



The Sainsbury Centre
for Mental Health

**A formal investigation into health inequalities experienced
by people with learning difficulties and people with mental
health problems - Area Studies Report.**

Report to the Disability Rights Commission (DRC)

by

**Chiara Samele, Linda Seymour, Brigid Morris,
Central England People First, Alan Cohen, Eric Emerson**

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Glossary of statistical terms

Term	Definition
Mean	The mean is the most common measure of central tendency or average of a distribution.
OR (odds ratios)	The odds ratio is a way of comparing whether the probability of a certain event is the same for two groups. An odds ratio of 1 implies that the event is equally likely in both groups. An odds ratio greater than 1 implies that the event is more likely in the first group. An odds ratio less than 1 implies that the event is less likely in the first group.
Prevalence	The total number of people with a particular disease in a population
P value	A p-value is a measure of how much evidence we have against the null hypotheses. It is associated with a test statistic. A null hypothesis, presumes no change or no effect of a treatment. A small p-value (less than 0.05) is evidence against the null hypothesis while a large p-value (above 0.05) means little or no evidence against the null hypothesis.
Standard deviation	A measure of the variability of a distribution of scores. The more the scores cluster around the mean, the smaller the standard deviation.

Terms used for the target groups

We have used terms such as people with ‘a mental health problem’ or more specifically those with depression or a severe mental health problem. We have also used the more general term ‘mental health service user’ for some parts of the report. For people with a learning disability we have opted for the preferred term ‘learning difficulty’ or ‘learning difficulties’, except with reference to specific titles of practitioners working with this group.

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Executive summary

1.1 Introduction

The growing evidence surrounding the increased risk of mortality from natural causes and medical co-morbidity in people with learning difficulties and those with mental health problems is notable. There has also been a simultaneous shortfall in the receipt of adequate and sufficient primary care services for physical health problems and the prevention of poorer lifestyles in these groups. A number of government policy initiatives have sought to tackle the physical health needs of these groups, with an emphasis largely on people with mental health problems.

Despite these government efforts there remains a considerable need to a) implement the current policy recommendations, and b) find practical solutions to improve access to health care for those with mental health problems and those with learning difficulties.

The Disability Rights Commission launched in December 2004 a Formal Investigation to examine the existing health inequalities concerning health outcomes and access to primary care for these target groups with the primary aim to examine and identify solutions to these disparities. The Sainsbury Centre for Mental Health, in collaboration with the Health Research Institute at Lancaster University, was commissioned primarily to:

1. examine access to primary care services for the target groups of interest with reference to their physical health;
2. identify the ways in which primary care services attempt to address the physical health care needs of the target groups.

Additional aims included building a profile of access to primary care services offered and the uptake of these by the target groups by exploring:

- target groups' experiences of primary care services;
- problems encountered;
- the provision of health promotion, health education or interventions;
- the views of target groups, primary care practitioners and other relevant secondary health care professionals on improving access to primary care services for physical health problems and health promotion;
- how GP practices identified the target groups; and
- a range of groups from within the target groups such as younger and older people, Black and ethnic minorities, those with multiple impairments, etc.

1.2 Methods

We applied a multi-method approach using two main sources of data to carry out the project. This involved a) a quantitative study of GP clinical data sets to examine questions relating to the identification of the target groups and access to primary care services for physical health problems; and, b) a qualitative study to explore the

questions regarding the difficulties encountered by the target groups when accessing services for physical health problems.

We selected three Primary Care Trust (PCT) areas in England (from the South East, North West and London) and one Local Health Board (LHB) in Wales using a number of criteria relating to geographical location, provision of health care services and population. GP practices were recruited via the PCTs and LHB. We collected data from:

- GP practice databases/registers;
- a postal survey of the target groups registered at participating GP practices;
- focus groups and interviews with the target groups recruited from voluntary organisations and statutory health services; and
- interviews with key managers, health care practitioners and advocates from primary, secondary and voluntary sector services.

Collection of clinical data from GP practice database registers was performed by the Primary Care Informatics Team at St George's Hospital Medical School. All interviews with the target groups were carried out by mental health service user researchers and Central England People First where relevant. Interviews with service professionals and managers were conducted by other members of the research team. The project was granted Local Ethics Committee approval.

1.3 Findings from GP clinical datasets

Introduction

Twenty two GP practices across the four local area sites agreed to take part in the project. A total of 150,181 people were included in the combined GP dataset. We identified 864 people with a severe mental health problem (SMI), defined as someone with a diagnosis of schizophrenia or bipolar affective disorder. This gave a prevalence of 5.75 per 1,000 patients or 0.6% for people with a SMI. We also included a group of people with depression in our analyses. There were 15,186 people diagnosed with depression giving a prevalence of 101.1 per 1000 patients or 10.1%. We identified 753 people with a learning difficulty with a prevalence of 5.01 per 1,000 patients or 0.5%.

Medical co-morbidity in the target groups: prevalence and clinical care

We examined the prevalence and clinical care (including health care, treatment/management, health education/prevention advice or interventions) of four major diseases in the target groups. These included: ischaemic heart disease (IHD); stroke; diabetes mellitus; and chronic obstructive pulmonary disease (COPD). They were chosen because of previous evidence showing increased risk of these in the target groups. We were also interested in other diseases like hepatitis and HIV/AIDS, however, the numbers identified were too few to analyse.

Ischaemic heart disease (IHD)

The prevalence of IHD in people with a SMI was 5.4%. It was 6.4% in people with depression. The comparison group for the mental health groups had a lower prevalence of IHD at 3.9%. The prevalence in people with a learning difficulty was very low at 0.7%, and much higher in their comparison group at 4.2%.

The extent of clinical care through recorded health checks for people with IHD was significantly lower for those with a SMI regarding total and LDL cholesterol, but higher for current smoking. Recorded health checks for people with a learning difficulty and IHD were lower than the mental health groups and the remaining population. People with a SMI and IHD were significantly less likely to receive lipid lowering therapy, but received much more advice concerning smoking. People with a learning difficulty and IHD were even less likely to receive health advice/treatments than the other groups.

Stroke

People with a SMI had a higher prevalence of stroke than those with depression or a learning difficulty. The prevalence for this group was 5.1%. The total prevalence for people with depression was 3.4% while that for the remaining population was 1.9%. The overall prevalence for people with a learning difficulty was 1.2%. Stroke was more prevalent in older age groups.

Recorded blood pressure checks were very high in people with a SMI and depression, but lower in people with a learning difficulty. The results of all recorded blood pressure for each of the target groups were within normal limits. Smoking advice was greater for those with depression or a learning difficulty and the same for those with a SMI compared with the remaining population.

Diabetes mellitus

The prevalence of diabetes mellitus in people with a SMI was 8.8%, and higher in women (10.2%) than men (7.6%). In people with depression the prevalence was lower at 4.7%. Both prevalence figures were higher than that of the remaining population (3.2%) and the differences were statistically significant ($P < 0.001$). The overall prevalence for diabetes in people with a learning difficulty was 2.4%, which was considerably lower than all other groups.

Recorded health checks for blood pressure and body mass index (BMI) in all the target groups with diabetes was very high, but less so for urine checks, particularly for people with learning difficulties. The results of recorded health checks showed that people with a learning difficulty and diabetes were more likely to be obese. We also found that the control of diabetes was better among the target groups than the remaining population. Dietary advice was provided around 80% of the time for both mental health groups, but slightly less so for those with a learning difficulty.

COPD

For people with a SMI the overall prevalence for COPD was 20.1%, and for those with depression 23.0%. These prevalence figures were significantly higher than those of the remaining population (14.7%, $P < 0.001$). In people with a learning difficulty the prevalence of COPD was 19.8% and again significantly higher than that of the remaining population (15.5%, $P < 0.001$).

We had limited data on certain health checks for COPD and are only able to report on current smoking status and relevant advice/interventions. People from the mental health target groups were more likely to be current smokers and so received more smoking advice. The learning difficulty group, who were less likely to be current smokers than the mental health groups and the remaining population, were less likely to receive smoking advice.

People at increased risk of medical co-morbidity

We examined data referring to a series of recorded health checks in the target groups without one of the four diseases described above, as well as in the sample as a whole. Included in these analyses were mammography, cervical screening, total cholesterol, urine analysis, current smoking, body mass index and blood pressure. People in the mental health groups as a whole were more likely to have these recorded health checks than the remaining population, and significantly so for the majority of checks. The complete inverse, however, was found for people with a learning difficulty, who were far less likely to receive the above listed health checks.

Smoking, obesity and total cholesterol were the most prominent of the risk factors found for the target groups. The overall prevalence of smoking in all people with a SMI was 49.6%, and for those with depression 45%. For the remaining population it was 22.3%. The prevalence of obesity in all those whose BMI was recorded was 28.5% for those with a SMI, 24.0% for people with depression and 19.8% for the remaining population. In all those with a learning difficulty the prevalence of obesity was 28.3%.

Health prevention advice/interventions in the target groups

As with the previous section we examined the receipt of health prevention services in those without one of the four diseases listed above and in all people in the target groups. Flu and tetanus vaccinations, dietary advice, advice on smoking, smoking therapy and referral to smoking cessation services were the health prevention services analysed. People with a SMI were significantly more likely to receive a flu jab, smoking advice and smoking therapy of some kind, but less likely to have a tetanus vaccine. People with depression were more likely to receive flu vaccination, smoking advice and smoking therapy compared to the remaining population. Similar percentages for dietary advice were found for those with a mental health problem and the remaining population. Those with a learning difficulty generally, however, were much less likely to receive dietary and smoking advice compared to the remaining population.

1.4 The postal survey

We report few findings from the postal survey due to the extremely low response rate received. Generally respondents were very positive about accessing their GP and the care they had received. Some, however, mentioned wishing to see their own GP rather than others based at the practice; needing more information about their medical condition; and wanting additional time with their GP.

1.5 Key themes from focus groups and interviews with the target groups

The key themes arising from the focus groups and interviews with the target groups were as follows:

- there appears to be a lack of knowledge and awareness among reception staff, GPs and physical health specialists about the needs of people with learning difficulties, if people with mental health problems and of their carers when using their GP surgery;
- the diagnosis of a learning difficulty and particularly a mental health problem often appears to overshadow a person's physical health issues;
- people with mental health problems often feel that they are treated with less respect than other people at their GP surgery due to having a label of a mental health diagnosis;
- the current way in which primary care operates, particularly with regards to the lack of time that can be spent with each patient and the financial implications of each referral or service provided, means that those who 'shout the loudest' get the most out of the system. People with learning difficulties often have difficulties in communicating their needs to others. People with mental health problems frequently have low self esteem and sometimes find it difficult to be assertive in GP consultations. Carers of people with learning difficulties spoke of how they sometimes felt that they were *bothering* the GP practice yet again with the problems of the person they cared for;
- people with learning difficulties and mental health problems are often on many types of medication, frequently on a long-term basis. It is essential that the complex interactions of drugs are always considered in prescribing decisions and that long-term medications are comprehensively reviewed in order to prevent physical damage to patients;
- people with learning difficulties and people with mental health problems often are on benefits and so have fewer financial resources with which to choose and pay for alternative health care interventions such as osteopathy or acupuncture. These groups of people also have less money to spend on healthy eating and on opportunities to exercise;
- due to the constraints experienced by GP surgeries, practices appear to work within a culture of crisis management rather than active health promotion;
- the voices of people with learning difficulties are often perceived to be hard to hear as they frequently require substantial time and skilled support to enable them to fully communicate their needs. Great effort and care needs to be taken in the future to ensure that the views of people with learning difficulties are

elicited, heard and taken into account in primary care. Only in this way can their needs begin to be fully met when they are visiting their GP practice.

1.6 Key themes from interviews with health professionals and senior managers

Access issues

Information systems to identify both groups of service users accurately were extremely variable. We had examples that ranged from utilising Read Codes by GPs to *'just knowing when someone is disabled'* from practice staff.

There was a clear reliance on carers – both formal and informal – as primary care access enablers for people with learning difficulties and also for people with enduring mental health problems who lived in supported housing. Carers were thought to need training to recognise when someone they are supporting needs to see the GP for physical health problems.

The physical fabric of buildings was clearly an issue for both target groups. Some GP practices are in buildings which do not allow for disabled access. There is often insufficient space to allow for the privacy that some service users would value.

