuff, who somebody is, where they live, their basic details, date of birth, national insurance number, that sort of stuff. But then it also keeps a record of all of the interventions that you have carried out on an individual and you can keep notes on action plans and progress made against them...If somebody is working with one of our partner agencies, and they refer the client to [Agency], because they need a service that we deliver, I believe we then get full access to the notes that they've kept on the database.'

(Database administrator, shared database)

As an illustration of the range of data collected in shared databases, the contents of two such databases centred on service provision for homeless people can be examined. Both of these systems involved several agencies operating across central London.

The CHAIN (Combined Homelessness and Information Network) database was centred on people sleeping rough and the associated 'vulnerable street using population' in London. A range of agencies that worked with these groups in London contributed to the system.

The database contained details of individuals, assessments of their needs and a record of service contacts and interventions. Basic demographic information, including age, gender and ethnicity were recorded. The CHAIN database also recorded the following support needs and characteristics (which were categorised simply according to whether the following questions can be answered 'yes' or 'no'):

- whether left armed services;
- whether left prison;
- whether left local authority care (young people);
- whether involved in sex work;
- whether mental health problems are present;
- whether drug and/or alcohol 'dependency' are present;
- whether physical health problems are present;
- whether someone has a learning difficulty.

The richest element of the data within CHAIN was the longitudinal data recorded on service use. Each arrival and departure that individuals made at short-stay supported hostels was recorded. A very short note could be made on the arrival at accommodation services and on the reason for departure from those services. Contacts made with what are defined as 'pre-tenancy' services (i.e. assistance with locating, securing and sustaining a home) were also recorded and again, a short note could be made. These data allowed CHAIN to construct a picture of service use over time, building up a longitudinal picture of basic data on service contact for each individual over months or years.

As the data were longitudinal, CHAIN was able to show that there was a highly marginalised population who were characterised by frequent but unsuccessful contact with services. In late 2004, CHAIN identified 194 people who had a five-year history of sleeping rough and there were a further 61 people on the database who had been referred to participating services more than ten times (House of Commons, 2005).

The Off the Streets and Into Work (OSW) database was run by a London-based charity, which supports people who are homeless or at risk of homelessness by helping them move towards employability. OSW is a commissioner of services that funds ETE support to homeless and potentially homeless people through contracts with a range of other agencies <<http://www.osw.org.uk/>>. The database provided both a client record system for a range of OSW commissioned services and a longitudinal statistical database covering some 9,000 individuals who had been engaged with an OSW service.

The OSW database recorded broadly the same information on demographics, institutional history and support needs as CHAIN, again, largely confining the data to whether or not support needs like 'mental health problems' are present by using

a 'yes/no' field. As the focus was on ETE service provision, fields detailing basic literacy, numeracy and qualifications were also part of the database. Details of service intervention were recorded and the database also included some 'soft' indicators (i.e. based on frontline staff judgements) that were designed to indicate progress towards work over time. These soft indicators included frontline staff assessments of individuals' progress in the following areas:

- motivation;
- lifestyle;
- readiness for work/training;
- basic skills;
- skills for finding work.

There was space for frontline staff to give an assessment and to make comments on each of these areas. For example, the 'soft indicator' based on staff assessment of 'skills for finding work' was as follows:

'Skills for Finding Work (Phone manner, CV, appropriate dress, interview skills, application forms, confidence) [tick one]

- *Few skills and/or confidence*
- *Some skills and/or confidence*
- *Most skills and appropriate confidence'*

(Source: OSW).

The OSW database was a longitudinal resource. These data were not highly detailed, but they did record broad details of every service intervention by OSW-funded services and also recorded perceptions of individual progress. This allowed a picture of service use and service outcomes to be built up over time.

3.4.3 'Walled gardens'

Shared databases of these sorts can be described as 'walled gardens' of information sharing between participating agencies. For those organisations that are members of a shared database, access to records is controlled through internal security protocols, but there is the capacity to allow data sharing between participant agencies when and where appropriate.

However, these systems and the data held on them were inaccessible to those agencies that were not part of the network running a shared database. Shared databases were not designed to allow the data within them to be shared with outside agencies, except in anonymous and aggregate form. Again, it was feared that if service users felt that shared databases were not secure, or that information would be shared within permission, that they might not engage with services.

As noted previously, considerable care tended to have been taken in ensuring compliance with the DPA when establishing these shared databases. The data held on these systems was held not to be accessible to outside agencies without an alteration of that free and informed consent:

'As I'm sure you're aware with the Data Protection Act, our clients sign a consent form to go onto the system and that form says that the information can be shared amongst agencies working within the partnership, but that's it...so we really under the existing consent it wouldn't be possible to share information...we'd need to check it out with the Office of the Information Commissioner.'

(Database administrator)

3.5 Attempts to merge existing large-scale datasets at local level

Large scale sharing of **existing**, identifiable personal data was generally perceived as quite difficult in Leeds and London. In large part, this was seen as a result of the legal framework surrounding data sharing, particularly the DPA. Larger agencies took the view that free and informed consent from the people who had supplied information would need to be sought **retrospectively** in order to be certain of DPA compliance, which was seen as being impractical.

Large agencies would not allow 'fishing trips' within their datasets. A 'fishing trip' (a US term) involves looking for individuals in whom an agency might be interested. For example, Jobcentre Plus might, in theory, look for potential candidates for specialist ETE services, using the databases held by a social landlord or other agencies.

There had been just one attempt to merge existing large-scale datasets containing personal information within the two case study areas. This had been confined to an initial exploration of merging DWP data with local authority records.

In 2002, Leeds City Council had developed a pilot programme that allowed the integration and mapping of council datasets using GIS (Geographical Information System) software. This system theoretically allowed the City Council to map the tenure and other characteristics of households, according to the data it held on them.

Preliminary discussions began between Leeds Jobcentre Plus and the City Council with respect to possibly combining this information with Jobcentre Plus datasets in order to 'profile' areas, as similar work on GIS was taking place within Jobcentre Plus. However, while it was theoretically possible to bring together DWP and council data and produce a detailed map of Leeds, showing households by composition, employment status, benefit claims and so forth, this was never actually attempted. Both agencies decided that they would have to have free and informed consent for sharing from all those individuals whose data they proposed to merge. This had not

been secured at the time that most of the data were collected and seeking informed consent retrospectively was felt to be too large an undertaking:

'The constraint throughout has been the legislation and that still remains the position with the legislation around data protection. So, we had solicitors and policy people that worked in those areas that prevented us from bringing the council and central government, if you like, together to use a consolidated database. And that is still the case, that's still where we are at this point in time.'

(Staff member, Leeds Jobcentre Plus)

If it had proceeded, this exercise in sharing data would not have involved actually merging databases. Jobcentre Plus and the local authority would have instead made available selected information for a new, shared, GIS database. If the process had actually occurred, a new dataset would have been established for a specific purpose of mapping.

Through contacts made in the Leeds and London fieldwork, the research team learned about another 'data matching' project involving Manchester City Council and Manchester Jobcentre Plus . Although this was outside the two geographical areas that were the main focus of the research, examples of sharing existing data appeared so scarce that the research team thought it logical to also examine this exercise.

The exercise in Manchester was found not to involve the matching of data on individuals or individual households. The local interpretation of the legislative framework was that free and informed consent would have to be sought retrospectively from a great many individuals before existing data could be shared and merged and that the cost of undertaking this exercise was too great. An alternative approach was, therefore, adopted, which was to attempt to use aggregate, anonymised data to improve the profiling of relatively small areas of the city.

Manchester City Council, along with the London Borough of Westminster, was one of the authorities in which the enumeration for the 2001 Census had been subject to serious difficulties. According to Office for National Statistics' estimates, between 12-16,000 households, some 22,400 to 29,900 people, were missed by the enumeration (source: Office of National Statistics). Attempts had been made by the Office of National Statistics, using data matching, to correct the problem, but the lack of data had made the accurate profiling of areas by the City Council problematic.

A Public Service Agreement had been designed to allow the City Council access to DWP data at 'super-output' level, which was fairly small scale, but still held to be sufficient in area size to make identification of specific households impractical. The City Council had combined these data with its own and produced enhanced area profiles, which could then be used to target services somewhat more accurately.

These exercises appeared to have run into difficulties because they were attempted with data for which free and informed consent for sharing had not been obtained. Modifications to the consents signed by individuals when disclosing data to these agencies would, at least theoretically, overcome this obstacle and allow the kind of data sharing that was intended in Leeds to take place.

3.6 Issues in current data sharing at local level

3.6.1 Case-by-case information sharing

Information sharing on a case-by-case basis was not generally reported as being problematic. However, according to some frontline staff, there were sometimes errors and difficulties, with information not always being made available when it perhaps should have been.

The role of frontline staff as mediators of case-by-case information exchange was also not always described as unproblematic. Some respondents characterised this as meaning that information was sometimes 'hoarded' and not shared when it was necessary to do so:

'I still sometimes think why is it so difficult to find out that piece of information. We have tried all different ways but I think at the end of the day unfortunately it's down to personalities...because some people understand the whole concept of sharing information and referring but some people as I say it's very difficult to just get them to think out of their work and what they do...Some of the bigger organisations have to teach their staff maybe that information sharing is a good idea.'

(Frontline worker, homelessness service)

3.6.2 The maintenance and quality of shared databases

When a shared database is administered by many agencies, it is dependent on those agencies for accurate and timely updates. Properly managed systems can reject inaccurately entered data within certain parameters, usually confined to obvious mistakes, and they can also ensure that all relevant fields are completed. However, the omission of entire entries cannot necessarily be detected.

Previous research by CHP which examined a much larger shared database, covering rough sleepers across all of Scotland, showed that considerable errors can arise in shared databases when resources for management and checking of data are limited (Fitzpatrick *et al.*, 2005). Within London, concerns have been raised about NOTIFY, a shared database designed to ensure continuity of access to services for homeless families, when it was found that some local authorities were regularly failing to submit information (*Community Care*, 9 February 2006).

This research gathered insufficient evidence to comment on the standard of data that was held on shared databases. However, a few respondents did raise concerns

that without proper incentives and controls, data quality in shared systems could be undermined.

'There's various other organisations that have got [same database software] as well and I'm sort of in touch with a lot of their database managers and you know, people that do the same sort of job as me, and with them because they're just an organisational thing and not a contractual thing. I think they find it a lot harder to enforce proper data entry because they haven't got the stick of withholding money, because it's not the same kind of relationship.'

(Database administrator)

In describing individuals' needs, these systems were confined to broad indicators, such as whether or not someone was a 'drug user'. Other research has noted that designating someone as being a 'drug user' is a categorisation that is of limited utility because it conceals a very wide range of issues that may or may not form barriers to employment (Kemp and Neale, 2005). The findings of the current study also suggest that broad designations of types of 'need' may not be particularly informative, as they fail to convey the specific reasons as to why individuals face multiple barriers to work. These issues are discussed in more detail in Chapter 4 of this report.

3.6.3 Limitations in the data available for strategic purposes

Commissioning bodies, situated within local authorities, and the larger service providers, reported that they sometimes lacked sufficiently detailed aggregate information to inform their strategic planning. A local authority or a large service provider, such as a major social landlord, tended to hold many large datasets. Records on thousands of individuals and households were available to them, but these records tended to be limited in three key respects:

- While basic demographic information was collected, the data tended to be restricted to those pertinent to a specific service function, i.e. housing agencies collected data on housing need, ETE services on barriers to employment and so forth. A large scale dataset which gave a rounded picture of individuals or households, detailing all their needs, characteristics and experiences alongside their patterns of service use, was not available at local authority level. Data of this sort were also not available at the level of individual housing estates, streets or postcodes.
- Detailed information on subgroups of people was also not available as one large dataset. None of the large agencies had detailed information on all the homeless people, drug users, ex-offenders, refugees and other groups facing multiple barriers to employment across a given locality, such as a local authority area.
- Data tended to be in 'snapshot' form. It was not uncommon for agencies to have collected information at first point of contact but then not to have updated it. While some longitudinal data existed on service use and need over time, these tended to be restricted to the shared databases described above.

It is important to stress that the problem was seen by respondents as a lack of **detailed information** at strategic level. These agencies had access to sufficient information to know broadly where services should be directed and also knew which groups tended to need those services. In part, these agencies built these pictures up through their own datasets, in part through small area statistics from the Census and in part through aggregated and anonymised data from services.

Limitations became evident when trying to reach the most marginalised groups of individuals, on whom data might be scarce because of low service contact. It could also be problematic to locate and reach those individuals who were characterised by multiple barriers to employment, but who were not living among a relative concentration of those with similar needs to themselves.

There was also a temporal limitation to much of the available data in large datasets held by local authorities and large providers like some social landlords. These agencies tended to be collected at point of first contact and then not updated until there was subsequent contact. Individuals and households might go for years at a time before a need to re-contact their social landlord or their local authority arose.

Individuals with a low level of service contact tend to have less information collected about them. This made it difficult to be certain that everyone with specific needs was being targeted by appropriate services and to fully understand any differences between 'successful' and 'unsuccessful' individuals, who seemingly shared many of the same characteristics:

'I think one of the issues we have is that the more 'successful', I suppose, an individual is, the more capable they are, the less information we have...The less easy to track what has made that tenancy, that individual, successful or got them into employment or whatever...if someone moves out of supported accommodation into more general property, the information that we hold is getting less and less.'

(Senior manager, social landlord)

Two of the major social landlords who took part in the research sought to address some gaps in their data through conducting surveys of their tenants. However, surveys were reported as being quite expensive and there was also some risk of respondent fatigue:

'...because we carry out quite a lot of surveys, we can get low response rates, so it's not necessarily that people are sensitive about the types of questions, it's just they're tired of answering questions generally...we've done postal and face-to-face, if we get a feeling that it's going to be a low response rate we'll invest more and do face-to-face, door knocking and that kind of thing.'

(Database administrator, social landlord)

The level of accuracy within which service targeting and service evaluation could be undertaken frustrated some large service providers and commissioners. It was not that there were no data available, but the lack of precision in some of those data that

was the issue. Some reported that there was at least some inaccuracy within strategic planning and service commissioning:

'If we actually have the information about the true characteristics and behaviours of the individuals, surely it will cut down on the almost scattergun approach we have to take in terms of intervention, because we're not sure about the client group...'

(Service commissioner, local authority)

3.7 Summary

Within the two case study areas it was highly unusual for agencies to be working in isolation from others in their field. Agencies constantly swapped information with one another.

It was equally apparent that this information exchange was often constrained. Agencies did not freely share the detailed information they held on individuals with one another, but instead exercised controls, both formal and informal, on what information was released under what circumstances. A fear of losing engagement with at least some service users if certain information was shared with other agencies was ubiquitous. There were also concerns about protecting the well-being and interests of service users. Conversely, the degree to which individual staff members controlled information exchange on a case-by-case basis was sometimes seen as preventing relevant information from being disseminated.

Local shared databases run on behalf of a network of agencies, were tightly governed by local interpretations of the DPA. Access to these datasets was controlled and confined to those agencies which were part of a network running a shared database. The data provided by these shared databases were restricted in some respects. While providing relatively rich longitudinal information on patterns of service use, these shared datasets tended to contain only quite basic data on individuals' needs, characteristics and experiences.

Many of the other data that were available at local level were limited to service-specific questions and were 'snapshot' data that were only collected at one point in time. Data collection was also dependent on service contact levels, in that the fewer services an individual saw, the less data tended to be available on that individual.

Attempts to merge data from large databases had rarely taken place. This was chiefly because of the costs of retrospectively seeking informed consent to share data from individuals who had not given consent for their data to be shared at the time it was originally collected.

Both the formal and informal systems governing information exchange were only routinely overridden when an individual posed a risk to themselves or to others, or if a lone individual was being investigated for alleged criminal offences.

The information held on individuals facing multiple barriers to work held at local level was fragmented and was sometimes partial, depending on the range and nature of services that individual had been in contact with. This was made evident by the difficulties, expressed by some service commissioners and large service providers in securing detailed longitudinal datasets for planning and commissioning purposes. Some difficulties were reported in respect of precise planning and assessment of service interventions, because of a perceived element of imprecision in available data and a lack of longitudinal data.

4 Local service providers' and service commissioners' views on sharing data with Government

4.1 Introduction

Thirty-seven service providers and commissioners in the two case study areas were asked for their views on sharing service users' records with Government (see the Appendix). This part of the research allowed respondents to express their perspectives on whether, and if so under what circumstances, personal information on identifiable individuals might be shared with Government.

The following section of the report begins with a discussion of the potential advantages of information sharing on individuals from the perspective of the respondents. This is followed by a discussion of the questions around the DPA and legislative framework for sharing information on individuals that were raised by respondents.

Some other concerns about sharing individual service user's records raised by the respondents are then considered. The report then briefly examines the views of respondents on the sharing of aggregate, anonymous information. This section of the report concludes with a summary of the key findings.

4.2 Views on the potential advantages of sharing individuals' records with DWP

Some of the respondents identified potential advantages to data sharing with DWP. These advantages were seen as centring on three main areas, which were specifically related to combining local data with DWP data:

- improved coordination and better targeting of services in respect of local services working jointly with Jobcentre Plus;
- improvements to longitudinal data on service users and service use using DWP datasets;
- enhanced mapping of need by combining Jobcentre Plus, DWP and local data.

It is important to note that respondents universally assumed that a two-way exchange of information would be involved in any kind of data sharing arrangement. There was always an assumption that JCP and DWP would make available some of their own information on individuals as part of data sharing.

4.2.1 Coordination between Jobcentre Plus and local services

Data sharing was seen as offering potential advantages in respect of improving service coordination. There was a view that it would facilitate the delivery of coordinated multi-agency packages of support to individuals and, in particular, help ensure that highly vulnerable people had their needs properly recognised and responded to:

'I can only see it positively...a lot of times you're trying to track back to when they lost their job, accommodation, ID...stopped getting benefit. If things were flagged up on, say, the social security database that said they were street homeless from there to there or were in a psychiatric hospital from there to there. That would certainly work to their advantage as far as I'm concerned. But I can understand how some people think it's a bit going down the Big Brother line...[but] then have a full history and then we can help them in all different ways.'

(Manager, ETE service)

Several respondents also mentioned what has been described as the 'zero-stop shop' model (Dornan and Hudson, 2003). This is a system that is designed to go beyond the 'one-stop shop' model (i.e. joint assessment through one point of contact which provides a coordinated response from all relevant services). A 'zero-stop' shop model actively searches for those who are entitled to specific benefits or who require support, care or other forms of assistance and ensures they are targeted by those services:

'...sharing data that would be helpful to identify, potentially, people who might be eligible for benefit.'

(Senior manager, local authority)

4.2.2 Longitudinal data

Some respondents thought data sharing would allow them to track the progress of individuals after contact with services. Many service providers wanted longitudinal data to demonstrate the effectiveness of their services, while service commissioners wished for data on effectiveness to inform commissioning decisions.

The wish to track individuals over time was particularly important to some of the services working with refugees. This group of people were hard to track over time, particularly in respect of monitoring their situation over the medium and long term. As refugees became integrated within society they became increasingly difficult to locate and their progress became harder and harder to follow. Agencies wanted to know if refugees were able to successfully integrate into mainstream social and economic life in the UK.

Sharing data with DWP provided a potential answer to these problems for some respondents. DWP has large longitudinal datasets that can theoretically track an individual through their benefit claims:

'A centralised database of basic tracking details I suppose would be very, very useful, particularly where we have clients that are quite mobile throughout the country and being able to share accurate information between agencies would be very, very useful and also for our own monitoring purposes to monitor where people are coming from and going to would be very, very useful.'

(Manager, homelessness service)

'Where these people go is a big thing, an empty space...keeping the information up to date would be very good and the only sure way of that would be via Jobcentre Plus...'

(Frontline worker, ETE service for ex-offenders)

'Wouldn't it be great if we had this tracking system which had a long enough history to produce meaningful results? So we could measure success, we knew better what the success or failure factors were, so we could change the way we operate...'

(Senior manager, social landlord)

4.2.3 Mapping need

The two attempts at combining DWP and local authority data described in Chapter 3 were focused on providing enhanced GIS. In Leeds, there was a brief consideration of mapping data at household level before it was determined that seeking informed consent for data sharing retrospectively would be too difficult. In Manchester, an attempt to combine data for GIS at the lowest point that was possible, without needing informed consent, had been attempted to make up for deficiencies in the 2001 Census data.

The Leeds experiment did not proceed beyond a theoretical stage, but it is worth briefly examining what the project might have involved if it had been fully developed. Taking a selected area, the project would have theoretically allowed the mapping of individual households, providing, for each household, the following sorts of data:

- whether the household was occupied or empty;
- household tenure;
- household landlord (if rented, including social landlords);
- whether the household contained an older person;
- whether the household contained a disabled person;
- whether the household contained children;
- the current attainment levels of the children attending the local schools;
- whether the households which were renting from the local authority were in arrears;
- which benefits the household was in receipt of (if any);
- whether the household contained a person eligible for the New Deal for 18-24 year-olds;
- whether the household contained a person eligible for the New Deal 25+.

The district Jobcentre Plus and the local authority had an ambition to draw a potentially highly detailed socioeconomic GIS map of Leeds. Such a GIS tool would have been powerful, able to draw maps of individual streets, wards and postcodes as well as the entire city. If longitudinal data were included in the data sharing, the impact of strategies and service provision could be monitored via GIS over time.

As noted above, such data sharing would have been possible if it had been deemed practical to seek the appropriate consent retrospectively. Such data sharing could take place in the future if suitable free and informed consent was in place.

The joint work in Manchester did not have the same goal. In this instance it was designed to enhance area profiling at a more detailed scale, but not to map the characteristics and needs of individuals or households within the city.

In both cases, data sharing was being attempted to enhance targeting. Jobcentre Plus wished to locate individuals who had been excluded from ETE services or who had not taken up the opportunities offered by these services. There was also a concern about trying to find individuals who were long-term benefit claimants who might have the capacity to work if they were given access to the proper support and ETE services.

Larger social landlords and local authorities were equally attracted by the idea of enhanced targeting and enhanced mapping of need. The idea of being able to more

accurately profile areas in addressing worklessness was viewed positively. These agencies were particularly interested in the possibility of longitudinal mapping using GIS, to show positive or negative changes as interventions progressed:

'I'm very interested in how you would map things on an area basis, so you could start to develop more sustainability indicators so that we would know what you need to make the community tick, make the community really work...'

(Senior manager, social landlord)

Social landlords' interest in better data on worklessness was linked to the issue of 'residualisation' within the social rented sector, which refers to the increasing concentration of workless adults in the tenure (Lee and Murie, 1999). Social landlords have become increasingly concerned with social cohesion within their housing as a result of this trend and many of the larger agencies are actively involved in providing or enabling ETE services within a wider regeneration agenda.

For local authorities the concerns were the same. The authorities wished promote social cohesion and economic regeneration. Cities characterised by higher degrees of social cohesion, lower crime rates and less anti-social behaviour tend to be able to attract investment and new, economically active, residents which improves living conditions and gives the city a better tax base. Leeds, for example, has successfully promoted its city centre as a socially cohesive and safe environment. This has delivered dividends in promoting significant economic growth in a city that had hitherto been experiencing decline (ODPM, 2006).

4.3 Views on the legislative framework and the sharing of individuals' records with DWP

Three main issues arose when discussing the DPA in relation to the sharing of personal information about individuals with DWP. These were:

- some confusion about the DPA and its provisions;
- uncertainty about the practicalities of securing free and informed consent from some service users;
- very limited enthusiasm for any alteration to the current legislative framework to lessen the controls on data sharing.

4.3.1 Confusion about the DPA

Some respondents had low levels of awareness of the details of the DPA and associated legislation. These individuals tended to interpret the legislative framework as meaning that the sharing of personal information was highly restricted and they tended to rely on their own agency's policies and procedures rather than seeking external guidance. It was universally the case that those frontline staff who had more limited knowledge of the legislation erred on the side of exercising a high level of control over information disclosure.

For a few respondents, some of the local interpretations of the DPA were a source of frustration. There was a feeling that a blanket interpretation that the DPA greatly restricted information exchange provided something of an 'excuse' not to share information, which could be unhelpful. This lack of understanding of the DPA, coupled with an assumption that it severely limits or prohibits all forms of personal record sharing, has been reported in other research on electronic service delivery at local authority level (Pleace and Quilgars, 2002):

'If you're trying to access information a lot of people sort of see the Data Protection Act as black and white, you don't share full stop...people don't totally understand where the mechanisms for moving [data] are in there...and others just don't understand anything so you're almost against a brick wall.'