Specialist health staff such as learning disability (LD) nurses or community psychiatric nurses (CPN) also played significant roles in enabling access for the target groups. The specialist LD posts tended to be short-term contracts or funded through non-recurring monies such as Health Action Zones, whereas the CPN posts are integral to and embedded within psychiatric services. The disparity between the two demonstrated the need for the extension of specialist learning difficulty expertise.

Staff attitudes

The subtext from the interviews with primary care staff and practitioners was a mix of fear, anxiety and some impatience combined with paternalism and kindness. Even though some of the interviews described the provision of awareness training in both mental health and learning difficulty, there was still a sense that patients from these groups were like time bombs ready to go off at any moment.

Time available to see patients once they had an appointment was a recurring issue. Carers and advocates mentioned the speed with which people were seen and treated, which did not allow for proper understanding or getting to the root cause of a physical health problem.

Doctors talked about *'heart sink'* patients from these groups, but there were also compassionate comments that acknowledged that people attending primary care should not have their lives made more difficult by that experience. Some practice staff expressed bewilderment as to why there should be any issues for people with mental health problems or learning difficulties in getting their needs understood.

There are many champions among GPs and other primary care staff, who are prepared to *'go the extra mile'* for patients from these groups. In the main, these champions have one common trait – they all seem to have personal experience of

either mental health problems or learning difficulties in their families or from within their social networks.

Physical health issues

In the view of those outside primary care services, diagnostic overshadowing was a significant obstacle to people with learning difficulties or mental health problems getting their physical health concerns taken seriously in primary care.

Most of the discussions about people with learning difficulties were skewed towards more severe or complex needs. It was acknowledged that people with more mild learning difficulties might be able to get access to services, for example health promotion information. But as practices' abilities to identify this group were so under-developed, it was difficult to know if and when the practice would know they had such a person attending for care.

There was a realisation among primary care practitioners that they did not have the specialist skills in learning difficulties or enduring mental health problems. However, in the former instance, low prevalence was given as a reason for not acquiring the knowledge and skills – they might never be used.

The most recurrent theme to emerge in learning difficulties is the demographic trend toward this population living on into later life. In the view of many of our sample, the social and service implications of this trend have not even begun to be addressed.

Services & treatments for physical health issues

In almost all interviews with primary care staff we heard about patients from these groups who don't follow advice as given, don't attend for appointments and who cannot cope with the implications of the advice they have been given. There did not seem to be any strategies in place to support these groups to follow any advice or guidance they might have been given.

Some of the good practice described went beyond individual practices. For example, clinical support networks on relevant themes or Local Strategic Partnerships that included active service user involvement or drop-in centres run by local voluntary organisations seemed not to make as much of an impact on individual practitioners as discrete clinicians like specialist nurses.

Interface between primary and secondary care

By far the majority of interviewees said quite categorically that primary care should be first port of call for these groups of people when they have concerns about their physical health. But there was also an understanding that primary care is faced with a plethora of demands from all of its patients. That, combined with lack of specialist skills and confidence working with these groups, meant that in many cases primary care was quick to offload onto specialist services.

From their perspective both specialist mental health and learning difficulty services were happy to both provide services and also to enable their clients to get access to primary care. In addition we heard about partnerships between specialist statutory and voluntary services.

However, structural change within primary care was perceived as both undermining of good practice and as threatening to established links.

Closing the gap

There is a clear-cut perception gap. Primary care practitioners and staff have a sense from individual interactions with their patients that they are providing as good a service as possible. Yet patients, their families and specialist service providers think that primary care services could be much improved, even when allowing for multiple demands on them.

Communication was one of the most significant issues. GPs and practice staff do not always have the skills or time to find out what people's needs and concerns are.

It is incumbent that primary care acquires some specialist knowledge on the health risks of these groups and effective lifestyle advice.

As a minimum, primary care practices could avail themselves of local knowledge on good practice in mental health and learning difficulty through their own management structures such as Professional Executive Committees. On a more national level websites such as www.networks.nhs.uk exist to provide easy access to online discussion groups on a range of topics with relevance to these groups.

What emerged clearly from the data was the importance of local champions: specialist LD nurses, GPs with experience of mental health issues, service user involvement on partnership groupings. Publicising good practice through relevant local arrangements and sharing process, input and outcomes can go some way towards alleviating understandable concerns about overload.

Primary care managers also have an important commissioning role for services for these groups. Partnerships between primary care practitioners and their own colleagues, for example in public health or social inclusion, have the potential to not only improve service design and delivery but also to enhance the interface between practitioners and their patients who use mental health or learning difficulty services.

1.7 Conclusion

A focused approach leads to positive results. This is no less true for addressing the physical health care and health prevention needs in people with a learning difficulty and those with a mental health problem. Good communication skills, the provision of appropriately formatted and accessible information, taking the time to understand the person's requirements, listening, and exercising sensitivity are especially important for these groups. Good practice examples show how championing the cause of people with a mental health problem or a learning difficulty can have an enormously beneficial impact on the physical health needs of these groups. Making these positive examples both permanent and widespread is the next challenge.

1.8 Main recommendations

- GP practices should consider developing a **protocol** for supporting people with learning difficulties and people with mental health problems to get the most from their GP practice.
- GP practices should ensure a system is put in place where people with learning difficulties and people with mental health problems are encouraged to attend regular preventative health checks, perhaps every six months or a year.
- GP practice staff, including reception staff, GPs and nurses, should receive **learning difficulty and mental health awareness training**, ideally from trainers who have learning difficulties themselves, mental health service user trainers and carer trainers.
- Staff should also be made aware of the ways in which the physical health problems of these two groups of people are frequently overshadowed by their learning difficulty or mental health diagnosis.
- GP practices should consider more effective health promotion advice and refer to appropriate interventions to improve dietary habits and encourage smoking cessation.
- For **guidance** to be provided to people with learning difficulties and people with mental health problems, and those who accompany them, to enable them to get the most out of their visits to their GP practice.
- People with learning difficulties, people with mental health problems and their carers should consider ways in which they can be more active and assertive in ensuring that their GP practice meets their health needs or those of the person they are caring for.

2 Introduction

2.1 Background

This project was funded by the Disability Rights Commission (DRC) as part of a Formal Investigation started in December 2004. The Formal Investigation was a response to the increasing evidence revealing health inequalities in health outcomes and access to primary care services for physical health problems in people with a learning difficulty and those with a mental health problem. This project was an endeavour to provide further evidence to the main aims of the Formal Investigation and to examine and identify solutions to these disparities.

Differences in health according to a person's socio-economic status have been well documented (Marmot 2005; Doran 2004). It is widely known that deprivation plays a prominent role in predicting increased mortality over the life course (Naess et al 2004). Inequalities in health and unequal access to health care services, particularly for disadvantaged or vulnerable groups, such as those with learning difficulties and people with mental health problems, are a major cause for concern. People with learning difficulties or mental health problems have been shown to have higher mortality rates and greater physical health problems compared to the general population (Ouellette-Kuntz et al 2004; Brown et al. 2000; Seymour 2003). Lifestyle factors such as high levels of tobacco smoking, poor diet, lack of exercise, psychotropic medication, substance and alcohol misuse all contribute to poorer physical health and avoidable death in people with a mental health problem, particularly those with schizophrenia (Connolly & Kelly 2005; Lambert et al. 2003). Common medical conditions in people with mental health problems include diabetes, cardiovascular disease, obesity, HIV/AIDS, hepatitis, osteoporosis, irritable bowel syndrome and helicobacter pylori infection (Lambert et al. 2003). For people with learning difficulties the main causes of mortality are respiratory disease, and swallowing and feeding problems (NHS Health Scotland 2004).

The barriers preventing access to health care for people with a learning difficulty or mental health problem exacerbate further these existing health inequalities. There is sufficient evidence to show that those with learning difficulties or mental health problems are likely to have their physical health needs go unrecognised, unnoticed or be poorly managed (Kerr 2004; Ouellette-Kuntz et al 2004; Brown et al 2000; Phelan et al 2001). In a literature review of the evidence highlighting the health inequalities experienced by these groups, Nocon (2004) lists some of the reasons for the poor access to health care. These reasons include being unawareness of and/or late recognition of symptoms, low expectations of health care services, difficulties in attending a GP surgery and potentially long waiting times, communication problems with health care professionals, stigma and discrimination on the part of health care professionals, problems with GP registration, and so forth. As a result, the detection, management and prevention of physical health problems are now of paramount concern (Samele 2004).

Efforts to remedy health inequalities by improving access to health care for those with a learning difficulty or mental health problems are relatively scant. However, a series of projects and recommendations has been introduced through a number of

good practice initiatives to identify and tackle the physical health needs of these groups with appropriate annual health checks and specialist health screening services (Martin et al. 2004; Seymour 2003; Cassidy et al. 2002; Cohen & Phelan 2001). Government policy has endorsed many of these initiatives, for example, in the English and Welsh National Service Frameworks for Mental Health (DH 1999; Welsh Assembly Government 2002) and in the new General Medical Services Contract (nGMS) (2004) for general practitioners. A Quality and Outcome Framework (QOF) was developed to encourage the delivery of high quality essential services according to a series of clinical and administrative domains. One such domain was for people with severe mental health problems. However, no similar clinical domain existed for with people with learning difficulties. Recent amendments to the QOF include the creation of a specific clinical domain for people with a learning difficulty.

Despite these efforts there remains an overwhelming need to a) implement many of the current policy recommendations, and b) find practical solutions to improve access to health care, and thereby reduce existing health inequalities for people with learning difficulties and those with mental health problems. A significant problem at the primary care level, where access to health care is concerned, is the capacity to identify people with learning difficulties and mental health problems, particularly if their condition is not especially severe (Emerson, Cohen personal communication). Some Primary Care Trusts have invested in developing practice-registers to reduce the health inequalities faced by people with learning difficulties and mental health problems. Without this, primary care services are unlikely to provide adequate screening or health care services to target the physical health needs of these groups. There is also an overarching need to identify and find practical and workable solutions likely to be effective in overcoming many of the difficulties experienced by people with learning difficulties and mental health problems, as far as their physical health care is concerned.

2.2 Aims and objectives

The following investigation had two principle aims. The primary aims were to:

1. examine access to primary care services of people with learning difficulties and people with mental health problems, with reference to their physical health, by looking at the capacity of a primary care service to identify the target groups and compare the physical health care they receive to those of the remaining population;
2. identify the ways in which primary care services attempt to address or overcome the inequalities in physical health care for people with learning difficulties and those with mental health problems, and ensure their physical health care needs are being met.

The secondary aims were to:

- i. identify the numbers of people with a learning difficulty or mental health problem from the local area cites using available general practice databases/computerised records, and other sources of information;
- ii. build a profile of access to primary care services, type of services offered, and service uptake of the target groups looking specifically at the:

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- target groups' experiences with primary care services;
 - problems encountered by the target groups in accessing primary care services for physical health problems;
 - issues concerning GP registration and whether this has presented any problems for the target group;
 - provision of health promotion advice, and/or referral to dietary, leisure activities, or smoking cessation services, and whether any materials provided are available in other formats suitable for people with multiple impairments (i.e. visual or auditory);
 - compliance with Part 3 of the DDA in achieving health targets and in attempts to overcome discriminatory policies, procedures and practices.
- iii. identify the differences in access to primary care services according to different age groups from children to older people and those from black and ethnic minority groups;
- iv. explore a PCT considered to be a beacon service for people with learning difficulties or mental health problems to identify the factors that are potentially effective in promoting better access and provision of health care for the target groups;
- v. explore the views and suggestions of the target groups, primary care practitioners, and other relevant secondary health care professionals, as to how primary care services can be improved to enable better access to health care services and management/treatment of physical health problems and health promotion.

3 Methods

3.1 Introduction

We used a multi-method approach and two main data sources to carry out the project. This involved:

- a) a quantitative study of GP data sets to examine questions relating to the identification of the target groups and access to primary care services for physical health problems;
- b) a qualitative study to explore the questions regarding the difficulties encountered by the target groups when accessing services for physical health problems, any problems with GP registration, and their views and suggestions for a better service.

We also explored the views of health care professionals and service directors/managers the difficulties in identifying the target groups and providing adequate health checks, health screening services and the solutions being sought to overcome any problems.