(Manager, ETE service for ex-offenders)

'People misunderstand the idea of data protection, freedom of information, so again they'll actually put a limit on information which can be shared due to the fact that they don't understand it.'

(Database manager, Probation Service)

A few respondents in management positions thought that there was insufficient accessible guidance on the DPA. These individuals wanted more information on the legislative framework and clear indications of what was acceptable, under what circumstances, in terms of data sharing:

'Well, part of the problem is that the procedures to do with information sharing just aren't that well developed at the moment. There's been very little information from central government, they talk a lot about information sharing, but don't tell you much about what it would look like...they talk about it in very grand terms, but don't actually tell you how to do it.'

(Service manager)

4.3.2 Views on seeking free and informed consent under the DPA

The respondents who had a more detailed awareness of the DPA took the view that personal information could be shared with DWP if the appropriate free and informed consent was in place. Providing this consent could be secured, there was not held to be any legal prohibition on sharing personal individual level data with DWP.

Shared interagency databases that operated using free and informed consent from service users were up and running in the case study areas. However, the consents used did not include data sharing with DWP, the Home Office or other interested departments, so the view of respondents was that the consents would need to be modified before such sharing could take place.

Three potential problems with using free and informed consent to allow data sharing with DWP were identified by respondents. These were that:

- 1 seeking consent could be time consuming and resource intensive;
- 2 there would be difficulties around ensuring that some service users had understood the consent they had given and that their consent had been given freely;
- 3 some service users might refuse to sign a consent or disengage with some service providers if certain information were shared with DWP.

There was a concern that seeking free and informed consent would add a layer of administration. As any system for seeking free and informed consent would have to theoretically stand up in court, some respondents thought that staff would need to be on hand to explain what the consent was and answer someone's questions. Simply presenting an individual with a form that they were to sign was seen as perhaps not being sufficient:

'Informed consent is labour intensive, therefore expensive, and the reason it's labour intensive is that you have to spend a lot of time obtaining the informed consent.'

(Senior manager)

Some respondents were concerned that there would be other difficulties in ensuring that a consent could be demonstrated to be 'informed' in court. One issue was that there was a perception that at least some service users would only have a limited grasp of what they were being asked to sign. This might be for many reasons, but essentially involved issues that might affect comprehension:

'...by informed, it means that they do understand all of it, and that's our biggest problem to be honest, with our people they're half zonked most of the time, they're not even informed about the time of day sometimes.'

(Service manager, drugs service)

Several respondents were concerned that service users would tend to sign a consent unquestioningly because they trusted staff advice. There was a worry that unless it was very carefully explained, service users would not be aware what they were giving consent to:

'I certainly would be distressed if I found out that any of my staff were not explaining fully to service users what they were signing. But I think quite often the temptation is that you'll sign something, I mean how often are we in travel agents and they give you a long form to sign and you never read it, I think the same is true through society. So, yeah, my suspicion is that some service users, even if it's explained to them carefully, don't understand the informed consent they are signing away.'

(Service manager, homelessness ETE service)

'In some respects, service users are tremendously trusting and depending on how it was sold to them, many would just go along with it, I think. There would be some who were a bit more in tune or cynical, or more anxious about it, but we work with people who are often in a very vulnerable state, so they are more open to suggestion...which is I suppose why you feel a bit more, not protective, that's probably the wrong word, but supportive.'

(Frontline worker, ex-offender ETE service)

'My feeling with the vulnerable tenants is that they are disempowered people and that they would agree to most things...there's probably a difference between the general let stock and the vulnerable, I do think they would be less critical.'

(Senior manager, social landlord)

Some respondents were concerned that signing a free and informed consent would be viewed by respondents as a form of 'barter'. In that service users would tend to assume that there was a requirement to sign in order to get access to the service.

There might also, according to a few respondents, be a simple expectation that forms had to be signed, since that process is always involved when claiming benefits or seeking a service:

'The client group is so used to signing a million different pieces of paper that they'll just sign anything. My concern is that they'll just sign it without really understanding what it is, just because they're presented with so many sheets of paper...'

(Service manager, drugs service)

'To be honest, nine times out of ten, my clientele, they would sign anything.'

(Service manager, homelessness ETE service)

Some respondents also thought that there would be pressures on the time available to agencies to process the consents. Workers might be too busy or pressured to explain everything to people who might have trouble grasping what they were being asked to do, unless someone could patiently supply considerable support:

'I think the difficulty comes when you are talking about vulnerable people, who are perhaps in a difficult position, who are more than willing to share life history that you don't actually need to know, in detail, if they think it will help them achieve a positive outcome for them. So the biggest danger with something like that, it's one more task to explain it, so we won't really, we'll just shove it in front of them for them to sign it, and they will, and ever after we can go "Aha, but you signed this!"'

(Service manager)

It was also anticipated that at least some service users would refuse to sign and might avoid services that wished to share their data. Again, there were particular concerns about how services users might react to information being disclosed to Jobcentre Plus or to criminal justice agencies (see Chapter 3 and Chapter 5):

'It could go either way. For some people, I don't think it will be an issue and I think they will be quite happy, you know, just to share that information with you and be very, very open. I think for some other people it's going to go completely the other way...they don't want to be counted, they don't want to be on registers...they just don't choose to go into any statutory systems.'

(Service manager, homelessness service)

'Probably we'd find that a lot less clients would be prepared to sign the consent form, if they read on there that the information was going to another agency, like DWP, so that would be an issue for us. Because basically we would be at risk of losing data ourselves.'

(Database administrator, homelessness ETE service)

'I think they don't like the labelling side of it...that comes up quite often...their confidence and morale is zero...I don't think they'd be too happy if we said here look, this is for our information but I have to tell you now that this is going on a database to say that you're an offender.'

(Frontline staff member, ex-offender ETE service)

Service providers were concerned that at least some of their users would cease contact with services if they were told that information would be shared with DWP. This was, in the view of some respondents, linked to a general cynicism about Government among some marginalised people. Respondents reported that the experience of interaction with public services among certain groups was often negative, ex-offenders and drug users often had experience of the 'State' through punishment. Others were service users who were reported as finding the interactions needed to get benefits or access to services demeaning or threatening. This led to a concern among some respondents that it would be the most difficult to reach individuals who might disengage with services if presented with a consent form to sign:

'If you want to engage the people that are harder to engage...the people who are economically inactive, you have to have the independent grass roots voluntary sector organisations where people feel they can go and it's not part of the establishment, it's not part of the government controlled whatever...I think if you introduce anything which will detract from the client 'centredness' of those voluntary sector organisations in relation to these groups it won't be effective in achieving the aim of getting people back into work, because to engage people they feel they need to trust the organisation.'

(Senior manager, ETE service)

However, some respondents thought that if both the presentation and content of a free and informed consent form were carefully managed, many service users could be persuaded to sign. Suggestions included the capacity to 'opt in' to sharing information with specific agencies, such as being able to tick boxes that showed it was alright to share personal data with Jobcentre Plus, the Police and other services. In addition, if service users could be reassured that the uses to which their data would be put were in their interest they would be more likely to sign a free and informed consent:

'I think it would have to be sold to them quite carefully. I think if I was a service and you said to me "You're homeless, we want to keep this information on a big computer in Whitehall", I'd say "What for? You can't". But if you said you were keeping information on a big computer in Whitehall because you were doing some research and you wanted to see what happens when someone has this sort of intervention and that's all you'll use it for, I'd say yes. Or if you said we want to keep this information because we want to be able to flag you up to appropriate services in the future, I might say yes. But I think it's how it's sold.'

(Service manager, homelessness ETE service)

4.3.3 Views on changing the legislative framework

Almost all of the respondents did not want the law around data protection changed. This finding has to be viewed in the context of some respondents only having a general sense that the DPA 'prohibited' most information exchange and lacked a detailed knowledge of its operation.

A very small number of respondents thought the requirement to seek free and informed consent should be ended and the legal protections lessened. These individuals viewed the collection of free and informed consent as being too costly and time consuming:

'If data sharing has real added value, is crucial to our future business in terms of bringing together localism and everything, then we're going to have to change that legislation.'

(Senior manager)

'There is a problem because people are not getting the benefits of the welfare state because the various arms of the welfare state are reluctant to share information because they're scared of consequences under the DPA. The government basically in my view can't have it both ways...either they want all these various disadvantaged groups helped in which case we've, everybody, has to go out and find the right level of information to find them, identify them and engage with them...'

(Senior manager)

4.4 Concerns about sharing service users' records with DWP

A number of concerns were raised by the respondents about sharing identifiable personal information from service users with DWP. These concerns included:

- ethical issues associated with the classification of individuals as being members of certain 'customer', 'client' or 'service' user groups;
- the risk that negative stereotyping might occur when certain kinds of data on individual needs or experiences were shared;
- the perceived risks of inaccuracy in shared data;
- the balance between practical advantages and ethical concerns in tracking service users longitudinally via shared data;
- unease among a few respondents about the potential within large shared datasets for surveillance.

4.4.1 Ethical issues in the classification of individuals

There is a need to sort and classify the workless and unemployed population in order to identify working age adults facing multiple barriers to employment. Such a process involves describing individuals through one datum, or a series of data, that 'classify' them as belonging to a given group. Some form of classification is necessary to ensure appropriate service responses from Jobcentre Plus or specialist ETE services, as a person has to be described on some level to ensure they are directed to the correct services. Equally, some classification of individuals is necessary in order to create a population or area profiles for strategic planning or for service commissioning.

For many of the respondents the act of classifying an individual was seen as a process that needed to be undertaken very carefully. Incorrect classification was seen as one form of potential risk, while the stigma attached to some forms of categorisation was seen as leading to the risk of discrimination. Labelling or classifying an individual, therefore, had to be handled carefully:

'...with the vulnerability issue and how we collect [data on] that. There are issues around how accurate it is, whether it is a true reflection of that person and then, over time, whether it remains a true reflection and there would be issues with residents' access to files, as they make take exception if they asked to see their records, which have to be open, they might say "why's this file saying X, Y and Z?".'

(Information manager, large social landlord)

In the view of some respondents, the descriptions of individuals as drug users, homeless people or ex-offenders were associated with images that were almost universally negative. Stigmatisation was a real risk in placing service users within

certain categorisations in their view. The topic guide for the research employed the database terminology of 'flags' or 'tags' when talking about classification, this is a reference to fields within a database that identify someone as belonging to a specific group. These terms were sometimes adopted by the respondents in their answers to these questions. Particular concerns existed about how classifications might be interpreted when referrals were made between agencies:

'Will people say "Flag! Don't stare them in the eye, don't let them into my office"?. Though someone might say "Oh they must be vulnerable" and be more helpful, its really dependent on who's on the other side of the computer. And I don't think we're in a position to be sure that the person on the other side of the computer is going to be well enough trained to deal with that information.'

(Database administrator)

'I also think, maybe to people who weren't involved in the drugs field, or only had a very incidental involvement, it might not be clear what that was supposed to tell them and it might end up actually stigmatising people and disadvantaging them somehow.'

(Service manager, drugs service)

Two respondents, who were senior managers working for a social landlord, discussed the issues as they saw them:

Respondent 1: *'Supposing someone comes into the system...he's flagged, because he's got a history of homelessness, a history of drug use.'*

Respondent 2: *'But don't I want to know that to place him successfully? The last thing I want to do is put him in 23 Acacia Avenue, if I've got another one just like him living at 25.'*

Respondent 1: *'Yes, but your processes that you have in place, your assessment processes, are going to identify that anyway, right? So you've got this flag on this man...how often is it updated? How accurate is it? What do you have to do to get a flag? Is a flag a bad thing, is it perceived as a bad thing?'*

4.4.2 Risks of inaccuracy

Two concerns existed around the accuracy of a shared dataset on individual service users' needs. The first was concern was maintenance. Some respondents wondered how local Jobcentre Plus offices or DWP itself could be confident that the shared data it held on individual need was up to date and accurate, given how rapidly the needs and circumstances of people facing multiple barriers to work could change. A large database was often viewed as, at least in part, a potentially out of date and possibly inaccurate one:

'That's my key concern-the quality of the information that would be held within that kind of system. How is it checked and how is it validated and how are you sure it's right and accurate and up to date.'