3.2 Examination of GP practice datasets

Selection of Local Area Sites

The quantitative study consisted of secondary analyses of available local GP datasets to identify people with learning difficulties or mental health problems. We chose three Primary Care Trust (PCT) areas in England and one Local Health Board (LHB) in Wales based on the extent to which they fulfilled the DRC Area Studies criteria of criteria whether:

- inner city/urban;
- rural; and
- an area with a high Black and minority ethnic population.

The sites were also chosen because of our knowledge of their current practice in areas pertinent to the investigation. However, the selection of local area sites was subject to the agreement of the PCTs and LHB to participate in the investigation. We aimed to recruit up to ten GP practices from each of the three PCTs and LHB selected. Given time restraints we were unable to randomly select GP practices and relied on PCTs to assist with the recruitment of practices.

3.3 Recruitment of GP practices

Site 1 – South East

This PCT area was a mixture of urban and semi-rural with high levels of deprivation on the Jarman indices. The PCT comprised of 25 GP practices. Recruitment of participating GP practices was via the mental health lead at the PCT, who gave a presentation on the DRC project to the PCT's Professional Executive Committee. The six GPs who were members of this group all agreed that they would participate if no other practices were recruited. A letter was sent to practices likely to have an interest in collaborating.

Site 2 - London

This PCT was an inner city area with a rich ethnic mix in its population and areas of affluence as well as deprivation in close proximity. The PCT comprised of 53 GP practices and 10 health centres. Each locality has two neighbourhoods made up of GP practices and community nursing staff, and acts as a unit of service delivery to integrate community nursing and primary care management.

Recruitment in this PCT was attempted in different ways. The Public Health Directorate of the PCT distributed a letter to practices identified as having the appropriate IT systems. The letter was signed by the Chair of the IT steering group - a local GP who also led on mental health. This method proved unproductive and so GP practices were recruited via a GP working at the Sainsbury Centre for Mental Health.

Site 3 North West

This PCT covers a largely rural area of England with no large urban centres. This PCT comprised of 55 GP practices. Through our contacts we knew that the area had good secondary care provision for learning difficulties. One of the incentives for potential primary care partners was the possibility of building on this local knowledge and also enhancing their mental health provision and awareness. GP practices were identified and recruited via the PCT's Director of Public Health who has been a champion for learning difficulty awareness in the locality.

Site 4 - Wales

This LHB was established in April 2003 and provides services in a principally urban environment to a largely non-Welsh speaking population. This was the one area where we did not have strong pre-existing links. Initial contacts were with local practitioners but these were not at a sufficiently high level to gain entry into the LHB. We therefore contacted the CEO of the LHB on a number of occasions and once he had a person who could liaise with the project, he acceded to participation. The Chair of the LHB wrote to all 23 practices, inviting participation. He also emphasised that his own practice would be a partner practice.

3.4 Identifying the target groups

We aimed to identify all people with a learning difficulty and with mental health problems registered at the selected GP practices. The criteria for including the target groups were people who:

- fall within the following age groups: 0-16, 17-65, and 65+. This is to ensure that problems specific to children, adults of working age and older people are identified;
- have been registered and formally acknowledged to have learning difficulty, and registered in some way. For example, on Special Educational Needs (SEN) databases held by LEAs or registered with learning difficulties services;
- have received a diagnosis of mental illness and been offered treatment (whether medication or psychological therapy) by their GP and by secondary mental health services or both.

In setting the above inclusion criteria we were conscious of the difficulty in identifying those with less severe learning difficulties or mental health problems. Our aim was to be inclusive and the search was extensive and intended to capture all those groups with less severe learning difficulties or mental health problems.

3.5 Data collection

From GP databases we aimed to collect information concerning:

- socio-demographic characteristics of patients (age, gender, ethnicity, and other available demographics);
- clinical information, such as:
 - diagnosis of a mental health problem (both severe and non-severe) and a learning difficulty;
 - treatment for a mental health problem;
 - the prevalence of a series of major diseases, including ischaemic heart disease, stroke, diabetes mellitus, COPD and some others;
 - the recording of several health screening services (i.e. blood pressure, body mass index, smoking levels, cholesterol, etc) and the test results of health checks;
 - health promotion/prevention advice or interventions (i.e. dietary and smoking advice);
 - any regular physical health checks, treatment for a physical health problem, referrals to secondary health care services for physical health problems; and
 - other relevant information, including practice size and postcode.

Practice registers were searched by researchers from the Primary Care Informatics (PCI) Group at St George's Hospital Medical School, London. Members of the PCI defined a dataset relevant to the research questions and took into account how clinical concepts could be coded by GPs. MIQUEST (Morbidity Information and Export Syntax), a Department of Health sponsored data extraction tool, was then used to extract anonymised data from a pilot GP practice (St George's, b). It was required that all selected GP practices had IT systems known to the PCI group and could accommodate the MIQUEST software. The pilot data were then presented to the group and modifications were made to the MIQUEST data extraction queries as necessary. Appendix 1 details the modified list of Read Code variables used to search GP databases for final dataset.

Data derived from the GP practices were processed using a five step method proposed by Berndt et al (2001), which involves an error reduction approach. These stages include: a) migration of the data into a data repository; b) combining data with data from other practices; c) data cleaning; d) data processing; and, e) transferring data into an appropriate package for statistical analyses.

3.6 Postal survey

We adapted a questionnaire used in a previous Department of Health National Survey Programme (2003). This was a semi-structured questionnaire that looked at

people's experiences of contacting their GP and the service they received. GP practices identified relevant people from the target groups, using practice databases. Once they were identified, GP practices then sent out questionnaire packs on our behalf in order to maintain patients' anonymity.

3.7 Focus groups and interviews with people with a mental health problem and people with a learning difficulty

Sample selection of the target groups and carers

The sample of people from the target groups and carers were primarily drawn from and contacted through local residential/nursing homes, advocacy organisations/representative networks, and where possible a medium secure unit for focus group discussions. We aimed to ensure all groups of interest were included in the qualitative sample, such as those within the age groups specified above, men and women, those from Black and ethnic minority groups, and those with multiple impairments (those with hearing, visual and mobility impairments).

People were recruited with the help of workers in local voluntary and statutory sector services and organisations. These workers either sent out a letter to service users and/or carers on their databases inviting them to take part or personally approached people who used their services. Those who indicated on their returned postal questionnaire, sent out as part of this study, that they would be willing to be approached to take part in a focus group or interview were additionally contacted. All the service users and carers who took part were provided with accessible information about the study, were asked to provide written consent and were paid to thank them for their time and expertise. Each participant was also offered the opportunity to receive a copy of the findings in summary form at the end of the project.

3.8 Telephone interviews with health care managers, practitioners and advocates

Sample selection of health care managers, practitioners and advocates

A purposive sample of key managers, health care practitioners and advocates was identified via local contacts from the local area sites for this part of the project. Managers included, for example, commissioning leads for mental health or learning difficulties, Board level PCT managers and senior mental health and also learning difficulty managers from local authorities.

Health care practitioners included general practitioners, especially any with a special interest in mental health or learning difficulty. We also interviewed key mental health and learning difficulty practitioners from secondary care and local authorities. Other key members of the primary care team, such as receptionists and practice managers were also included.

Advocate interviewees were drawn from local branches of national agencies such as Mind or MENCAP as well as relevant local voluntary sector advocacy groups.

Data collection

Data for the qualitative study were collected from a series of focus groups and depth interviews with target groups and carers; and telephone interviews with key managers, health practitioners; and relevant key contacts from advocacy agencies/organisations.

A semi-structured topic guide/interview schedule was developed and piloted to elicit narrative accounts of the target groups' positive and negative experiences of getting access to primary care services for physical health problems and how they were treated and managed. These topic guides and questions were compiled by the two teams of researchers who also undertook the focus groups and interviews. A team of researchers with learning difficulties, from the organisation Central England People First, carried out the focus groups and interviews with people with learning difficulties. A team of five service user researchers, coordinated via SCMh, carried out the focus groups and interviews with the mental health service users and also with the carers of both groups of people. An additional researcher from SCMh was involved in facilitating some of the focus groups with carers.

The interview questions used by Central England People First can be found in Appendix 3. The topic guide used by the researchers speaking with people with mental health problems and then adapted for carers of people with learning difficulties and people with mental health problems is located in Appendix 2. The method of data collection was flexible in order to enable people to take part in a way that was most comfortable and appropriate to their individual needs and circumstance. The focus groups lasted for about an hour and a half while individual interviews took around half an hour. Focus groups and interviews were recorded in note form and/or were taped were tape recorded, with the consent of interviewees/participants and anonymised to preserve confidentiality. Both service user research teams were involved in developing the questions and topic guides used in the focus groups and interviews.

For managers, practitioners and advocates, interviews explored issues of unrecognised need, implementing relevant policy recommendations and their impact on practice. Potential solutions to the problems raised were explored (see Appendix 3 for copies of the telephone interview questionnaires).

Telephone interviews were conducted by four researchers, all from the Sainsbury Centre for Mental Health.

The project was granted approval by relevant local ethics committees.

3.9 Analysis of data

GP practice and postal survey data

Descriptive statistics were used in the first instance to calculate frequencies, mean values and percentages. For the clinical data derived from GP practices, appropriate statistical tests of significance were performed to look at differences between age and gender groups, as well as comparison populations for the prevalence of physical health problems, health screening, health advice and interventions. We also used multivariate regression techniques to control for potential confounders where relevant.

Focus groups, depth interviews and telephone interview data

The thematic content of interviews was used to analyse qualitative data through a process of detailed reading, annotating and categorising of data. These analyses focused on the problems experienced in accessing primary care services for physical health problems and the potential solutions; the differences and similarities of people in the different PCT and LHB locations, and groups (gender, age, ethnicity, etc). These analyses also addressed the primary research questions as to *why* unequal access to health care for physical health problems exists for the target groups and how this can be overcome.

At set points in the data collection, debriefing sessions with fieldwork researchers were conducted to explore themes with them and feed this into the analysis in an iterative fashion. This method is intended to minimise individual researcher bias as well as to ensure that contradictory findings are highlighted and discussed. The mental health service user consultants and researchers from CEPF were involved in analysing the data, its write up and in producing subsequent recommendations.

All interview materials, information sheets and consent forms were made accessible to people with learning difficulties and translated into Welsh for the Wales LHB area.

4 Findings from the study

4.1 Results from GP practice databases

The specific aims of this part of the project were to look at the:

- a) prevalence of mental health problems, and learning difficulties;
- b) prevalence of people with co-morbid physical health problems and the clinical care they receive in primary care. In other words, the extent to which they are monitored, treated and managed in primary care;
- c) extent to which the target groups without a co-morbid physical health problem are at risk of developing one; and
- d) extent to which the target groups without a co-morbid physical health problem are being offered health promotion/prevention advice or interventions.

4.2 Prevalence of the target groups

Twenty two GP practices across the four sites took part in the study, 16 of which were multi-practices. Practices varied in size from 1,700 to 14,500 registered patients. A total of 150,181 people were included in the combined GP dataset. These data were collected over a period of three weeks during July and August 2005. The gender distribution was roughly equal for this population where 50.2% (75,457/150,177) were female. Seventeen percent of the entire sample was aged between 0-17 years; 66.2% aged between 18-65 years; and 16.1% over the age of 65. Ethnicity was very poorly recorded and available for only 7.2% (10,792/150,181) of patients. Where ethnicity was recorded the available categories were too numerous to describe or regroup meaningfully. We therefore did not include ethnicity our analyses.

Prevalence of severe mental health problems

We identified 864 people with a severe mental health problem (SMI) based on the earliest recorded diagnosis. SMI was defined as someone with either a diagnosis of schizophrenia or bipolar affective disorder. The number of people diagnosed with bipolar affective disorder was 162, with an overall prevalence of 1.08 per 1,000 people. Given this relatively small number we combined this group with those diagnosed with schizophrenia.

The overall prevalence of SMI therefore was 5.75 per 1,000 patients. These prevalence figures are similar to that found by Jenkins et al (1997). Table 1 shows the prevalence of SMI according to age and gender. Men had the highest prevalence of SMI at 6.33 per 1,000 patients compared to women at 5.18 per 1,000. In terms of age the prevalence was greatest for men between the ages of 51 to 60 reaching 9.98 per 1,000 patients. For women the prevalence of SMI was highest between the ages of 71 to 80 years of age at 12.07 per 1,000 patients.

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Table 1. Prevalence of severe mental illness (SMI)¹ per 1000 patients²

Age bands (years)	Males			Females		
	People with SMI	Total population	Prevalence per 1000 with SMI	People with SMI	Total population	Prevalence per 1000 with SMI
0 to 10	0	8,658	0.00	0	8,397	0.00
11 to 20	8	9,598	0.83	5	9,075	0.55
21 to 30	68	9,288	7.32	15	9,415	1.59
31 to 40	88	12,068	7.29	60	11,438	5.24
41 to 50	110	11,390	9.66	69	10,610	6.50
51 to 60	98	9,823	9.98	77	9,659	7.97
61 to 70	62	7,229	8.57	61	7,311	8.34
71 to 80	25	4,709	5.31	68	5,632	12.07
81 to 90	12	1,742	6.89	32	3,216	9.95
91and over	2	207	9.66	4	704	5.68
Total	473	74,712	6.33	391	75,457	5.18

¹ SMI defined as having a diagnosis of psychosis or bipolar disorder – earliest date of diagnosis

² Crude age and gender specific prevalence

Treatment received for a SMI

This section describes the number and percentage of people who were receiving treatment for a SMI. In total 659 (76.3%) of people with a SMI were prescribed either antipsychotic or antidepressant medication (including lithium). Overall more women with a SMI were prescribed medication by their GP (83.6%; 327/391) compared to men (70.2%; 332/473). Women aged between 21 to 30 years had the highest percentage prescriptions for medication at 100% (15/15). Among men, those aged between 61 to 70 years had the highest percentage of prescribed medication at 80.6% (50/62).

Prevalence of depression

There were 15,186 people diagnosed with depression giving an overall prevalence of 101.1 per 1,000 patients. Table 2 shows the breakdown of the numbers and prevalence of people with depression by gender and age group. As expected the prevalence of women diagnosed with depression was almost double that of men at 131.8 per 1,000 population compared to 70.1 per 1,000. The age groups with the highest prevalence of depression were for people between the ages of 31 to 60 years.

Treatment received for depression

Overall 75.4% (11,443/15,186) of people diagnosed with depression were prescribed treatment from their GP. The percentage was similar for both men (71.4%; 3,742/5,240) and women (77.4%; 7,701/9,946) and across the different age groups.

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Table 2. Prevalence of depression¹ per 1000 population

Age bands (years)	Males			Females		
	People with depression	Total population	Prevalence per 1000 with depression	People with depression	Total population	Prevalence per 1000 with depression
0 to 10	3	8,659	0.3	2	8,397	0.2
11 to 20	101	9,598	10.5	210	9,075	23.1
21 to 30	587	9,296	63.1	1,269	9,415	134.8
31 to 40	1,104	12,068	91.5	2,182	11,438	190.8
41 to 50	1,163	11,390	102.1	2,042	10,610	192.5
51 to 60	1,084	9,823	110.4	1,785	9,660	184.8
61 to 70	666	7,229	92.1	1,155	7,311	158.0
71 to 80	362	4,709	76.9	781	5,632	138.7
81 to 90	151	1,742	86.7	432	3,217	134.3
91and over	19	207	91.8	88	705	124.8
Total	5240	74,721	70.1	9946	75,460	131.8

¹ Excludes people with a SMI

Prevalence of learning difficulties

We identified a total of 5.01 per 1000 patients (753/150,181) with a learning difficulty. Table 3 shows the distribution of people with a learning difficulty according to age and gender. The prevalence for men (6.68, 499/74,721) was almost double that compared to women (3.37%, 254/75,460). The highest prevalence of a learning difficulty is found among those aged between 11 to 20 years and the lowest in older age groups from 61 years and above.

Comparison of prevalence with other surveys

Our prevalence of a SMI was similar to that found by other studies (Jenkins et al 1997). The prevalence for learning difficulties was also similar to that of an overall administrative prevalence rate of 0.4% and tailing off at older age ranges (Emerson and Hatton 2004).

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Table 3. Prevalence of learning difficulties (LD) per 1000 patients

Age bands (years)	Males			Females		
	People with LD	Total population	Prevalence per 1000 with LD	People with LD	Total population	Prevalence per 1000 with LD
0 to 10	91	8,659	10.51	34	8,397	4.05
11 to 20	168	9,598	17.50	59	9,075	6.50
21 to 30	65	9,296	6.99	44	9,415	4.67
31 to 40	52	12,068	4.31	34	11,438	2.97
41 to 50	46	11,390	4.04	31	10,610	2.92
51 to 60	45	9,823	4.58	29	9,660	3.00
61 to 70	18	7,229	2.49	8	7,311	1.09
71 to 80	12	4,709	2.55	10	5,632	1.78
81 to 90	2	1,742	1.15	4	3,217	1.24
91and over	0	207	0.00	1	705	1.42
Total	499	74,721	6.68	254	75,460	3.37

5 Diagnosed medical co-morbidity and clinical care in people with a SMI, depression and learning difficulty

5.1 Introduction

In this section we report the prevalence of four major diseases diagnosed in the target groups. These are ischaemic heart disease (IHD); stroke; diabetes mellitus; and, chronic obstructive pulmonary disease (COPD) including asthma, bronchitis and pneumonia. However, we briefly examined the prevalence of other diseases: hepatitis and HIV/AIDS. The total prevalence for hepatitis in people with a SMI was 0.8% (7/864) and similar to that for people with depression (0.7%; 110/15,475). There were no recorded cases of HIV/AIDS in people with a SMI. For people with depression there was a prevalence of 0.2% (32/15,475) for HIV/AIDS, although it is likely that the depression may have been a consequence of HIV/AIDS. Recorded cases of hepatitis and HIV/AIDS were extremely low for people with a learning difficulty. There was only one reported case of hepatitis in this group and no recorded cases of HIV/AIDS.

The prevalence figures for the four diseases were based on the earliest recorded date of diagnosis. We also report on the extent of clinical care provided by primary care services for people with a SMI, depression and a learning difficulty diagnosed with these major diseases. The clinical care includes health checks, treatment/management of the disease and health education advice/interventions. We report on whether a record of such health checks/advice/intervention existed, and where applicable the recorded test result. Although we had some information on referrals to secondary health care this was too varied to group coherently.

5.2 Prevalence of ischaemic heart disease (IHD)

SMI and depression

We looked at the differences between those with a SMI and depression and compared them to the remaining population. Table 4 shows the distribution of IHD by age group and gender. The total prevalence of IHD in people with a SMI was 5.4% (47/864). The prevalence of IHD for men and women with a SMI was almost identical (5.3%, 25/473 and 5.6%, 22/391 respectively).

The overall prevalence of IHD in people with depression was slightly higher compared to people with a SMI at 6.4% (973/15,186). There were notable age differences where the prevalence was highest for people with depression aged 65 years and above. The prevalence of IHD in men with depression was 8.4% (442/5,240) and greater than that of women at 5.3% (531/9,946) (adjusted for age OR 2.07, 95% CIs 1.8 to 2.4, $p > 0.001$).

The prevalence of IHD in the remaining population (i.e. those without a SMI or depression) was much lower at 3.9% (5,251/134,128). Although people with a SMI had a higher prevalence of IHD this was not shown to be statistically different compared to the remaining population (adjusted for age & gender OR 0.94, 95% CIs 0.1 to 1.3, $P = 0.749$).

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This was not the case in people with depression. When compared to the remaining population people with depression were at significantly more likely to have a diagnosis of IHD even after taking into account age and gender (Adjusted OR 1.70, CIs 1.6 to 1.8, $P < 0.001$).

Learning difficulties

There were very few cases of IHD in people with learning difficulties where the overall prevalence was 0.7% (5/753). The prevalence for the remaining population was greater at 4.2% (6,266/149,428).

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Table 4. Ischaemic heart disease (IHD) in people with SMI and depression

	SMI			Depression ¹			Remaining Population ²		
	No. of people with IHD	Total no. with SMI	%	No. of people with IHD	Total no. with depression	%	No. of people with IHD	Total no.	%
Males									
0 to 24	0	35	0.0	0	272	0.0	2	21,480	0.0
25 to 54	8	280	2.9	68	3,093	2.2	274	29,644	0.9
55 to 64	8	88	9.1	129	1,019	12.7	734	8,174	9.0
65 to 74	6	41	14.6	122	487	25.1	1,101	5,672	19.4
75 to 84	2	21	9.5	102	294	34.7	912	3,192	28.6
85 and over	1	8	12.5	21	75	28.0	222	845	26.3
Total	25	473	5.3	442	5,240	8.4	3,245	69,007	4.7
Females									
0 to 24	0	10	0.0	0	633	0.0	2	20,337	0.01
25 to 54	1	166	0.6	38	5,794	0.7	82	25,784	0.3
55 to 64	4	79	5.1	114	1,608	7.1	245	7,429	3.3
65 to 74	8	62	12.9	148	957	15.5	551	5,527	10.0
75 to 84	5	59	8.5	166	673	24.7	713	4,118	17.3
85 and over	4	15	26.7	65	281	23.1	413	1,926	21.4
Total	22	391	5.6	531	9,946	5.3	2,006	65,121	3.1
Overall total	47	864	5.4	973	15,186	6.4	5,251	134,128	3.9

¹ Excludes people with SMI

² Excludes people with SMI and depression

5.3 Clinical care for people with IHD - recorded health checks & test results

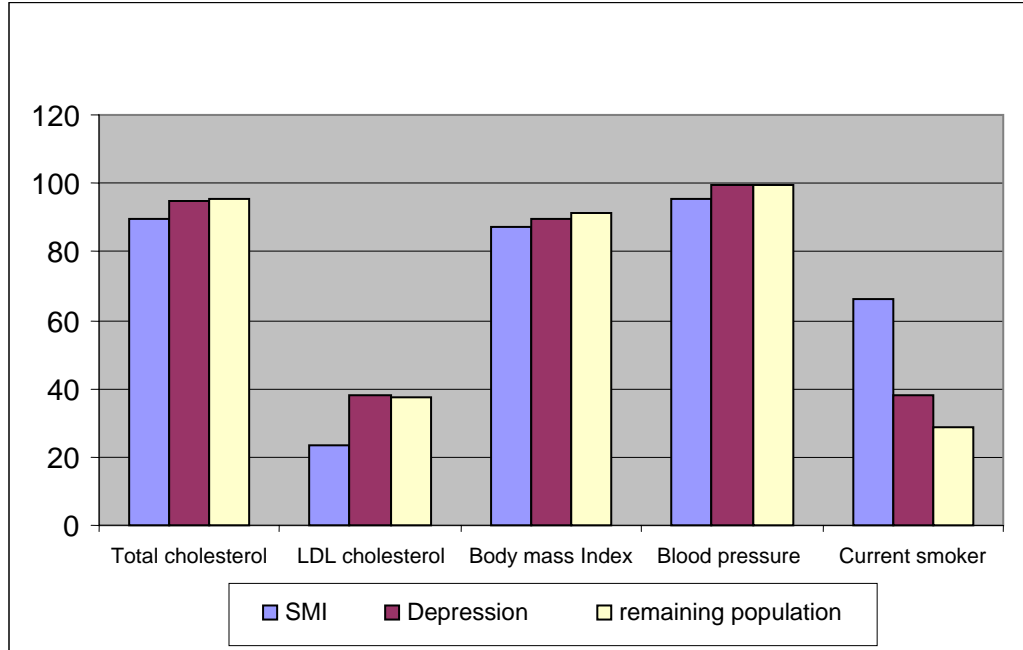
Data on relevant health checks and test results were available for total cholesterol, LDL cholesterol, body mass index (BMI), blood pressure and whether a current smoker. We also present findings on the provision of lipid lowering therapy and health advice on smoking and diet.

SMI and depression

Figure 1 shows the percentage recorded health checks for people with a SMI and depression compared to the remaining population. Of the people with a SMI and diagnosed with IHD 89.4% (42/47) had a record of total cholesterol. This was lower than that of the remaining population which was 95.5% (5,014/5,251) and statistically significant (age and gender adjusted OR 0.33, 95% CIs 0.1 to 0.9, P=0.027). Recorded LDL cholesterol was again lower in the SMI group with IHD compared to the remaining population (23.4%, 11/47 and 37.7%, 1,981/5,251 respectively). This difference was significant (age and gender adjusted OR 0.4, 95% CIs 0.2 to 0.9, P=0.019). The percentage of recorded body mass index for people with a SMI was also lower than the remaining population (87.2%, 41/47 and 91.1%, 4,783/5,251 respectively), although the difference was not statistically significant. This was also the case for blood pressure measurement. However, recorded current smoking was much higher in the SMI group compared to the remaining population (66.0%, 31/47 and 28.8%, 1,512/5,251) and statistically significant (age and gender adjusted OR 4.09, 95% CIs 2.1 to 7.8, P<0.001).