(Service manager, homelessness service)

'It would be an issue of who would have access to it and why and also how up to date it was. Because someone could be an active user committing offences three months ago and actually scripted and not commencing any offences today. And that's quite a lot of input isn't it?'

(Frontline worker, drugs service)

'Overall, a database that comes with caveats is worse than useless, because everything has to be checked again.'

(Senior manager, local authority)

The second concern was in respect of the detail of the information within a shared database. One issue here was held to be a risk of over-simplification, which tended to be expressed in terms of complex and varied needs being grouped together using one indicator, or 'flag' or 'tag':

'This thing about tagging somebody 'drug user' though, is a bit more controversial...there are lots of different types of drug use. You need to know what type of drugs they are using, how often are they using and is it on a habitual or recreational basis, what combinations of drugs are they using, are there surrounding factors, do they know other drug users? Now, one tick box is not going to tell you all that.'

(Service manager, drugs service)

'They are quite varied in their needs...also you get other issues as well, are they heroin users only or are they using heroin and crack cocaine as well and do you want to identify people using multiple drugs or people using one type of drug? There are people using heroin and crack, people just using heroin and people using all kinds of other substances as well. I don't think putting everyone together as 'heroin users' is really going to help you.'

(Service commissioner, local authority)

A few respondents also identified a more complex question surrounding the meaning of data on individual needs. This was in respect of how much of the information on need that was collected was based on the interpretations and opinions of frontline staff rather than an objective measure. For these respondents, who tended to be in senior management positions, there were questions around the status that should be ascribed to some of the information held on service users:

'I think the problem obviously is always going to come back to how people code things and actually ensuring that people effectively pick up, or as far as you possibly can, you effectively pick up whether someone is vulnerable or not. I mean you have to have an assessment process in place, in a number of places possibly, to see if someone has a drug and alcohol problem, for example...you would need everybody codifying things in the same way...'

(Service commissioner, ETE services)

'...the interpretation that people put on that can be completely different. Well, not completely different, but different in terms of what that officer might see to be as a requirement for support or whatever.'

(Manager, local authority)

Problems were held to exist around common categorisations such as 'potentially violent', which was a recording of opinion, from a staff member in an agency, on the risk that an individual might pose. The measurement of some support needs and their extent, for example of 'soft indicators' on readiness for work, were similarly viewed as recordings of a worker's opinion. When data were a matter of perception, influenced by organisational culture and other factors such as professional training, interpretation was viewed as being likely to be variable:

'We don't have a common language across agencies. What I perceive as a risk may not be perceived as a risk by someone else.'

(Manager, ETE service for homeless people)

4.4.3 Practical and ethical questions in tracking service users

A few service commissioners and providers were unresolved on the balance between what they saw as the utility of being able to track service users, as against what they interpreted as the risks that tracking might pose to service users. They were uncertain whether possible gains for planning and evaluation outweighed possible threats to privacy and the risk of discrimination:

'I think it's interesting, because I think there is value in looking at things on that larger scale. There are clear dangers, because we're tracking drug users or ex-offenders, so is that an inclusion or an exclusion process? But obviously, there are ways to work round those things, but those are the immediate cautions you have. I suppose the question mark then would be, to a certain degree, not whether you can do it, I am sure you can, but what value were you going to get out of it?'

(Service commissioner, local authority)

'There's pros and cons isn't there?...for individuals approaching services like ours, if they know we're going to be passing on information, we're basically going to be flagging them up to the government, then it's gonna have an impact on their relationship with us and the trust and confidence they have in us, yeah? It would also have generally a kind of stigmatising effect I think. But then on the other hand, we have big problems not being able to identify groups, you know refugee communities in particular places, and so provide the sort of services that local communities need...'

(Senior manager, refugee ETE service)

'Feels like a double-edged sword that, doesn't it? Because, on the one hand if it really did allocate resources and support and all those positive aspects that would be really good. But it sort of goes against the grain in that, you know, if people want to change their lives, all that information being held on a database somewhere just doesn't fit with that does it?'

(Service manager, ex-offender ETE service)

'If the information can usefully benefit the individual, then I think the idea is sellable to the individual and [organisation]. One of the really real problems is tracking people, what happens to them, what happens to a formerly homeless person, if they get a job, do they stay in housing? Do they stay in employment? What happens to an offender, do they leave prison and get a job? Do they re-offend? And it would be invaluable information because it would help to tackle some of these social problems. But at the same time, when can an individual leave his or her past behind, when can someone stop being regarded as a formerly homeless person or an ex-offender? So, I am uncomfortable about the idea of Big Brother and keeping that much information on an individual for an indefinite amount of time, but I can also see the advantages.'

(Service manager, ETE service for homeless people)

Several respondents were concerned with how long any 'classification' of an individual would endure within tracking systems. For many individuals, their situation as a 'homeless person', 'drug user' or 'ex-offender' was held to be transient, while refugees were generally felt not to want to be described as 'refugees' for long. The concern was that a 'label' would be applied after it had ceased to be applicable and might lead to disadvantage or inappropriate responses from services:

'...there are so many questions there and...somebody who's been involved with drugs are they gonna be tagged as a person with a drug dependency for the rest of their lives are they even if they become clean? In addition to data protection issues, I would have thought there's a very serious human rights issue there isn't there?'

(Service manager)

'I can see so many positives in that [data sharing with government], but I don't want it to happen. I think the risks are that people will become stigmatised in some way, if you go into a benefits office, let's say you been homeless, and then you go to the benefits office, or maybe the tax office and you're working now, it's ten years later, and a little flag appears, "oh what's that about?"... You know people discriminate, "they were homeless, they were a junkie", it's interesting to people, it's entertainment, the idea that I'm ringing the tax office to sort out my return and someone knows my history...'

(Database administrator, homelessness service)

4.4.4 Concerns about surveillance

'Surveillance' is being used as a shorthand term to describe academics' and social commentators' concerns about the capacities of database technologies to sort, classify and regulate the population in ways that are not necessarily desirable (see Chapter 6e). A few respondents saw a potential for the abuse in creating a large shared dataset of personal information on identifiable individuals.

These concerns were about privacy, data protection and control, but can perhaps be best characterised as a kind of general anxiety about the power of such a dataset:

'If it's about directing help and assistance, I think that's interesting. If it's used as a barrier or obstruction, then it's problematic. We talk about opportunities and choice for all, but what do we actually mean by that? Because ultimately this process could actually be about social engineering and that's the challenge really.'

(Senior manager, social landlord)

4.5 Sharing aggregate, anonymised data

Representatives of a few of the smaller agencies that took part in the research were unlikely to possess aggregate information and would be reluctant to release it if they did, because their numbers of service users were so small that there was a risk of individuals being identified. In general terms, however, agencies were quite prepared to share information with DWP and other arms of Government on this basis.

However, this was essentially the current practice of these agencies. Many produced aggregate and anonymous information for the purposes of performance monitoring, which was sent to local or central government, or used such data to demonstrate service effectiveness in their annual reports.

Again, there was a concern about administrative workload and cost in producing additional information. A few respondents had mentioned duplication of effort involved in delivering all the anonymous information that was requested and sometimes questioned the uses to which it was put.

4.6 Summary

It was apparent that larger service providers and local authorities had an interest in improved statistical data on workless populations at local authority and ward level. These agencies had an interest in improving joint working with Jobcentre Plus, in having better data to facilitate GIS aided planning and to learn more about subgroups of people with shared characteristics. There was also an interest in having better data to find individuals with specific needs. These agencies had an interest in longitudinal data, both in respect of strategic planning and for service evaluation and performance monitoring. These objectives, on a smaller scale, mirrored many of

DWP's interests in data sharing. Among smaller agencies too, there were attractions in the idea of being able to track service users after contact with their service had ceased via DWP datasets.

Awareness of the legislation varied. Some respondents had little direct knowledge of the DPA beyond a general sense that it outlawed the transfer of personal data which contained personal identifiers.

Among those respondents who had a greater knowledge of the DPA, there was a broad consensus that personal data could be shared with DWP via a suitable free and informed consent. There were no legal obstacles, in their view, to sharing data once such a consent had been obtained.

However, difficulties were foreseen in securing free and informed consent from service users which would be sufficiently robust to be tested in court. There were seen to be problems with ensuring the proper effort was involved in explaining the consent to people who might need a lot of support to understand it. In addition, there were concerns that vulnerable and easily led people might sign a consent without questioning its contents. As was the case with information sharing at local level, there were worries that some more marginalised service users might disengage with services if they were asked to sign a consent.

However, some respondents thought that with the proper explanation, service users would be prepared to sign a consent. This would allow their data to be shared with DWP.

Very few respondents thought that the legislation should be changed to allow data sharing to take place without the need for consent. Most respondents with an awareness of the legislation reported that the DPA provided appropriate protection in their view.

Several questions were raised about data sharing that were centred on the use to which information might be put. There were concerns that the process of classification of individuals could lead to service users encountering prejudice or being disadvantaged. There were also uncertainties about the accuracy of shared data on individual needs, in terms of how far summary data might properly and fairly represent someone. Within this, a few respondents worried that too much status might be given to data that were actually records of opinion rather than clear fact. There was also a concern that once someone had been described in a certain way in shared data, this 'label' might stay with them, perhaps to their disadvantage.

While many agencies had an interest in tracking service users longitudinally, the respondents often talked of being unsure about where to strike a balance between agency interests and those of the individual. It was potentially very useful to map the trajectories of populations, but there were concerns about individuals being disadvantaged by being classified in certain ways and then tracked.

Concerns about the wider implications of creating a large shared database of personal information were present among some of the respondents. These concerns centred on the use which was to be made of this information and whether it benefited those on whom the data were held.

5 The views of people facing multiple barriers to work on data collection and sharing

5.1 Introduction

Fieldwork was undertaken with a number of people from each of the 'service user' groups who fell within the remit of the research. Seven focus groups were held with a total of 40 homeless individuals, refugee households, people using drugs or who were alcohol dependent and recent former offenders.

This section of the report begins with an overview of the characteristics of the focus group participants. This is followed by a discussion of the views of the respondents on having information collected from them by agencies. The views of service users on sharing information with DWP and other Government departments are then examined. This chapter concludes with a summary of the findings on the views of people facing multiple barriers to work.

5.2 The characteristics of the respondents

There was considerable overlap between the characteristics of participants in the 'homeless', 'drug and alcohol users' and 'ex-offender' focus groups. Many of the participants in these groups might be more accurately described as people with multiple needs. It was not uncommon for participants to be simultaneously homeless, a former offender and a drug user, for example, nor was it uncommon for such issues to be present alongside mental health problems.

Seven groups in total were engaged in discussion for the study with between five and ten participants in each, encompassing an age range of between 18 and 50

years old. All groups were accessed via local level services from which they were receiving assistance. The two refugee groups consisted primarily of professional men and women of various origins who were having difficulties accessing services and/or finding employment in the UK. Both were lively discussions with no evidence of any language barrier. Two of the other groups were made up of former offenders who had recently been released from prison. The remaining three focus groups were people with multiple needs recruited via homelessness services. Two of these three groups contained some people who were currently sleeping rough (i.e. sleeping on the street).

5.3 Views on information collection

Service users were asked about their views on having information collected from them, and also about the ways that information was used. This was an attempt to elicit opinions on providing data when approaching a given service. The key issues discussed by service users in respect of information collection were as follows:

- limits governing disclosure of personal information when seeking services;
- risks when disclosing personal information to services;
- information collection as a deterrent or bar to applications for services;
- concerns regarding the processing of information by agencies;
- the security of information once it had been computerised.

5.3.1 Limits governing disclosure of personal information when seeking services

For many respondents, information disclosure was seen as a process that had to be completed in order to obtain access to required services. Forms had to be filled in and questions answered in order to obtain what was needed. The descriptions of service users gave a strong sense that they perceived information disclosure as the 'price' that they were required to pay for assistance. The disclosure of basic information when seeking services was not seen as problematic by most service users, who regarded it as being routine:

'It's usually surname, name, date of birth, National Insurance number, address, pretty much the same...you get asked that often you just get used to it.'

(Homeless person)

Personal questions were viewed as acceptable when they were seen as relevant to the concerns of a service being sought. One example given by respondents was being asked about back problems by Jobcentre Plus. This was perceived as being acceptable since it related to the work they could be expected to do.