People with depression and IHD had similar percentages compared with the remaining population for almost all the health checks examined.

Figure 1. Recorded health checks in people with IHD (percentage)



Test results for people with a SMI and IHD were lower for total cholesterol (0.89 vs 0.95mmol/L) and systolic blood pressure compared to the remaining population (129.5 vs 134.9mmHg); and marginally higher for LDL cholesterol (2.79 vs 2.69) and body mass index (28.6 vs 27.9). However, none of these differences were statistically significant. Mean test results for people with depression and IHD were very similar to the remaining population.

Learning difficulties

The percentages of recorded health checks in people with IHD were much lower than the other target groups and the remaining population. Total cholesterol, LDL cholesterol, body mass index and current smoking status were recorded in 40% (2/5) cases. Blood pressure was recorded for 80% (4/5) of cases. Test results were highest for body mass index (30.9 vs 27.9), but not significantly different from the remaining population. Some caution must be exercised in interpreting these figures given the very small numbers involved.

5.4 Health advice and prevention for IHD

SMI and depression

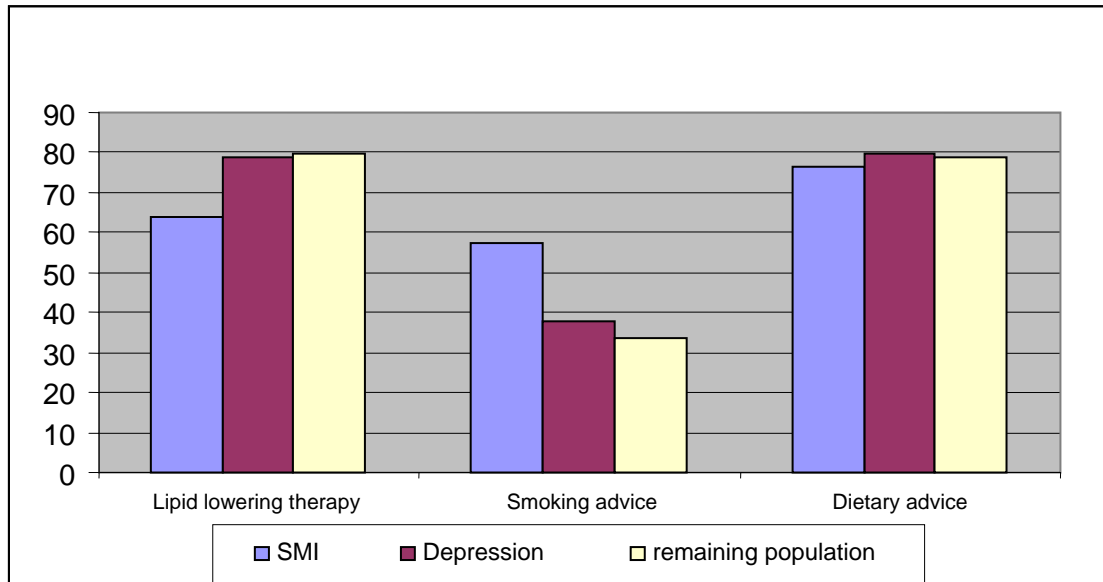
Figure 2 illustrates the percentage health advice/prevention offered to the mental health groups with IHD. Lipid lowering therapy was provided for 63.8% (30/47) people with a SMI and IHD which was less than the remaining population (79.9%, 4,193/5,251). This difference was statistically significant (age and gender adjusted OR 0.42, 95% CIs 0.2 to 0.7, P=0.006). There was a higher percentage of smoking advice provided to people with a SMI and IHD than the remaining population (57.4%, 27/47 vs 33.5%,

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1,760/5,251) and statistically significant (age and gender adjusted OR 2.25, 95% CIs 1.2 to 4.1, $P=0.010$). The percentage of dietary advice offered to the SMI group was lower than the remaining population (76.6% 36/47 vs 79.0%, 4,148/5,251) but not statistically different.

People with depression and IHD were offered health advice and lipid lowering therapy at similar percentages to the remaining population.

Figure 2. Recorded health advice for people with IHD (percentage)



Learning difficulties

Lipid lowering therapy, smoking and dietary advice were offered in 40% (2/5) of cases for people with a learning difficulty and IHD, which was substantially lower than the remaining population.

Gender differences in the target groups for people with IHD

There were few gender differences in the number of recorded health checks for the mental health target groups with IHD. The numbers for those with a learning difficulty were too few to analyse. Of the health checks examined – total cholesterol, LDL cholesterol, body mass index, blood pressure and current smoking – only total cholesterol and current smoking status for those with a SMI revealed any significant difference. Women with a SMI and IHD were less likely to have a recording for total cholesterol and less likely to be a current smoker. There were no significant gender differences for those with depression and IHD or in the health advice/interventions, except for the provision of lipid lowering therapy in which women were less likely to receive this compared to men ($P<0.001$). (See Appendix 4, tables v and vi)

5.5 Prevalence of stroke

SMI and depression

People with a SMI had the highest prevalence of stroke compared to those with depression and a learning difficulty. The prevalence for this group was 5.1% (44/864). The total prevalence for people with depression was 3.4% (522/15,186). Both prevalence figures were higher than that of the remaining population (1.9%; 2,498/134,128). For each mental health group the highest prevalence figures were found in older age groups of 75 years+ (see Table 5 below). Women with a SMI had a higher prevalence of stroke compared to men (5.9%, 23/391 and 4.4%, 21/473 respectively).

People with a SMI had double the risk of being diagnosed with a stroke compared to the remaining population (age and gender adjusted OR 2.01; 95% CIs 1.4 to 2.8; P<0.001). A similar finding was also found for people with depression (age and gender adjusted OR 1.75; 95% CIs 1.6 to 1.9; P<0.001).

Learning difficulties

As with IHD the prevalence of stroke in people with a learning difficulty was small. The overall prevalence was 1.2% (9/753) and half that for the remaining population (2.0%; 3,055/149,428). There were no statistically significant differences compared to the remaining population for stroke in people with a learning difficulty.

No differences existed in the prevalence between men and women which was 1.2% (6/499 and 3/254 respectively) for both gender groups. Strokes occurred mostly in older age groups between 65 to 74 and 85+ years.

5.6 Clinical care for people with a stroke - recorded health checks & test results

SMI and depression

All 44 people with a SMI and a stroke had a systolic and diastolic blood pressure record compared to 98.6% (558/566) for the remaining population. The latest recorded mean systolic blood pressure value for people with a SMI and a stroke was lower at 127.9mmHg (SD 18.2) compared to 136.7mmHg (SD17.7) although the difference was not significant. Diastolic blood pressure for this group was 75.5 (SD 10.7) and exactly the same for the remaining population. Current smoking was recorded for 45.5% (20/44) people with SMI and a stroke compared to 28.8% (719/2,498) for the remaining population. However, the difference was not significant after adjustment for age and gender.

For people with depression and a stroke blood pressure was recorded in 98.5% (514/522) cases. The mean systolic blood pressure was 134.8mmHg (SD 17.9). Diastolic blood pressure for those with depression and a stroke was 76.7mmHg (SD 9.9). Current smoking was 39.6% (207/522) for this group.

Learning difficulties

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In people with a learning difficulty and a stroke blood pressure was recorded in 77.8% (7/9) of cases compared to 98.5% (3,008/3,055) for the remaining population. This difference was statistically significant (age and gender adjusted OR 0.10; 95% CIs 0.1 to 0.5; P=0.008). The mean systolic blood pressure was 129.8mmHg (SD 15.1) and 71.1mmHg (SD 9.5) for the diastolic mean value. Current recorded smoking was less in people with a learning difficulty and a stroke than the remaining population (22.2%, 2/9 vs 30.9%, 944/3,055), but not significantly different from it.

All blood pressure mean values reported in this section were all within normal limits.

Gender differences in recorded health checks in the target groups with a stroke

No gender differences existed for the mental health groups with a stroke concerning recorded health checks (see Appendix 4, table vii). The numbers were too small to examine for those with a learning difficulty and stroke.

5.7 Health advice and interventions for stroke

SMI and depression

Smoking advice was received by 25.0% (11/44) of those with a SMI and a stroke and similar to the remaining population at 26.3% (656/2,498). For those with depression the percentage for smoking advice was greater than both the SMI group and remaining population (32.6%, 170/522), and statistically significant (age and gender adjusted OR 1.27; 95% CIs 1.0 to 1.6; P=0.023).

Learning difficulties

Smoking advice was provided to 33.3% (3/9) of current smokers with a learning difficulty and a stroke, which was higher than that of the remaining population (27.3%, 834/3,055) but not significant.

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Table 5. Stroke in people with SMI and depression

	SMI			Depression*			Remaining Population**		
	No. of people	Total no.		No. of people	Total no. with depression		No. of people	Total	
	with stroke	with SMI	%	with stroke	n	%	with stroke	no.	%
Males									
0 to 24	0	35	0.0	0	272	0.0	10	21,480	0.0
25 to 54	5	280	1.8	25	3,093	0.8	75	29,644	0.3
55 to 64	7	88	8.0	37	1,019	3.6	223	8,174	2.7
65 to 74	2	41	4.9	65	487	13.3	424	5,672	7.5
75 to 84	5	21	23.8	72	294	24.5	429	3,192	13.4
85 and over	2	8	25.0	17	75	22.7	147	845	17.4
Total	21	473	4.4	216	5,240	4.1	1,308	69,007	1.9
Females									
0 to 24	0	10	0.0	0	633	0.0	5	20,337	0.0
25 to 54	3	166	1.8	44	5,794	0.8	82	25,784	0.3
55 to 64	5	79	6.3	40	1,608	2.5	120	7,429	1.6
65 to 74	4	62	6.5	72	957	7.5	247	5,527	4.5
75 to 84	9	59	15.3	94	673	14.0	410	4,118	10.0
85 and over	2	15	13.0	56	281	19.9	326	1,926	16.9
Total	23	391	5.9	306	9,946	3.1	1,190	65,121	1.8
Overall total	44	864	5.1	522	15,186	3.4	2,498	134,128	1.9

* Excludes people with SMI

** Excludes people with SMI and depression

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5.8 Prevalence of diabetes mellitus

SMI and depression

Table 6 lists the prevalence figures for diabetes mellitus in both mental health groups. The overall prevalence of diabetes mellitus in people with a SMI was 8.8% (76/864). Women had a higher prevalence (10.2%, 40/391) compared with men (7.6%, 36/473), although this difference was not statistically significant. However, there was a significant difference between those with a SMI and diabetes mellitus compared with the remaining population (age and gender adjusted OR 2.20, 95% CIs 1.7 to 2.8, $P < 0.001$). The presence of diabetes mellitus in people with a SMI largely affected those aged 65 and above.

In people with depression the overall prevalence was lower at 4.7% (714/15,186), but still higher than that of the remaining population at 3.2% (4,313/134,128). This was also statistically significant (age and gender adjusted OR 1.34, 95% CIs 1.2 to 1.4, $P < 0.001$). Men with depression had a higher prevalence of diabetes mellitus than women (5.6%, 293/5,240 and 4.2%, 421/9,946 respectively). People aged 65 and above had the highest prevalence of diabetes mellitus.

Learning difficulty

The overall prevalence for diabetes in people with a learning difficulty was 2.4% (18/753). Unlike people with a SMI and depression the prevalence of diabetes mellitus was higher in women 3.1% (8/254) compared to men at 2.0%, (10/499). This difference, however, was not statistically significant.

Antipsychotic medication and diabetes mellitus

Previous research has shown that people with schizophrenia are at greater risk of developing diabetes if receiving antipsychotic, particularly atypical or newer antipsychotic, medication. We examined whether this was the case in our population. Sixty-seven percent (579/864) of people with a SMI were taking antipsychotic medication. Fifty-seven percent of these were taking atypical antipsychotics. Although there was an increased risk of having diabetes mellitus in this group and being prescribed antipsychotics the association was not statistically significant (adjusted OR 1.38, 95% CIs 1.2 to 1.6, $P > 0.05$), even when looking specifically at atypical antipsychotics. This finding may be due to the relatively small numbers used in the analysis.

Antipsychotic medication, however, was not limited to those with a SMI. Eight percent of people with depression were prescribed antipsychotic medication (1,330/154,475), 38% of whom were taking atypicals (499, 1,321). Of those with a learning difficulty 13.4% (101/ 753) were receiving antipsychotic medication. In the remaining population 1.2% (1,649/134,706) were prescribed antipsychotic medication. In analysing the figures for all those receiving some form of antipsychotic medication and having a diagnosis of diabetes mellitus is significant (adjusted OR 1.41, 95% CIs 1.2 to 1.6, $P < 0.001$). However, this is not the case when looking at only at atypical antipsychotics.

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Table 6. Prevalence of diabetes mellitus in people with SMI and depression

	SMI			Depression ¹			Remaining Population ²		
	No. of People with diabetes mellitus	Total no. with SMI	%	No. of People with diabetes mellitus	Total no. with depression	%	No. of People with diabetes mellitus	Total no.	%
Males									
0 to 24	1	35	2.9	2	272	0.7	70	21,480	0.3
25 to 54	12	280	4.3	85	3,093	2.7	550	29,644	1.9
55 to 64	11	88	12.5	90	1,019	8.8	572	8,174	7.0
65 to 74	9	41	22.0	65	487	13.3	685	5,672	12.1
75 to 84	3	21	14.3	42	294	14.3	436	3,192	13.7
85 and over	0	8	0.0	9	75	12.0	96	845	11.4
Total	36	473	7.6	293	5,240	5.6	2,409	69,007	3.5
Females									
0 to 24	0	10	0.0	2	633	0.3	54	20,337	0.3
25 to 54	6	166	3.6	109	5,794	1.9	374	25,784	1.5
55 to 64	5	79	6.3	96	1,608	6.0	372	7,429	5.0
65 to 74	14	62	22.6	109	957	11.4	512	5,527	9.3
75 to 84	12	59	20.3	74	673	11.0	451	4,118	11.0
85 and over	3	15	20.0	31	281	11.0	141	1,926	7.3
Total	40	391	10.2	421	9,946	4.2	1,904	65,121	2.9
Overall total	76	864	8.8	714	15,186	4.7	4,313	134,128	3.2

¹ Excludes people with a SMI

² Excludes people with a SMI and depression

5.9 Clinical care for people with diabetes mellitus - recorded health checks & test results

SMI and depression

Blood pressure in people with a SMI and diabetes mellitus was well recorded in 98.7% (75/76) cases. A similarly high percentage of blood pressure recording was also found for people with depression and diabetes mellitus (99.7%, 712/714). Body mass index was recorded in 86.8% (66/76) cases. This was lower than that of the remaining population (94.6%, 4,755/5,027). This difference was statistically significant (age and gender adjusted OR 0.38, 95% CIs 0.2 to 0.7, P=0.005). This was not the case for people with depression and diabetes mellitus where the recording of body mass index was slightly higher than the remaining population (96.1%, 686/714 vs 94.2%, 4,135/4,389). Urine checks for people with a SMI and diabetes were recorded in 60.5% (46/76) of cases and significantly lower than the remaining population at 75.1% (593/790) (age and gender adjusted OR 0.46, 95% CIs 0.3 to 0.7, P=0.001). For those with depression the percentage who had urine checks was 76.6% (547/714) and was identical to that of the remaining population (76.6%, 3,303/4,313).

Test results for mean systolic blood pressure and people with a SMI and diabetes was lower than the remaining population (129.6, SD 19.7 vs 132.7, SD 14.3). This was the same for mean diastolic blood pressure (75.0, SD 12.5 vs 78.3, SD 7.0). Body mass index was also lower in people with SMI and diabetes (mean BMI 28.9, SD 5.9 vs 29.9, SD 6.0). Urine results were found to be abnormal for 38.9% (7/18) of those with a SMI and diabetes. Among the remaining population, however, the percentage was 18.1% (281/1,550). This difference was significant (age and gender adjusted OR 3.10, 95% CIs 1.2 to 1.8, P=0.021). People with depression had a similar percentage of urine abnormality (20%, 42/210) to that of the remaining population.

None of these differences was statistically significant.

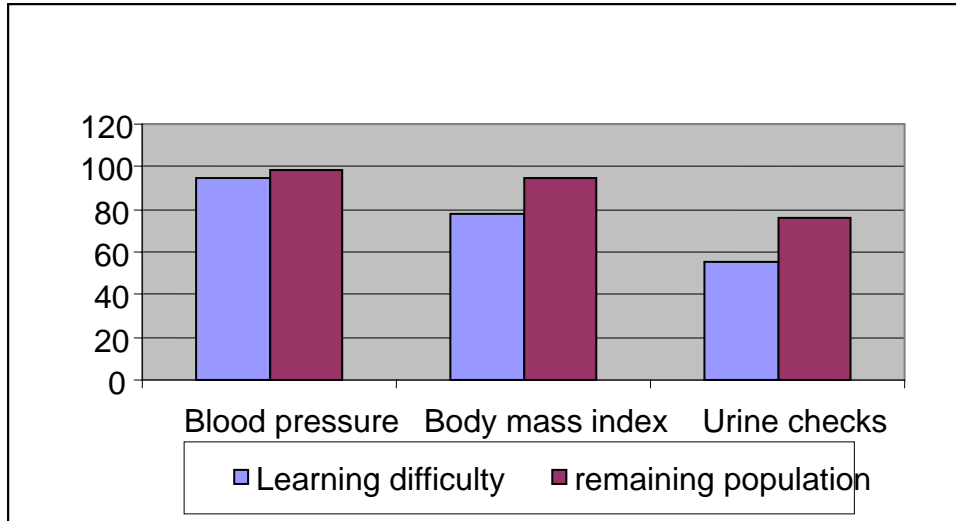
Learning difficulty

Figure 3 charts the percentage of recorded health checks in people with a learning difficulty and diabetes mellitus. Blood pressure recording was marginally less (94.4%, 17/18) than the remaining population (98.2%, 4,996/5,085), but not significantly different. Body mass index was recorded in 77.8% (14/18) of people with a learning difficulty and diabetes. For the remaining population with diabetes, body mass index was recorded for 94.5% (4,807/5,085) and statistically different (age and gender adjusted OR 0.22, 95% CIs 0.1 to 0.7, P=0.009). Recorded urine checks were also lower for people with a learning difficulty and diabetes (55.5%, 10/18 vs 76.4, 3,886/5,085), although not statistically significant.

Test results for people with learning difficulties for systolic (132.7, SD 14.3) and diastolic (78.3, SD 7.0) blood pressure were within normal limits. A body mass index indicating obesity was much higher in people with a learning difficulty and diabetes compared with the remaining population with the same condition (71.4%, 10/14 vs 44.2%,

2,127/4,807), although the difference was not statistically significant. Both people with a learning difficulty had abnormal urine results.

Figure 3. Recorded health checks in people with diabetes mellitus



Recorded health checks in people from the target groups with diabetes mellitus

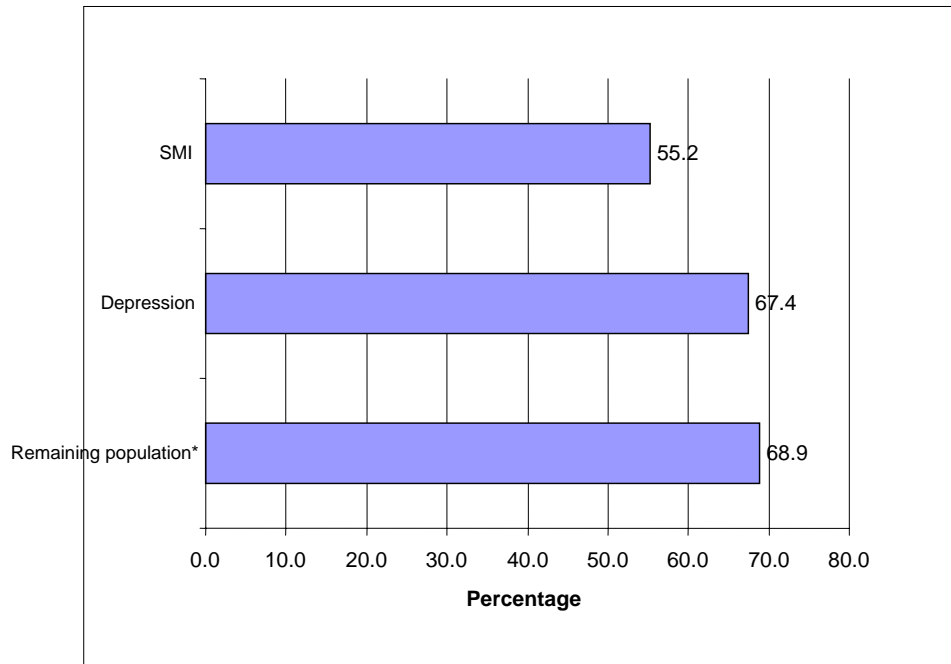
No gender differences were found for the mental health groups and diabetes in terms of recorded health checks. Numbers were too small to analyse those with a learning difficulty and diabetes. (See Appendix 4, table viii)

5.10 Management of diabetes mellitus

SMI and depression

HbA1c is an indicator of how well diabetes is being controlled. We assessed this to compare the management of those with diabetes mellitus between the target groups and the remaining population. We grouped HbA1c according to good (6.5% and below) or poor (above 6.5%) control. Figure 4 displays the percentages of people with poor control of their diabetes mellitus. The percentage of people with poor management of their diabetes was high in all groups. Interestingly, people with a SMI and diabetes were less likely to have poorer management of their diabetes (55.2%, 37/67) than the remaining population (68.8%, 2,820/4,093). The difference was only just significant after adjustment for age, gender and area site (OR 0.53, 95% CIs 0.3 to 0.8, P=0.013). People with depression had a similar percentage to the remaining population.

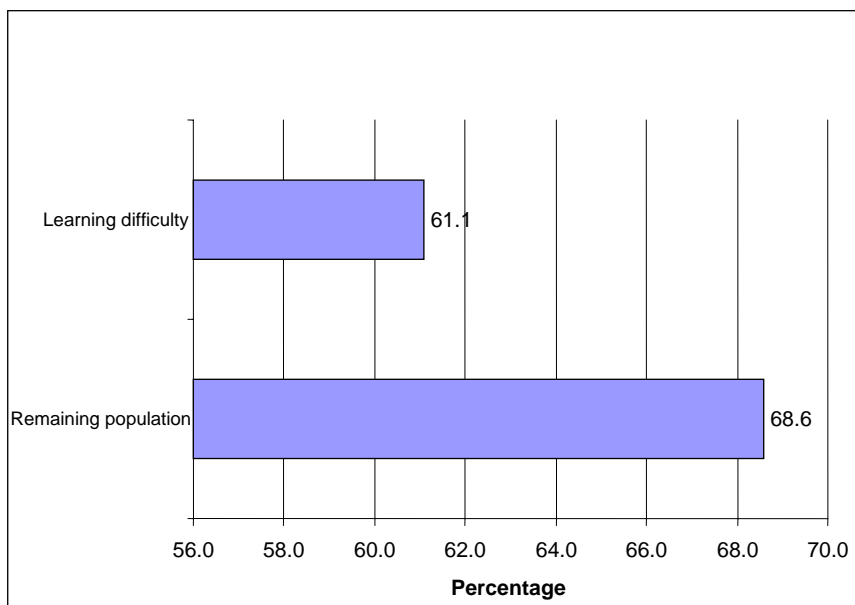
Figure 4. Poor control of diabetes mellitus in people with a SMI and depression - HbA1c



Learning difficulty

People with a learning difficulty were also less likely to have poorer management of their diabetes mellitus when compared to the remaining population (61.1%, 11/18 vs 68.6%, 3,313/4,828) (see Figure 5). However, this difference was not statistically significant after adjustment for age, gender and site.

Figure 5. Poor control of diabetes mellitus in people with a learning difficulty - HbA1c



5.11 Management of diabetes using stricter HbA1c criteria

We also examined the management of diabetes in the target groups using stricter cut off points. When using a cut off point of 7.5% we found the management of diabetes for all target groups was broadly comparable to the remaining population. The percentages were that those with a SMI 59.7% (40/67) had good control of their diabetes; compared with 63.4% (453/714) for those with depression; and 62.7% (2,568/4,093) for the remaining population. These differences were not statistically significant.