There was also an awareness among respondents that certain key pieces of information were of central importance in accessing some services. Being in a

household containing a child, as opposed to a lone individual, was seen by some respondents as a passport to a wider range of services. Such information might, therefore, be volunteered because it would convey advantages:

'If you've got a girlfriend who's pregnant...you can get everything. But if you've got a girlfriend who isn't pregnant, you get nothing.'

(Homeless person)

However, there were, for many of the respondents, limits to the information 'price' they were prepared to pay for services. These limits centred on what was seen as an intrusion of privacy. Respondents very often expressed these limits by discussing what they described as the questionable 'relevance' of some of the questions they were asked. As one female refugee stated:

'You want to know the reason why they need that information...I may not be willing to share information sometimes if I'm not really sure of the reason or if I think it's not really concerned with the problem I have to solve.'

It was apparent that respondents were definitely not comfortable with service providers asking for information that the service user deemed them as 'not needing to know'. No clear and consistent definition was given from the groups as to what constituted information being 'irrelevant', but it seemed to centre on personal or potentially embarrassing information that they would only disclose under certain circumstances. Medical histories and a criminal past were mentioned as areas that respondents would want to 'keep quiet', unless it was directly relevant to the service they are interacting with. One exchange was representative of the views of many respondents:

Respondent 1: *'Like someone knowing your criminal record, it's embarrassing, it will be really embarrassing you know. I'm not proud of some of the things in my past and I'd rather it was kept quiet.'*

Respondent 2: *'We've all got stuff we want to keep quiet.'*

Two homeless respondents, in different focus groups, reported the conditions they applied to disclosure when responding to requests for personal information from services:

'I will answer, well, I will only tell them what I want...if they pry too far and ask questions that I don't like, I'll say well, I'm not going to tell you. It depends what they ask and how they ask it.'

'It's a need to know basis, if they don't need to know then you don't tell 'em. If they need to know, then tell 'em.'

Under some circumstances, respondents were prepared to share highly detailed personal information with service providers. Some respondents reported the view that full and frank disclosure was required to get the best response from services. Quite often this information exchange was face-to-face with a staff member with whom a respondent was working directly. Two respondents reported:

'They need to ask you kind of questions like that so they know what kind of help you need and what treatment you need...you're not gonna get the help unless you tell them.'

'It's a lot more personal now...The people you work with become your team workers so you spend a lot more time with that person anyway so you're probably gonna answer these questions while you're together anyway do you know what I mean, so its best for both of you...it gives you a better understanding of that person who's asking you questions as well...'

For many respondents the relationship between themselves and a staff member they trusted was described as being very important. Such relationships were described as facilitating personal information disclosure and, as trust grew, as creating a situation in which more and more information could be disclosed. This kind of trust seemed to be more strongly associated with more specialised services, but there were a few respondents who reported positive trusting relationships with staff in mainstream services, including Jobcentre Plus. This face-to-face interaction with a known individual was key to many respondents feeling comfortable in talking about themselves and their experiences; two respondents, in different focus groups, reported:

'It is definitely different when you are talking to someone and you know that this is a person that you are giving information to, so you are not worried about anything else. I think that's a very important point, very good point, to give the information to the person that you want to, but not somebody else.'

'I actually think right, if they don't go too far deep into your personal life it's ok. Do you understand? But if somebody comes along that you've never met in your life before... like me New Deal advisor, I would open up to them, because me New Deal advisor and me are mates.'

5.3.2 Risks when disclosing personal information to services

Service providers did sometimes report that service users would try to present a picture of themselves that corresponded to what they thought of as being a 'service worthy' individual. There was some evidence that certain information was withheld from some services, because there was an anticipation of a negative and prejudicial response were it to be disclosed.

This practice appeared to be most prevalent in respect of what might be described as mainstream agencies, i.e. those services which tended to mainly engage with the general public. In these instances, the respondents were dealing with staff who were not necessarily trained or experienced in understanding their needs.

Respondents were also sometimes embarrassed by some of their needs or their experiences. A respondent could potentially feel simultaneously upset at having to talk about something embarrassing, but then also have to deal with that information eliciting what they saw as a hostile response. The following exchange between two recently released ex-offenders illustrates these points:

Respondent 1: *'...if I go into Benefits Agency [Jobcentre Plus]...I don't like explaining to them...they don't know nothing about it and they categorise you as a drug user...but then you come into here [drug service] talking to people who know...so I'd probably lie at the Benefits Agency...but coming here and expecting help I'd probably give them as much information as possible.'*

Respondent 2: *'Yeah, I think when you go to benefits agency when you come out of prison, they just look at you as though...you're crap, you're nobody...When I went down to make a claim, she said we do have to ask this [about drug use]...I thought what has this got to do with my claim?'*

Many respondents commented negatively about the lack of 'understanding' encountered in mainstream agencies. Some respondents argued for a greater degree of specialisation within mainstream agencies to better orientate them towards their needs:

'We're not different from other people, but it's like different circumstances, like some of us sleep on streets and stuff like that, like in social [Jobcentre Plus] and [council] housing and all that they should just have like special workers that work with people who understand our circumstances. Because we are not like them who have got houses and all that, if we sleep on street, it's like hard for them to understand that, they just treat us like you know, like you know, Joe Public, but we're not like that, because we're sleeping on streets...'

(Woman sleeping rough at time of interview)

These negative experiences were often a matter of a staff member in a generalist service asking, for example, a single 'tick-box' question on whether someone was a 'current drug user' or 'homeless'. According to some of the service users, if the answer to a question like that was 'yes', then they would be treated differently from other members of the public.

Equally, there was a concern among some respondents that once personal information was conveyed to staff in generalist agencies, there was often uncertainty about how to meet their specific needs, which led to inappropriate responses. One of the areas where this pattern appeared most pronounced was in the reaction of services to refugees who were seeking employment. Refugee respondents spoke of administrative inflexibility and the need to process information according to set patterns, resulting in negative encounters with Jobcentre Plus in particular. As one refugee respondent put it:

'Sometimes when you go to the jobcentre, they don't want to listen to you, they seem to want to dictate, to tell you what to do. For example, you have qualified doctors, it's your right to look for a job in your field, but they just say "no, you apply for cleaning, for anything"...''

From the perspective of some respondents, personal information on need was being conveyed, but was then sometimes being misinterpreted, ignored or used as a basis to arbitrarily disadvantage them. This made the process of information giving

distressing for these respondents. When the collection of personal information did not tailor the response of mainstream agencies to better suit their needs, they questioned why they should hand over that information to begin with.

5.3.3 Information collection as a deterrent or bar to applications for services

Complex forms and processes can be a deterrent to those seeking benefits or access to services. Bureaucracy can also be a particular deterrent to highly marginalised individuals. Recent National Audit Office research found that the complexity within the benefits system could act as a significant barrier to people with multiple needs (National Audit Office, 2005).

The act of information collection was very often associated with what were perceived as barriers to services by service users. This manifested itself in a belief that data collection was **intentionally** troublesome and designed to discourage service access.

Disapproving statements, concerning repetition of processes, complicated application forms and what was seen as a lack of coordination, were common across the seven focus groups. Being asked by service providers to repeat the same information, either verbally or on a form, time and again was described as frustrating by some respondents. One ex-offender reported:

'Time and time again...it feels like people aren't listening to you...you've told them that information and then two weeks later they tell you to fill out another form for the same information.'

Service users reported the need to repeat identical information within single agencies. Jobcentre Plus and the claiming of Housing Benefit were cited as specific problem areas in this respect. In some instances this was seen by some respondents as being mainly about fraud detection, with agencies looking for inconsistency by repeating questions. One homeless group described the experience of seeking benefits from Jobcentre Plus in the following terms:

Respondent 1: *'They'll ask you the same question maybe eleven times.'*

Respondent 2: *'Yeah, but in a different way.'*

Respondent 3: *'To try and trip you up and change your answers or see if you're lying.'*

Respondent 1: *'To me there's only one way of answering that question...getting asked that question eleven ways, you can only answer it the one way.'*

Many respondents described what they saw as having to negotiate a minefield of interlinked questions that were intended to test for inconsistencies, to get the services they needed:

'It's necessary ain't it? So you do it. You need the help so you do it, you know? Sometimes it's stupid questions...you expect it...when I say stupid questions, a lot of the time it's not stupid questions, it's trick questions. Like they'll ask you a question on a page and then they'll ask you the same question on another page, but in a different manner...'

(Homeless person)

Refugee respondents seemed to face more intensive questioning. This would be anticipated because of the need to ensure that someone had refugee status and was not an asylum seeker or in the UK illegally:

'Another concern is with the bureaucracy, you know. Because you can go to the Jobcentre today for example, you will talk to one advisor and tomorrow you are invited to attend another interview, you attend the interview, the same questions again from someone else.'

(Refugee)

An exchange between three women within one of the refugee focus groups provided a further illustration:

Respondent 1: *'If you go to housing as well it's the same thing. They ask you so many silly questions...Benefits is the same.'*

Respondent 2: *'When it comes to housing and like benefits I think it's one of the policies these days to ask people so many questions so they can scare them off and they think instead of asking for this benefit they go find a job.'*

Respondent 3: *'It often feels like they're making them so long winded specifically to put us off...'*

5.3.4 Concerns regarding the processing of information by agencies

A few respondents had concerns over agencies holding incorrect information about them. In some instances, the way in which staff opinions took on the status of 'fact' was questioned by respondents. This had also been a concern among some service providers and commissioners (see Chapter 4). One alcohol dependent person with a range of other needs questioned how the definition of himself as a 'suicidal' person had appeared on his file:

'I said I was feeling down right, once, and he wrote down 'suicidal', which was total bullshit. How come it ended up on paper, this information?'

However, respondents were much more likely to report basic errors in records held on them and information being lost by agencies. Details were confused, papers were lost or mixed messages were sent out. Service users reported what they saw as disorganisation and confusion, particularly within the larger services. One respondent talked about what they saw as confusion in the administration of their benefits:

'You talk to somebody, they just bring something up on the computer and it's saying like, you're owed a giro...You turn up at the one stop shop and suddenly you're not owed money...or sick notes being lost down the line, or whatever, and if you ain't got a photocopy of your sick note, that means you got to go all the way back to your GP, organise an appointment with your GP...'

Respondents also quite frequently complained of a lack of information dissemination from agencies. This included difficulties because someone needed a service urgently and the administration involved in making a decision or delivering that service was slow, or seen as slow from their perspective. There was also, for some respondents, a general lack of explanation of processes and a lack of information as to when decisions might be made, services made available or, in some cases, just a wish for a sense of what was going on. Two respondents interviewed in a homelessness service reported:

Respondent 1: *'They don't tell you. You don't get told.'*

Respondent 2: *'They want all the information from you, but they won't give you any, that's what it is...but when you want them to help you with information you're not getting owt back.'*

5.3.5 Security

Respondents tended to view information stored on computers as being vulnerable. There was a tendency among respondents to conflate computers and the Internet. Mass media images of the Internet as an insecure and unsafe environment were mentioned by respondents and applied to computerised information storage in general:

'The Internet isn't policed, is it, really? It's an international thing and no-one's setting guidelines on it.'

Among some respondents there was an assumption that once data is held on any computer system, it was inherently insecure:

'I personally think that there are rules but with the amount of hacking and all of the things that go on with computers and the Internet...they're sidelined anyway. Nobody adheres to them. It's ridiculous and your whole lives are on a computer, whatever service that you go to. Anywhere they will have information about you and it will be on a computer...It can be accessed by anyone if they're inclined to do so.'

Previous research has indicated that this is a shared perception of computerisation among vulnerable and marginalised groups. For some people, computerisation of personal information is seen as making that information inherently insecure (Pleace and Quilgars, 2002).

5.3.6 Data collection by mainstream agencies as an often negative experience

Data collection by mainstream agencies was often a quite negative experience for service users. As they saw it, people tried to 'trip them up' and 'stop them' from getting services through questioning, while they could meet with prejudice if they were wholly honest. When data were handed over they might, from the perspective of service users, be subject to maladministration and also not be secure.