For those with a learning difficulty the percentage of those with good management of their diabetes was lower than the mental health target groups at 55.5% (10/18), and the remaining population (62.8% (3,034/4,828)). The difference however was not statistically significant.

We then examined a cut off point of 8.5%. This revealed that 80.6% (54/67) of people with a SMI had a HbA1c score below 8.5%, compared with 80.4% (574/714) for those with depression and 81.7% (3,347/4,093) for the remaining population. For people with a learning difficulty 61.1% (11/18) had a HbA1c score below 8.5% and although much lower than the remaining population (81.6%, 3,942/4,828) was not significant.

5.12 Health advice for people with diabetes mellitus

Dietary advice was received by 80.3% (61/76) of people with SMI and diabetes. For those with depression the percentage was greater at 86.8% (648/746) and 82.8% (3,572/4,313) for the remaining population. Dietary advice for those with a learning difficulty was lower at 72.2% (13/18), but not significantly different to those without.

5.13 Prevalence of chronic obstructive pulmonary disease (COPD)

SMI and depression

For people with a SMI the overall prevalence for COPD was 20.1% (174/864). Table 7 shows the prevalence of COPD by gender and age group. This prevalence differed significantly when compared to the remaining population (age and gender adjusted OR 1.33, 95% CIs 1.1 to 1.6, $P < 0.001$). More men than women were diagnosed with COPD (21.1%, 100/473 and 18.9%, 74/391 respectively). COPD was prevalent across all age groups, but increases from the age of 55 years.

In people with depression the overall prevalence of COPD was higher at 23.0% (3,492/15,186) and was significantly different compared to the remaining population (age and gender adjusted OR 1.70, 95% CIs 1.6 to 1.8, $P < 0.001$). The prevalence was higher in women (23.8% 2,366/9,946) than in men (21.5%, 1,126/5,240) and this was consistent across all age groups.

Learning difficulty

The overall prevalence of COPD for people with a learning difficulty was 19.8% (149/753). Although slightly lower than the mental health groups it was still higher than the remaining population (15.5%, 23,189/149,428) and significantly different from them

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(age and gender adjusted OR 1.41, 95% CIs 1.2 to 1.7, $P < 0.001$). More men were diagnosed with COPD than women (20.8%, 104/499 and 17.7%, 45/254 respectively).

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Table 7. Chronic obstructive pulmonary disease (COPD) in people with a SMI and depression

	SMI			Depression*			Remaining Population**		
	No. of people with COPD	Total no. with SMI	%	No. of people with COPD	Total no. with depression	%	No. of people with COPD	Total no.	%
Males									
0 to 24	7	35	20.0	61	272	22.4	3,654	21,480	17.0
25 to 54	50	280	17.9	626	3,093	20.2	3,624	29,644	12.2
55 to 64	21	88	23.9	215	1,019	21.1	1,113	8,174	13.6
65 to 74	11	41	26.8	122	487	25.1	1,020	5,672	18.0
75 to 84	9	21	42.9	81	294	27.2	663	3,192	20.8
85 and over	2	8	25.0	21	75	28.0	176	845	20.8
Total	100	473	21.1	1,126	5,240	21.5	10,250	69,007	14.9
Females									
0 to 24	1	10	10.0	175	633	27.6	2,796	20,337	13.7
25 to 54	28	166	16.9	1,296	5,794	22.4	3,479	25,784	13.5
55 to 64	19	79	24.1	393	1,608	24.4	1,149	7,429	15.5
65 to 74	12	62	19.3	265	957	27.7	951	5,527	17.2
75 to 84	7	59	11.9	171	673	25.4	778	4,118	18.9
85 and over	7	15	46.7	66	281	23.5	268	1,926	13.9

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Total	74	391	18. 9	2,366	9,946	23. 8	9,421	65,121	14.5
Overall total	174	864	20. 1	3,492	15,186	23. 0	19,671	134,128	14.7

* Excludes people with SMI

** Excludes people with SMI and depression

5.14 Clinical care for people with COPD

Health checks for those with COPD

Data was not available for some health checks that would ordinarily be carried out to assess COPD, such as tests to measure lung function. Instead we report on the extent of recorded current smoking which is a major risk factor for COPD.

SMI and depression

Fifty seven percent (100/174) of people with a SMI and COPD were recorded as current smokers. The percentage was slightly less for those with depression and COPD (50.9%, 1,813/3,559). These percentages were much higher when compared with the remaining population (20.8%, 31/149) and the differences were statistically significant after adjustment for age and gender ($P < 0.001$).

Learning difficulty

For people with a learning difficulty and COPD the percentage of being a current smoker was 20.8% (31/149). This was not significantly different from the remaining population (31.2%, 7,244/23,189).

Recorded health checks in people from the target groups with COPD

No significant gender differences were found for all the target groups and COPD, including those with a learning difficulty (see Appendix 4, tables ix and x).

5.15 Health advice for people with diabetes mellitus

SMI and depression

More people with a SMI and COPD received smoking advice (44.8%, 78/174) than the remaining population (23.6%, 4,640/19,671) and the difference was significant (age and gender adjusted OR 2.13, 95% CIs 1.5 to 2.8, $P < 0.001$). The percentage for people with depression and COPD was comparable at 41.4% (1,474/3,559).

Learning difficulty

However, those with a learning difficulty and COPD were less likely to receive advice on smoking compared with the remaining population (19.4%, 29/149 vs 26.4%, 6,132/23,189), although the difference was not statistically significant.

5.16 Summary of findings: Diagnosed medical co-morbidity and clinical care

Ischaemic heart disease

- the prevalence of IHD was highest in people with depression, more likely to be diagnosed in men and in older age groups from the age of 65 years and above;
- there were very few cases of IHD in people with a learning difficulty;
- the extent of clinical care through recorded health checks for people with IHD was significantly lower for those with a SMI regarding total and LDL cholesterol, but higher for current smoking;

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- recorded health checks for people with a learning difficulty and IHD were lower than the mental health groups and the remaining population;
- test results showed marginally lower total cholesterol and mean blood pressure for those with a SMI;
- people with a SMI and IHD were significantly less likely to receive lipid lowering therapy, but received much more advice concerning smoking;
- people with a learning difficulty and IHD were even less likely to receive health advice/treatments compared to the other groups.

Stroke

- people with a SMI had double the risk of being diagnosed with a stroke, with those with depression also showing a significantly higher prevalence of stroke;
- recorded blood pressure checks were very high in people with a SMI and depression, but lower in people with a learning difficulty;
- the results of all recorded blood pressure for each of the target groups were within normal limits;
- smoking advice was greater for those with depression and a learning difficulty and the same for those with a SMI compared to the remaining population.

Diabetes mellitus

- people with a SMI were more likely to be diagnosed with diabetes mellitus;
- the prevalence of diabetes in people with depression was higher to that of the remaining population and affected more men in older age groups;
- people with a learning difficulty had a lower prevalence of diabetes compared to other groups, and were present was found in women above the age of 75 years;
- recorded health checks for blood pressure and body mass index (BMI) in all the target groups with diabetes was very high, but less so for urine checks, particularly for people with learning difficulties;
- people with a learning difficulty and diabetes were more likely to be obese;
- the control of diabetes as measured by HbA1c showed that despite the high percentages of poorer control in all groups, people with a SMI and a learning difficulty fared better;
- dietary advice was provided around 80% of the time for both mental health groups, but slightly lower for those with a learning difficulty.

COPD

- of the four major diseases examined COPD was the most prevalent amongst all target groups and significantly higher compared to the remaining population;
- the prevalence of COPD was highest in those with depression;
- COPD affected more men than women with a SMI, occurred in all age groups, but rising after the age of 55 years;

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- COPD also more likely to occur in people with a learning difficulty compared to the remaining population;
- people in the target groups were more likely to have a record of being a current smoker;
- people with a SMI and COPD were significantly more likely to receive smoking advice;
- people with a learning difficulty and COPD were less likely to have received advice on smoking compared to the remaining population.

6 Identifying people at increased risk of medical co-morbidity or physical health problems

6.1 Introduction

In this section we look at the extent to which health screening is performed in the target groups and assess the percentage of people at increased risk of developing a major disease. We excluded from this analysis those who have been diagnosed with one of the four diseases examined above. We have included some additional figures for *all* people included in the target groups to look in more detail at obesity and health prevention/interventions received. The health checks selected for this purpose include mammography and cervical screening for women; total cholesterol; urine analysis; smoking; BMI; and blood pressure. In this analysis we took into account age, gender and site differences.

6.2 Health screening in the target groups

SMI and depression

A high percentage of women with a SMI had received cervical screening (71.8%, 191/266), and although this was greater than that of the comparison population it was not statistically significant. There were similarly high percentages for recorded smoking, body mass index and blood pressure, all of which were significantly higher than the comparison population (see Table 8). For people with depression the percentages were even higher for all the health checks examined (see Table 8).

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Table 8. Recorded health checks in people with a SMI and depression

Type of health check ¹	SMI			Depression			Remaining population		
	No. with recorded check	Total	%	No. with recorded check	Total	%	No. with recorded check	Total	%
Mammography ²	39	266	14.7	1101	6957	15.8**	7,027	52,183	13.5
Cervical screening ²	191	266	71.8	5,800	6957	83.4*	29,609	52,183	56.7
Total cholesterol	169	590	28.6	3,284	10,580	31.0*	20,299	106,229	19.1
Urine analysis	171	590	29.0	3,628	10,580	34.3*	27,469	106,229	25.9
Smoking	526	590	89.2**	9,736	10,580	92.0**	68,978	106,229	64.9
Body mass index	385	590	65.3**	7,252	10,580	68.5*	50,745	106,229	47.8
Systolic blood pressure	486	590	82.4**	9,510	10,580	89.9*	65,057	106,229	61.2
Diastolic blood pressure	484	590	82.0*	9,460	10,580	89.4*	64,302	106,229	60.5

¹ Based on the latest recorded health check and excludes those with the four diseases examined above and all age groups

² Women only

* P<0.001 ** P<0.005 (adjusted for age, site and gender. The latter where applicable)

Learning difficulties

Table 9 shows the number of recorded health checks in people with a learning difficulty. These percentages were a stark contrast to those for the mental health groups. Here the differences are statistically different for the majority of health checks and show a much lower rate of health monitoring in this group. For example, total cholesterol was recorded in only 9.2% (53/579) of cases for those with a learning difficulty. Smoking, as with the mental health groups, was the most commonly recorded health check 51.6%, (299/579) but a great deal lower than the remaining population (72.0%, 107,557/149,428).

Table 9. Recorded health checks in people with a learning difficulty

Health check ¹	LD			Remaining population		
	No. with recorded check	Total	%	No. with recorded check	Total	%
Mammography ²	16	199	8.0	11,204	75,206	14.9
Cervical screening ²	49	199	24.6*	45,568	75,206	60.6
Total cholesterol	53	579	9.2*	40,017	149,428	26.8
Urine analysis	132	579	22.8	44,232	149,428	29.6
Smoking	299	579	51.6**	107,557	149,428	72.0
Body mass index	209	579	36.1*	81,260	149,428	54.4
Systolic blood pressure	267	579	46.1*	101,414	149,428	67.9
Diastolic blood pressure	265	579	45.8**	100,475	149,428	67.2

¹ Based on the latest recorded health check and excludes those with the four diseases examined above and all age groups

² Women only

* P<0.001 ** P<0.005 (adjusted for age and gender. The latter where applicable)

Mammography & cervical screening according to age group in women with a SMI or depression

Appendix 4 lists the results of women receiving mammography and cervical screening according to age group. Approximately 27% (67/246) of women aged 50 years or more with a SMI received a mammography. This was much lower than that received by the remaining population at 40.4% (9192/22,777). Cervical screening was particularly low in women with a learning difficulty aged between 25 to 64 years at 47.1% (56/119) when compared to the remaining population at 89.3% (36,394/40,742) (see Appendix 4, Tables iii & iv).

6.3 Health checks in all groups

We examined the figures for health checks, including those not related to the four major diseases (eg cervical screening), in all people with a mental health problem and those with a learning difficulty compared to the remaining population.