These findings have to be balanced against the extent to which the individuals who were being talked to were sometimes quite chaotic and vulnerable people who might not necessarily be able to engage with any bureaucracy very successfully (National Audit Office, 2005). Nevertheless, for these respondents, data collection and processing often had negative associations, particularly in respect of mainstream agencies.

5.4 Views on the sharing of information

Respondents were well used to the sharing of information between local agencies. Many were simultaneously interacting with several agencies at once, something very common among people with multiple needs (Lownsborough, 2005). Many had experienced at least some information being transferred between frontline staff in different local agencies through interagency referral. The service users identified the following concerns in respect of the sharing of personal information:

- a need for trust, control and incentives when allowing the sharing of personal information;
- experiences of data or information sharing that had produced negative effects from their perspectives;
- a view among some respondents of being within a situation of surveillance;
- concerns about labelling or categorisation and tracking;
- mixed views about the degree of protection offered by free and informed consents.

5.4.1 A need for trust, incentive and control

As noted already, respondents were more likely to trust known individuals with personal information. Reassurance came from specialised workers who appeared to understand their needs and circumstances and was reinforced by those workers becoming familiar, making service users much more confident about disclosing personal information. Part of this 'trust' was linked to the person to whom the information was disclosed being viewed as someone who would 'protect' personal information on behalf of the service user.

This did not prohibit the sharing of personal information. Some respondents were happy for information disclosed to a trusted staff member or worker to be passed on, but with two caveats.

The first of these was that the information sharing would be for purposes that respondents saw as benefiting them. When the example of a GP referring someone to a specialist and transferring medical records to facilitate this was given, respondents did not raise objections. However, when the example of transferring personal information to the JCP was used, respondents tended to be more negative.

The respondents generally reported that if they knew sharing information between services would be of use to them, they were prepared to contemplate it. The respondents reported what could be described as a sense of 'bartering' with their personal data. Information would be offered when there was a direct payback. In general, however, the respondents weren't willing to hand over anything, at least in terms of personal information, when there was no obvious advantage to them.

The second caveat that service users identified was that information sharing should only occur with their permission. There were clear anxieties about uncontrolled information sharing among the agencies. Previous research has found similar anxieties and concerns. Fletcher *et al.* (1998) argue that one disadvantage former offenders have in attempting to access the labour market was a mistrust of mainstream agencies. Other groups, such as young people and adults who have been looked after as children (i.e. in the care of social services) have also been shown to distrust mainstream agencies (Banister *et al.*, 1993).

For the respondents, a loss of face-to-face interaction with a known person was seen as meaning a loss of **control** over information disclosure and over information sharing. Without an opportunity to exercise an element of control in what was passed on about them, respondents became uncomfortable with data sharing. There was sometimes a sense that respondents thought information would flow everywhere, in an uncontrolled way, unless it was with someone they trusted not to release it without their consent, two homeless people reported:

'There's different departments. Somebody way down at reception doesn't need to get into my file and read all about me, they're a receptionist, you know what I mean?'

'It should be up to me how I tell, what I want to tell, about my past.'

Both refugee groups were especially zealous about having prior knowledge of any sharing of information. Some wished to have an added element of control over exactly which organisations view their information. This would be in the form of an 'approved' list. Two refugee women stated:

Respondent 1: *'If they could give you a list of the organisations that they do share information with.'*

Respondent 2: *'... if we actually knew who they were sharing with that would be much better.'*

There was general agreement amongst most participants that the passing on of any of their information had to be explained to them clearly, simply and with maximum transparency. It was also their view that their permission should also be sought and there should be a reason for sharing data that was centred on meeting their needs.

5.4.2 Negative experiences associated with data sharing

Just as respondents were concerned that disclosure of some information would lead to negative responses, particularly from mainstream agencies, they were concerned about the impact of potentially damaging information being shared. The most prominent concern was prejudice. It was feared that an application for service access may be disadvantaged if a particular piece, or pieces of information, had been shared. A conversation between two homeless people illustrated the point:

Respondent 1: *'Especially if they have a look at your records and I'm alcohol dependent, do you know what I mean? As soon as they see alcohol dependent, a brick wall goes up, "you're scum" sort of thing, that's the attitude you get coming across to you. It's just crap.'*

Respondent 2: *'It's like when you go to hospital, if they've got down that you use drugs or whatever, straightaway you're treat(ed) different.'*

This fear of a prejudicial or negative response through information sharing, appeared to often be grounded in direct experience. A number of respondents reported negative experiences within the NHS and other agencies. Two service users reported their experiences as follows:

'If you let someone know, i.e. a doctor...that you are a heroin addict, what the problem is that they write it down...then you get asked these questions, they're written down as well. You're took onto a ward, the nurses get to see this and in some cases, I mean it's horrible, the nurses will actually warn other patients, you've come on this ward and you've got other patients being told "put you wallet away".'

Every college that I've ever got to, well I've always done college in jail. Every time I go to X college across the road here, I can't get in there...you get a form, you fill it in, at the end of the day, you know they're going to check all your background and everything, so you write down and you tell them your convictions and you can't get in.

5.4.3 A sense of surveillance

Many respondents within the groups assumed that large scale information sharing was already in existence. There was a widespread belief that sharing of personal data was more extensive than was actually the case.

A key point here was that this sense of surveillance was associated most directly with those mainstream agencies that were, by many respondents, seen as part of an overarching state. In their view, mainstream agencies were all part of a kind of mega-bureaucracy, rather than being distinct entities.

These beliefs produced some interesting findings. Alongside a sense of being monitored by forces over which they had no control, respondents were also frustrated by what they perceived as the 'inefficiencies' of this mega-bureaucracy. The inability of a local authority Housing Benefit section to know about what had been said to Jobcentre Plus became a matter of 'incompetence' across a huge, unwieldy agency. Respondents had no sense of there being two separately administered agencies that did not share a computer system with each other.

These findings were echoed by service providers and service managers. In the experience of these professionals, people with multiple needs often saw one huge Kafkaesque agency:

'They [service users] see local authorities and the jobcentre and the benefit agencies as one, they don't see that we're three separate organisations...I've come across it several times where people say "I told people at the Jobcentre that...".'

(Service manager, local authority)

'I think one of the problems is that people out there do assume that if they've told somebody in the public sector then the rest of the public sector knows...'

(Senior manager, local authority)

Some of the early research on the introduction of e-government suggested that the general public have difficulties in telling the different arms of central and local government apart. This was often seen as an argument in favour of single point of access for public services that is a central tenet of e-government policy (Pleace and Quilgars, 2002).

The picture of a mega-bureaucracy was associated by some respondents with State 'surveillance'. Unprompted, a discussion on sharing data would quite frequently head off into the perceived increases in close circuit television (CCTV) cameras in the locality, the current debate around ID cards, or with some service users' experiences of the extent of the data the Police held on them. Two drug dependent service users conveyed what appeared to be the impression of many respondents:

Respondent 1: *'I don't know about future generations, already you go outside to the shops and you're being filmed, like in a movie, when I was growing up that was unheard of.'*

Respondent 2: *'They have a computer with everything on it about everyone whether we like it or not anyway...they've got their Official Secrets Act so they can do what they want...'*

Some of the participants reported that they thought personal information was being passed around various organisations, without their consent or knowledge. Furthermore, there was a belief among a few respondents that Government departments could access their details at will, using National Insurance numbers as universal identifier to match records together:

'It's just like Big Brother is watching and that... well it is scary, thinking that this information is available and how do we know that other people can't get to it...'

'...it's like ID cards...it's about finding out where everyone is, what they're doing, it's a controlling thing, it might help some people in some ways, but they're not doing it for that reason, they're doing it because they helps the government.'

'All this stuff is all turning us into robots, taking our individuality away...that's what it feels like to me anyway...like products, bar codes, that's the way it's all going.'

'They'll end up going to give us a card with a chip in it and all the information on it...there's no getting around them.'

5.4.4 Concerns about classification and tracking

Some respondents were also concerned about the implications of possible tracking. These worries echoed those of service commissioners and service providers who had doubts about whether the classification of an individual might disadvantage them, particularly if a label remained with them over time (see Chapter 4).

These respondents took the view that if agencies knew about their background over the medium to long term, it was going to prejudice their chances of making a fresh start. The following example was given by a person who had been drug dependent, who thought that a mainstream agency, in this instance a social landlord, would place them in a location that raised the risk of their use of drugs restarting:

'I don't think people out there need to know. Because at the end of the day if you're a user or an ex-user, no matter what you've taken... If you come from a bad background at any stage, and you want to move into a quiet neighbourhood [if the social landlord knows] the first thing they're going to do is stick you into a neighbourhood that's full of drugs, full of everything...if you try to better yourself, to move yourself up, what are your chances of that?'

Ex-drug users and recent former offenders were the most concerned about possible tracking. They felt that records of their previous lives would disadvantage them in seeking services and would affect job seeking success:

'I think it can come back later on and bite can't it?...If it's on their records and then you go for a job where they can check up and stuff like that and then it comes up and he's got a long history of...whatever.'

The same concerns about privacy and the need to control the sharing of personal information were again present. Some respondents had a concern that information that they had, for example, at one point been a registered drug user, or committed an offence, would be accessible across a network of agencies. It was anticipated by some respondents that information would be insecure:

'If you've got all this information on one system, what stops, say, anyone, accessing that information?...If it's hooked up to all sorts of departments, there's a whole scope of people that could get access to that information, connect to that information.'

5.4.5 Free and informed consent

During the dialogue centred on Government possibly having access to personal data there was a real sense of malaise among some of the respondents. It was quite widely believed that Government would implement and undertake any changes it deemed necessary to access personal data in an arbitrary way:

'Talking to us is a waste of time, what the government's going to do it's going to do, isn't it? People have no control over that.'

(Homeless person)

This feeling of powerlessness and of 'not being able to beat the system' was repeated in several of the focus groups. In the refugee groups, there were sometimes strong views about a lack of protection being offered by the law in the UK.

General awareness of the legal protections offered by the DPA and HRA was very low indeed, although some ex-offenders had a sense of there being some form of protection. A few respondents had prior experience of free and informed consent forms through various drug or homeless services, hostels and other projects. However respondent's awareness of the protections offered by these consents was generally very low. Most service users were unable to name the relevant legislation. There was no awareness of the ICO, nor of any protections being offered by the policies of service providing agencies.

Many respondents assumed they were less protected than they were and saw Government as an arbitrary entity. Some respondents expressed this through describing law as offering impermanent and unreliable protection. There was a view that if the law did provide any protection and that protection was an obstacle to Government's aims, then the law would simply be changed or removed. Some respondents also thought that a consent could be ignored once it had been signed as it provided only 'lip-service' to the idea of protecting privacy and individual rights:

'Cos you haven't really got their word, you're signing a bit of paper and that's it, you haven't got their word, how do you know they're not going to just use it anyway.'

(Homeless person with multiple needs)

'[consent form]...would go into one hand and then with the other, straight in the bin, you know?'

(Homeless person with multiple needs)

A few respondents also anticipated a degree of compulsion. There was expected to be a requirement to sign a consent otherwise a service would not be offered. Some gave examples of this as already occurring in their view, as some services were refused without signing a consent:

'They say it's a choice, but in a place like that you have to, you either sign it or you can't stay there.'

(Homeless woman)

Again, only those smaller scale specialised services, in which the respondents tended to know the staff, were seen as offering some data protection. In some cases, only a face-to-face reassurance about data safety from a known member of staff to whom information was being disclosed, provided sufficient reassurance for respondents.

These views were not held universally. When some service users were asked if signing a free and informed consent form would alleviate fears on local services sharing information nationally with the Government, some were more positive. A few respondents were reassured to a degree and said it would lessen their concerns on sharing with Government to a certain extent.

One consent form was spoken of in very positive terms. This was utilised by an ETE service for former offenders and allowed the user of the service to select which organisations, agencies and people with which the information cannot be shared. This resulted in the respondents feeling comfortable with signing the form, as they believed it was wholly in their favour and gave them control over information sharing.

However, it was the case that many of the respondents thought a consent form offered them no guarantees. Many thought that little could protect them from having details about themselves accessed once they were on a centralised system.

5.5 Summary

This chapter has described the perceptions of seven groups of homeless people, recent former offenders, refugees and drug and alcohol dependent people. The aim of working with these groups was to explore any concerns or anxieties around the collecting, storing and sharing of potentially sensitive information.

Attitudes to information collection were influenced by the extent to which the service users trusted the agency collecting personal data. Respondents were also influenced by whether or not they could see benefits or disadvantages to themselves from information being collected. The 'price' of sensitive information collection could be seen as being acceptable, or as being too high, depending on what benefits and risks the service user thought would be associated with a given level of disclosure. At the same time, data collection was also viewed as a tool that was sometimes designed to block access to services which created some degree of hostility towards certain agencies.

Views on data sharing were heavily influenced by these same factors, particularly the extent to which an agency asking to share information could be 'trusted'. The risks and potential gains from sharing sensitive personal information were also seen as important.

Many respondents reported what they perceived as experiences of prejudicial treatment by mainstream agencies that were associated, in their view, with information sharing. There was also evidence of wishing to withhold certain information from some services in order to minimise the risk of meeting with a hostile reception. Most were happiest in disclosing personal information face-to-face with a known staff member with whom they felt they had a trusting relationship.

There was general negativity towards the idea of information sharing without direct consent. Few protections were held to be in place and risks were associated with data sharing, particularly in respect of disadvantaging the service users.

Most of the respondents had a perception that information sharing was occurring in an unchecked way and was open to abuse. There was almost no mention of current legal protections by service users, although some had signed consent forms designed to be compliant with the DPA.

The idea of having the capacity to exercise choice on what information is to be shared and with whom and why, alleviated some of the reluctance about data sharing among some respondents. Furthermore, the receipt of tangible beneficial outcomes for themselves was perceived as a worthwhile exchange for the allowing of shared information. Again, these perceived advantages were associated with service users having a sense that a given agency could be trusted with sensitive information.

Some saw little reassurance being offered by informed consent when they thought themselves to be in a situation in which they had little control over information sharing. However, some of the respondents were reassured by the protections offered by informed consents and were particularly positive about consents that allowed them to select which agencies information was shared with.

6 Conclusions

6.1 Introduction

This final chapter discusses the main themes that have emerged from the research findings. The discussion begins by considering the extent to which information sharing between local agencies and Government is a practicable proposition at the time of writing. The doubts and questions raised by respondents in respect of how information would be used, centred on the act of classification within datasets, are then discussed. The discussion next moves on to examine those findings that suggested a cynicism towards Government and its motivations in seeking to share data. The report concludes with a discussion of the ways in which information on groups who face multiple barriers to employment might be improved.

6.2 The practicalities of sharing personal data

The theoretical goal of data sharing might be seen as a shared database, detailing the needs, characteristics, experiences and service use of identifiable workless adults. A standardised local authority level model could be rolled out and used in combination with national level datasets to provide a potentially rich resource for small areas, local authorities, regions and across the UK. Services providers could acquire the capacity for tracking former service users, service commissioners could map need using GIS and programmes and services could be evaluated longitudinally. Individual service users could be located and targeted with the correct interventions. The life paths of workless adults facing multiple barriers to employment could be analysed longitudinally.

Service commissioners and providers at local authority level often saw such potential gains in participating in data sharing with DWP. Enhanced information was seen as being likely to raise service effectiveness, as benefiting people facing multiple barriers to work and as facilitating better strategic planning and service commissioning.

Two commonly cited obstacles to e-government and electronic service delivery in publicly-funded services can be seen as applicable to the sharing of electronic data between agencies (Margetts and Dunleavy, 2002). These two obstacles are the:

- logistical and administrative obstacles to data sharing;
- provisions of the DPA.

These issues are considered in detail below.

6.2.1 Logistical and administrative obstacles to sharing data

Any data sharing on workless people facing multiple barriers to employment is likely to involve the agreed transfer of information from participating agencies to a shared resource. The shared databases operating in Leeds and London were examples of this kind of model on a small scale.

In the case of the shared databases in Leeds and London, it was web-based data entry applications linked to databases that made the creation of a shared dataset practical. Agencies were able to access the database and enter data simply by using a web browser. However, the use of these technologies pushed the costs of delivery onto participating agencies. Staff within each participating agency completed the returns for the shared database. This meant that these shared databases were limited in scope in some respects, although they provided rich longitudinal data on individuals' service use. There were incentives for agencies to participate in these shared databases, but their participation was also required as part of their participation in specific interagency working arrangements or through contract.

Some risks were held to exist around the completeness and reliability of data when many agencies are involved in a shared minimum dataset. Certain individuals or agencies may be more diligent than others and some service activity might go unrecorded.

These issues could be addressed by the use of programmed data transfer. For example, it is possible to envisage a series of databases across agencies that all delivered the required data for a shared dataset on workless adults via pre-programmed reports. The 're-keying' of data would, therefore, be unnecessary and agencies would be able to participate in data sharing without any greater administrative burden than that required for their own administration. As processes were automated, the risks of incomplete returns would also be reduced.

However, at least some work would be needed within local agencies participating in data sharing through automated data transfer. Databases might need to be modified, as they can sometimes reflect the original record keeping systems rather than being optimised for generating data for sharing (Margetts, 1991; Pleace and Quilgars, 2002). It also needs to be recognised that some coordination will be necessary to facilitate data sharing, in that data on an individual can be quite 'fragmented' because several agencies could be engaged with a workless adult facing multiple barriers to employment.

Data may also be variable in their extent. Some smaller services engaging with very marginalised people do not tend to collect extensive data and may not always check those data. The point that data increase with service contact also needs to be borne in mind, in that it is 'heavy users' of services about whom the most data will be available. There is the potential that some of the very 'hardest to reach' individuals, who may avoid almost all contact with services or not engage with them at all, will remain people about whom little is known. However, the extensive work CHP has conducted on people sleeping rough in the last decade strongly suggests there are only likely to be very low numbers of such individuals (Pleace, 1998; Fitzpatrick *et al.*, 2005).

Another potential obstacle to data sharing could be the self interest of agencies. There may be reasons linked to protecting their own position which might make agencies hesitant about sharing data (Margetts and Dunleavy, 2002).

However, the findings of the present research did **not** suggest that agencies were apprehensive about sharing data on their performance. These agencies already had to supply extensive information to funding bodies and report on their performance in detail, which meant that data sharing did not raise any particular concerns for them.

Concerns were raised that agencies would lose contact with some service users by sharing information. The worry was that some groups, particularly the most marginalised individuals, might disengage from services or not approach them in the first instance if asked to sign a consent.

Yet it was apparent that the sharing of personal data could occur if service users felt comfortable with the process. Thus, services using shared databases, which were working with drug users, ex-offenders and homeless people, were successfully sharing information between agencies with the consent of service users, apparently without running any risk that potential service users would not engage with them.

The research cannot comment in detail on technical matters, but it is worth noting the ongoing progress in software and hardware development. Private corporations that describe themselves as 'data aggregators' are able to orchestrate highly detailed datasets assembled from many sources for the purposes of consumer profiling. Examples include Oracle and Acxiom. Technologies that facilitate data merging seem likely to simplify the logistics of sharing information further.

While there are some logistical and administrative obstacles, it does appear to be the case that these are not insurmountable, although there may well be resources implications in overcoming them. The merging and sharing of local and national data appears feasible on a practical level.

6.2.2 Sharing data within the legislative framework

An overview of the legislative framework was provided in Chapter 2 to help the reader understand the context in which the research took place. At the risk of repetition, a brief description of the key points will again be given here.

The DPA requires that eight principles are followed, which are that data must be:

- 1 fairly and lawfully processed;
- 2 processed for limited purposes;
- 3 adequate, relevant and not excessive;
- 4 accurate;
- 5 not kept for longer than is necessary;
- 6 processed in line with an individual's rights;
- 7 secure;
- 8 not transferred to other countries outside the European Economic Area (EEA) without adequate protection.

DWP must be confident that there has not been a third party breach of the DPA if sensitive, identifiable personal data are transferred to it by other agencies. The DWP must also be confident that the manner in which it processes any such data is compatible with the DPA. Equally, local agencies must be confident that any data transferred to them by DWP is being processed in compliance with the DPA.

As noted in Chapter 2, a free and informed consent can allow data sharing and matching within the eight principles, but it cannot provide a mechanism by which an agency can break these principles. Informed consent can also be withdrawn at any point.

The HRA provides individuals with the right to respect for their private and family life. Data processing must be deemed 'necessary' and the greater the intrusion into someone's privacy, the stronger the case for that 'necessary' intrusion needs to be (Department for Constitutional Affairs, 2003). Finally, the Freedom of Information Act (2000) gives individuals a general right of access to information held by, or on behalf of, public bodies.

The research found strong evidence that people facing multiple barriers to work were unaware of the legal protections governing the use of personal information. In addition, it was found that service users quite frequently assumed that they were under a situation of surveillance from a government that used their personal information in an arbitrary way. Some frontline staff also had limited awareness of the legislation and were often highly protective of their clients when taking decisions about whether or not personal information should be shared.

This situation meant that service users were unaware of their rights and thus unaware of when it might be legitimate to view their rights as having been violated. At service delivery level, some legitimate information sharing may have been blocked by misinterpretation of the DPA by some frontline staff while, equally, some questionable data sharing may have been allowed to take place.

A key finding from this research is that if data sharing were to take place between local agencies and DWP, the education of service users and frontline staff in their rights (and responsibilities) under the DPA would need to be a priority. Confidence that free and informed consent had been secured would be dependent on better awareness of the law among participating individuals and agencies.

There is evidence of a similar problem across society. In a survey conducted by MORI for the Department of Constitutional Affairs (MORI, 2003), 53 per cent of the public did not know what their rights were regarding their personal information. Only four per cent were aware of the ICO. The levels of awareness of the legislation and their rights were higher among more educated respondents, something that was paralleled by the findings of the present study, where it was almost exclusively highly educated senior staff who had a clear knowledge of the legislative framework.

Some commentators have identified what they refer to as a 'tension' between Government's objectives in respect of social and welfare policy and the data protection legislation. These tensions are held to exist because the coordination of welfare and social policy responses that rely ever more on joint working, which necessitates the free flow of information, are 'blocked' by the DPA (6 *et al.*, 2005a and 2005b).

The current research found evidence that ignorance and misinterpretation of the DPA might have limited the flow of information between frontline staff exchanging data on a case-by-case basis. Some difficulties had also arisen in the sharing of data for which informed consent had not been obtained. However, this was an administrative issue, in that the law had not been followed in the necessary way, rather than the law, in any sense, 'prohibiting' such data sharing from taking place.

There was no evidence to suggest that the DPA formed a significant barrier to information sharing in those circumstances in which it was fully understood and its requirements were planned for. If a suitable consent was obtained, the legislation was interpreted as forming no barrier to data sharing at local level. The use of shared databases by agencies using informed consents allowed interagency data sharing that was seen as being DPA compliant, without apparent problems. From the perspective of respondents with a detailed understanding of the legislation, data sharing at local level and between local agencies and DWP could occur providing the appropriate free and informed consent was in place.

Questions do exist about the resources that might be required to ensure that a consent could be demonstrably both free and informed. People facing multiple barriers to work are often vulnerable and might also need assistance in understanding

what they were giving consent to. Opinions were divided about the extent to which some adults facing multiple barriers to work might refuse to sign a consent. A few individuals might, in some circumstances, be judged as being unable to give free and informed consent, for example, people with mental health problems.

Bearing in mind these caveats, data sharing between DWP and local agencies within the terms of the DPA seems quite possible. There are examples of such data sharing at national and local level at the time of writing.

6.3 Ethical and political questions

6.3.1 The perceived risks associated with classification

There was evidence that the act of classification of workless adults could bring disadvantage and elicit prejudiced responses. For example, if someone were described as a former 'drug user', mainstream services, potential employers and ordinary individuals might well react negatively were that information to reach them.

Many academics and other commentators have raised questions about the use of databases to sort and classify the population. These concerns are focused on what happens to those who might be stigmatised, excluded or otherwise disadvantaged by the classification they are given. Common examples include the disadvantages conferred on individuals by consumer profiling. If an individual is found to be 'undesirable' as a customer by consumer profiling databases, this tends to exclude that person from many mainstream financial services (Lyon, 2001). Another common example given is the process of classification of certain individuals or groups as being likely to constitute a 'threat' to society, which has been linked to cultural and racial discrimination in the US (Stanley, 2004).

There are also specific concerns about the extent to which databases might be used to classify, sort and regulate economically and politically marginalised populations, particularly where this increases risks of sustained disadvantage. These concerns are strongest in respect of the potential for systematic exclusion of some elements within the population. Anxieties include the possible return of Nineteenth Century ideas of a 'criminal class', who are defined as 'deviant' and who risk exclusion, merely on the basis of characteristics that are assumed to be associated with certain types of criminality (Bauman, 2000 and 2001; Fitzpatrick, 2002; Lyon 2001).

There is also the question of representation within classification. Some commentators have also questioned the extent to which someone, particularly a socioeconomically marginalised person, can exercise control over their database profile. For some commentators, there is the risk that agencies may take decisions based on a possibly misrepresentative 'data double' of an individual, rather than assessing the individual themselves (Lyon, 2001; Fitzpatrick, 2002 and 2005).

The interviews with service providers, commissioners and adults facing multiple barriers to work conducted for this study showed that they shared some of these concerns. Questions were raised about 'flagging' or 'tagging', including the envisaged risk of someone being disadvantaged for sustained periods by a 'tag'. The risks of tags being inaccurate, misrepresentative or incurring negative responses and exclusion were raised by adults facing multiple barriers to work, service providers and service commissioners.

There were also the questions of individual privacy and dignity. The disclosure of some personal information was embarrassing or humiliating to some adults facing multiple barriers to work. There are clearly questions about when it is appropriate to ask individuals for personal information and when it is appropriate to share that information. There are also issues in respect of how individuals are asked about sensitive subjects.

It is not difficult to envisage how a classification as being a 'workless' individual of working age facing multiple barriers to employment, might be associated with risks to an individual. However, the impacts would of course depend on how data were collected and processed and under what conditions they were shared.

6.3.2 Cynicism and distrust of government

Distrust of what they saw as an overarching 'State' was pronounced among adults facing multiple barriers to employment. This 'State' and its collection and processing of personal data seemed hostile to many of these respondents. This has obvious implications in terms of seeking informed consent from people in the same position as these respondents.

There are indications that similar concerns exist in the general population. Research by MORI has found that 60 per cent of the public are fairly or very concerned about public services sharing their personal information. Awareness of the level of information held on them by public services was also low among the general population, with 64 per cent saying they did not feel 'well informed' about the data being kept about them (MORI, 2003). A more general distrust of central government, regardless of the party in power, has also been reported by successive surveys of the UK population (MORI, 2002).

While many service providers and commissioners saw advantages in being able to find, map and track workless individuals, some also raised questions about whether this should happen. Their concerns were focused on how data were used. To illustrate this point an extreme, though only theoretical, example can be used. Data sharing could be employed to force vulnerable people with support needs, who should not really be in the labour market, into low quality employment. This is something that is alleged to have happened within the 'Workfare' programmes in a few US states (Fitzpatrick, 2002 and 2005).

Of course, data sharing can be used in other ways as well. In another theoretical example, data merging might be used to actively seek out individuals eligible for unclaimed benefits, or other forms of support, in a 'zero-stop shop' model, without there being an expectation that they seek work (Dornan and Hudson, 2003).

Database technologies and their capacity to merge, sort and match information are not value neutral. It would be misleading to suggest that these technologies can only be used in one way (Pleace, 2005).

It is the potential power of data matching and sharing that causes concerns for many commentators. These concerns date back to when it first became apparent what powerful computers with large sets of personal data would be able to do:

'The "bureaucratic weaponry" represented by these systems is simply so formidable as to require limitation, even in the absence of obvious repressive inclination on behalf of any specific regime.'

(Rule, 1973, p.351)

These kinds of concern, usually expressed as anxieties about an 'Orwellian' society or 'Big Brother', may seem melodramatic in the context of the UK. However, such images appeared to be important in understanding the reactions of some respondents to data sharing and they were found among service commissioners, service providers and adults facing multiple barriers to work.

6.4 Ways forward

'I suppose the difficulty I've got, in terms of the blunt instrument, is I would need to see the philosophical argument and the practicalities of how we'd make it work, how we'd protect people in terms of staying with what's quite robust legislation to protect people's rights, you know, and I think if that's done then that's fine. We do have to move forward from a position which I was describing, which is unhelpful, which is when people don't tell you stuff that you need to know, there is a place for progress here.'

(Senior manager, social landlord)

This research has identified some barriers and doubts about data sharing on workless individuals with multiple needs. However, there are three ways in which the sharing of data on workless adults might be taken forward:

- work on the presentation and content of informed consents;
- incentives for participation;
- a 'ninth principle' in controlling the uses of shared data.

6.4.1 The presentation of informed consents

Adults facing multiple barriers to work were generally content to share personal information with agencies under three conditions:

- 1 information disclosure would not elicit a negative or potentially damaging response, that their needs would be 'understood' rather than 'judged';
- 2 disclosure was to a known and trusted person and generally through face-to-face communication;
- 3 sensitive information was judged to be 'safe', including there being consultation and controls over whom it was shared with.

These were also the circumstances in which adults facing multiple barriers to work would sign consents for information sharing. Trust in the agency with whom they were working tended to give service users trust in the information sharing undertaken by that agency.

The attitudes they encountered had a profound effect on how workless adults felt about sharing personal information with agencies. The negative attitude towards Jobcentre Plus among these marginalised people was clearly a barrier to data sharing. This is in line with other recent evidence about people with multiple needs finding it difficult to engage with the benefits system (National Audit Office, 2005).

Clear information, reassurance and explanation of informed consents might help address these issues. If adults facing multiple barriers to work understood the protection they were being offered by an informed consent and were reassured by that protection, many of the potential barriers and concerns in relation to data sharing could be removed. However, it is recommended that further research is undertaken to clarify which methods of seeking demonstrably free and informed consent may be most effective with people facing multiple barriers to work.

6.4.2 Incentives for participation

Greater transparency would not, in itself, be sufficient to secure the required consents from adults facing multiple barriers to work. A need to provide an incentive for engagement has been identified as one of the key cultural barriers to electronic government, in that a 'price' is being paid in personal data and something is expected in return (Margetts and Dunleavy, 2002). Some work on data sharing in the US has also identified the 'exchange' that occurs when data are given to private sector companies by individuals (Elmer, 2004).

The advantages to individuals in allowing data sharing, which centre on enhanced multi-agency services, would need to be clear. To participate in data sharing, adults facing multiple barriers to work would need a sense of how such participation could help meet their needs.

6.4.3 A 'ninth principle' in controlling the uses of shared data

If the uses to which shared data on individual need were restricted in some respects, some of the ethical and political concerns about data sharing might theoretically be overcome. These concerns centred, the categorisation of individuals and the possible uses to which shared data might be put.

One possibility might be for informed consents to offer stronger controls over the sharing of particularly sensitive data. Another might be to avoid the use of simplistic descriptors, such as 'homeless', which are of limited utility and which are associated with negative stereotypes.

The informal and formal protocols that governed local information sharing on a case-by-case basis are also potentially useful here. Sensitive information was released according to frontline staff judgements about whether such disclosure was necessary for reasons of risk management or was in a service user's interest. These working practices essentially reflected the logic of the DPA, but added what might be termed a 'ninth principle', which was that information disclosure should not cause an individual to suffer disadvantage, harm or prejudice.

This 'ninth principle' might, in theory, be something that could be incorporated into informed consents, providing an extra level of reassurance that data processing would not damage an individual's life chances or undermine their well-being. If shared data were used at national level by DWP, for example, to target certain individuals in receipt of Incapacity Benefit with specialised ETE services, it would need to again be clear that this ninth principle was being followed. The same criteria would apply in respect of information sharing between local agencies.

Further reassurance might be provided by reference to the Freedom of Information legislation which gives individuals rights to check and dispute the information held on them. The chance to regularly review the data held on oneself and to check their accuracy might provide an additional mechanism through which to ensure a 'ninth principle' was being followed.

A 'ninth principle' need not limit the use of shared data containing highly personal information for research and planning purposes. Highly sensitive data could be analysed on, say, the users of a particular programme or the inhabitants of an estate characterised by unusually high levels of worklessness, and extensive longitudinal analysis undertaken. However, if such material were to be released publicly, it would need to be anonymised to protect individuals' privacy.

There would need to be caveats to a 'ninth principle'. For example, it would need to be clear that an individual could not claim that a violation in agreed terms of data sharing had occurred because it had led to a benefit fraud being detected, which had 'disadvantaged' them.

Careful management of shared data using a 'ninth principle' might help overcome the ethical questions raised by adults facing multiple barriers to work and by service commissioners and providers. It may be productive to pursue further research on this possibility.

6.5 Overall conclusions

The attitudes of some service providers, service commissioners and adults facing multiple barriers to work do create some potential hurdles for data sharing between DWP and local agencies. Doubts about the consequences of information sharing for individuals and about the motivations behind data sharing are widespread. It is also apparent that many people view information disclosure as involving an element of exchange and are more comfortable when there are tangible benefits associated with sharing personal information.

Administrative costs may result if demonstrably free and informed consents are to be obtained from workless adults facing multiple barriers to work, though data sharing with informed consent might also reduce the need for agencies to re-enter the same data. The coordination of data sharing, which may involve many agencies, may well require some sort of dedicated resource.

However, neither the logistical nor the legal issues that arise in data sharing between local agencies and DWP are insurmountable. The oft-cited 'barriers' of the DPA and the complex logistics of data sharing (Margetts and Dunleavy, 2002), while they should not be underestimated, are not necessarily the main issue, as they can be overcome.

Suspicion and cynicism are potentially significant barriers. In some respects, the suspicions of respondents had a slightly unfocused quality, as exemplified by the general associations drawn between data sharing and wider issues of surveillance such as CCTV or the ID card debate. For adults facing multiple barriers to work, the fear was that what they saw as the 'state' would use data sharing as a way to disadvantage or discriminate against them.

There is no single or simple answer to this, though providing education on data protection rights, clear and transparent informed consents and appropriate reassurances and guarantees about data use might represent a way forward. As suggested above, a 'ninth principle' governing data use, that prevents data being used in a way that might harm or disadvantage an individual, might also provide some reassurance.

Beyond this, there needs to be a clear sense that gain can result when allowing personal information to be shared. Individuals need to know that, when personal data are requested, there are likely to be 'rewards' in the sense of enabling better and more coordinated responses to their needs. A sense of fair exchange, coupled with a greater awareness and a greater belief that data will not be abused, may help with engaging adults facing multiple barriers to work and local agencies in data sharing with DWP.

Appendix

List of participating agencies

The Big Life Group <<http://www.thebiglifegroup.com/biglife/index.asp>>

The Big Issue, Leeds < <http://www.bigissue.com/>>

Carr Gomm < <http://www.carrgomm.org.uk/>>

Druglink Peer Education Programme, London.

Drug Intervention Programme (DIP), Leeds:

<<http://www.drugs.gov.uk/drug-interventions-programme/>>

Family Housing Group, London: <<http://www.familyhousing.org.uk/>>

The Fair Play Partnership <<http://www.fairplaypartnership.org.uk/>>

First Rung, Leeds (Progress2work).

Jobcentre Plus, Leeds < <http://www.jobcentreplus.gov.uk/JCP/>>

Jobcentre Plus, Hammersmith and Fulham < <http://www.jobcentreplus.gov.uk/JCP/>>

Off the Streets and Into Work <<http://www.osw.org.uk/>>

Leeds City Council < <http://www.leeds.gov.uk/>>

London Borough of Hammersmith and Fulham <<http://www.lbhf.gov.uk/>>

London Homeless Services Team (DWP):

<<http://www.homeless.org.uk/regionalNational/london/resources/jobcentre/>>

Manchester City Council <<http://www.manchester.gov.uk>>

Places for People Group < <http://www.placesforpeople.co.uk/>>

NACRO (Leeds and London) < <http://www.nacro.org.uk/>>

Red Kite Learning, London < <http://www.rkl.org.uk/>>

RETAS, Leeds < <http://www.retas-leeds.org/>>

RETAS, London

St Anne's Community Services <<http://www.st-annes.org.uk/>>

St Mungos < <http://www.mungos.org/>>

West Yorkshire Probation Service < <http://www.westyorksprobation.org.uk/>>

West Yorkshire Employers Coalition:
<www.nationalemploymentpanel.gov.uk/work/employers/coalition_w_yorkshire.htm>

Working Future < <http://www.workingfuture.org.uk/>>

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