Table 10 lists the percentages of all people from both mental health groups with a recorded health check. The percentage of mammography and cervical screening check were similar for each mental health group at 17.4%, and higher than the remaining population at 14.4%. The difference, however, for people with a SMI was not significant, but was for people with depression (OR 1.69, 95% CIs 1.6 to 1.7, $P < 0.001$). The percentage of all people receiving these particular health checks was comparatively low overall, particularly cervical screening. Figures for mammography and cervical screening refer to women from the age of 20+.

Gender differences in recorded health checks in all groups

Appendix 4 (tables xi and xii) shows the figures for health checks for all people in the sample. Women compared to men with a SMI and those with depression were significantly more likely to receive checks for urine analysis, their weight and blood pressure. This was also the case for women with a learning difficulty. However, women compared to men with depression were less likely to receive checks for total cholesterol ($P < 0.05$).

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Table 10. Recorded health checks in *all* people with a SMI and depression

Type of health check ¹	SMI			Depression			Remaining population		
	No. with recorded check	Total	%	No. with recorded check	Total	%	No. with recorded check	Total	%
Mammography ²	68	391	17.4	1,759	10,105	17.4*	9,417	65,121	14.4
Cervical screening ²	15	391	3.8	315	10,105	3.1**	1,389	65,121	2.1
Total cholesterol	326	864	37.7**	6,058	15,475	39.1*	33,835	134,128	25.2
Urine analysis	287	864	33.2	5,769	15,475	37.3*	38,448	134,128	28.6
Current smoker	429	864	51.7*	6,968	15,475	45.0*	29,963	134,128	22.3
Body mass index	592	864	68.5*	11,202	15,475	72.4*	69,959	134,128	52.1
Systolic blood pressure	740	864	85.6*	14,179	15,475	91.6*	87,110	134,128	64.9
Diastolic blood pressure	738	864	85.4*	14,117	15,475	91.2*	86,232	134,128	64.3

¹ Based on the latest recorded health check and all age groups

² Women only

* P<0.001 ** P<0.005 (adjusted for age, site and gender. The latter where applicable)

Table 11. Recorded health checks in all people with a learning difficulty

Health check ¹	LD			Remaining population		
	No. with recorded check	Total	%	No. with recorded check	Total	%
Mammography ²	20	254	7.9*	11,204	75,206	14.9
Cervical screening ²	2	254	0.8	1,713	75,206	2.3
Total cholesterol	80	753	10.6*	40,017	149,421	26.8
Urine analysis	179	753	23.8	44,232	149,421	29.6
Current smoker	111	753	14.7*	37,101	149,421	24.8
Body mass index	290	753	38.5**	81,260	149,421	54.4
Systolic blood pressure	358	753	47.5	101,414	149,421	67.9
Diastolic blood pressure	356	753	47.3	100,475	149,421	67.2

¹ Based on the latest recorded health check and all age groups

² Women only

* P<0.001 ** P<0.005 (adjusted for age, gender and site. Gender only where applicable)

Percentages for the remaining types of health checks were much higher (i.e. from total cholesterol to diastolic blood pressure). The most frequently performed health check for all groups was for blood pressure. Again the percentages of these remaining health checks were higher for people with a mental health problem than for the remaining population. Table 10 indicates that the differences were statistically significant.

For people with a learning difficulty the pattern is again reversed (see Table 11). This group was less likely to receive any of the health checks listed above. This was statistically significant for mammography, total cholesterol, current smoking and body mass index.

6.4 Test results from recorded health checks in people without a major disease

SMI and depression

Figure 6 displays the test results from recorded health checks in the target groups with one of the four diseases examined above. These figures are percentages of those with abnormal mammography and cervical screening results, high levels of total cholesterol, abnormal urine results, current smoker (1+ cigarette per day), a body mass index of 30+ indicating obesity and hypertension for systolic (150+mmHg) and diastolic (90+mmHg) blood pressure.

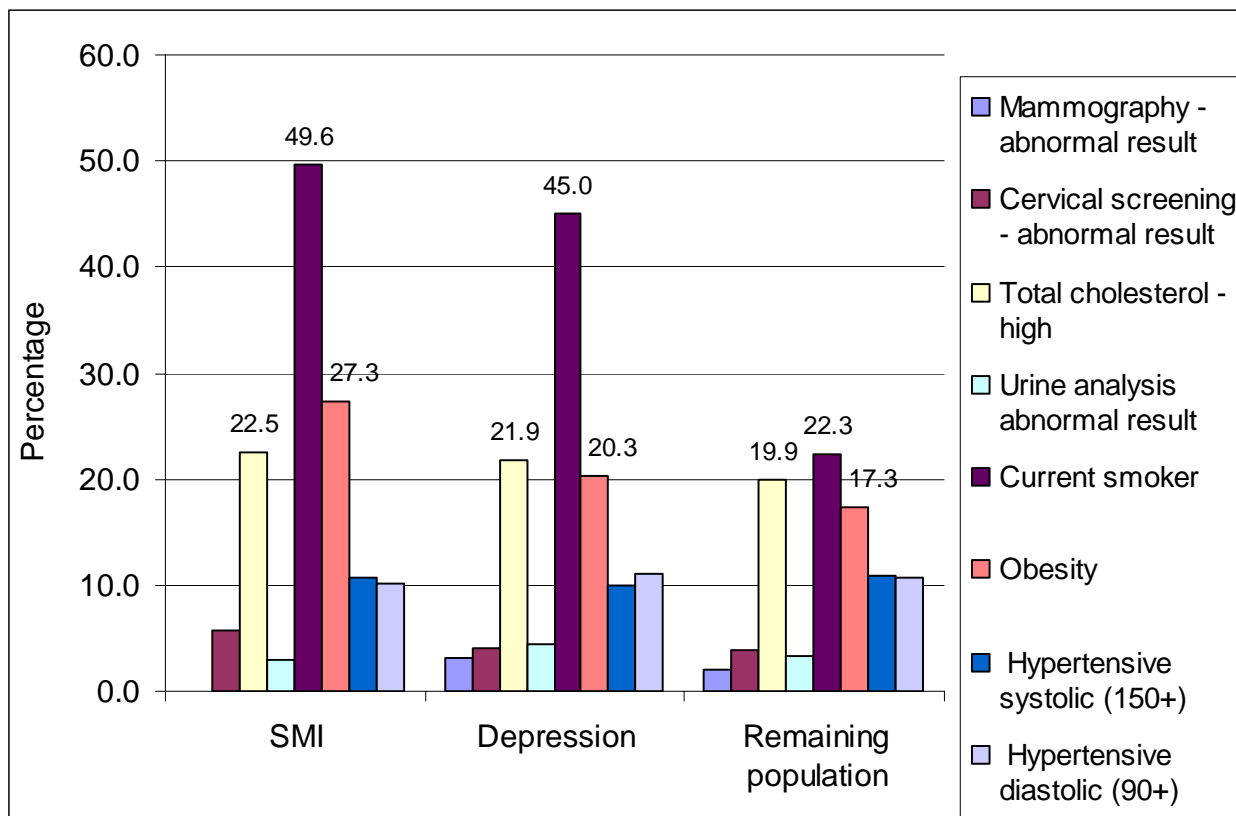
People with a SMI were two and half times more likely to be a current smoker compared to the remaining population (adjusted OR 2.5, 95% CIs 2.2 to 2.9, P<0.001). A similarly high percentage was also found in people with depression. The level of obesity was

also increased in people with a SMI (27.3%, 105/385) compared with the remaining population (17.3%, 8,761/50,745). This percentage differed significantly from the remaining population (adjusted OR 1.50, 95% CIs 1.2 to 1.9, $P < 0.001$). High levels of total cholesterol were also found for people with a SMI (22.5%, 38/169), but this was of borderline significance statistically when compared with the remaining population (19.9%, 4,038/20,299) (age, gender and site adjusted OR 1.47, 95% CIs 1.0 to 2.1, $P = 0.038$). The prevalence of recorded current smoking levels in people with a SMI without one of the major diseases examined above was 46.6% (275/590). For all those with a SMI the prevalence was 49.6% (429/864).

In people with depression, obesity levels were higher than the remaining population (20.3%, 1,471/7,252 vs 17.3%, 8,761/50,745), but less than the SMI group. For all those with depression the prevalence of smoking was 45% (6,968/15,475) and for the remaining population as a whole 22.3% (29,963/134,128). Total cholesterol is also high for those with depression at 21.9% (718/3,284) but not too dissimilar from the remaining population (19.9%, 4,038/20,299).

Levels of hypertension were similar in both mental health groups and the remaining population at around 10% for each.

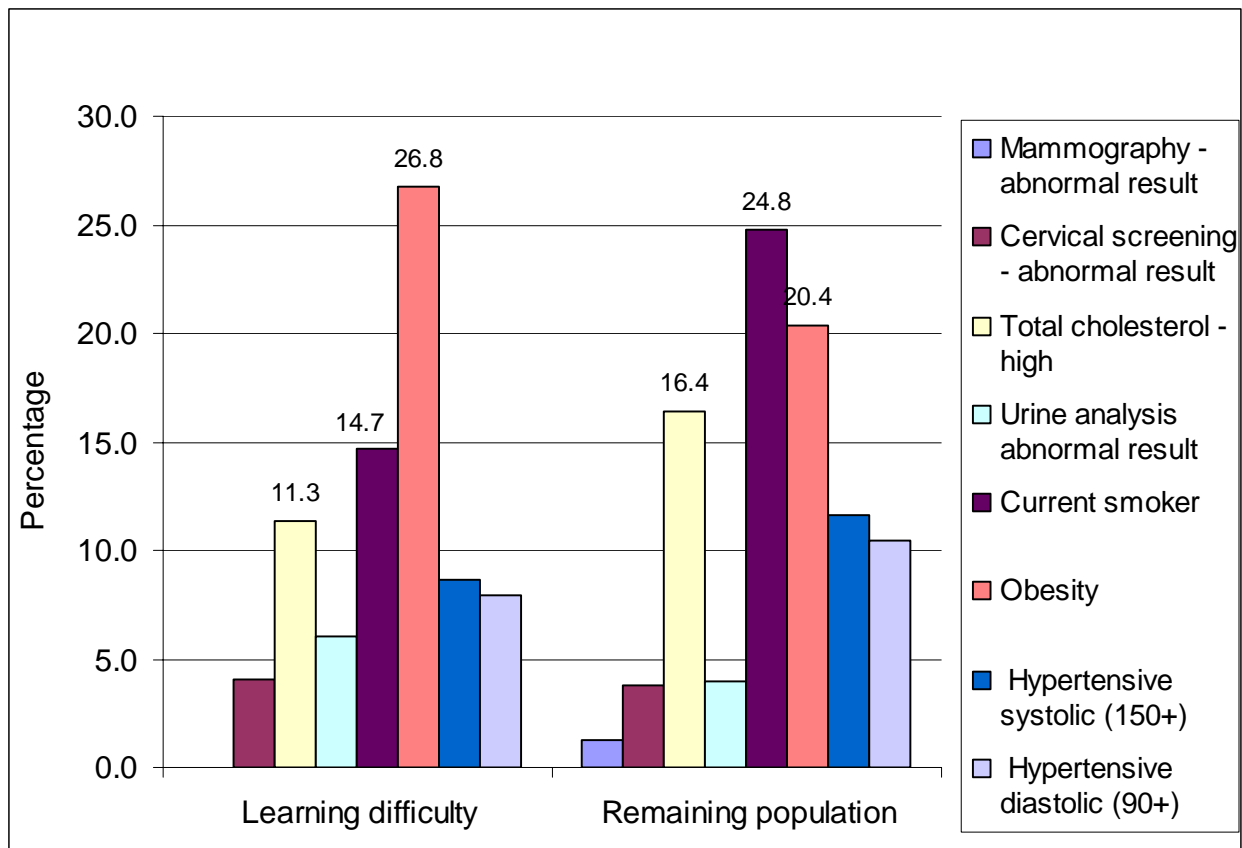
Figure 6. Test results of health checks in people with a SMI and those with depression without a major disease



Learning difficulties

Figure 7 shows the results of health checks for people with a learning difficulty without one of the major diseases examined above. Obesity rather than smoking is a key issue for this group. The percentage of those with a learning difficulty and a body mass index of 30+ (indicating obesity) was 26.8% (56/209). This was significantly different from the remaining population (adjusted OR 1.81, 95% CIs 1.4 to 2.3, P<0.001). There were no differences in the percentage of obesity between men and women with a learning difficulty (0.5%, 46/9615 for women; 0.5% 36/7010 for men). Current smoking was lower in this group compared to people with a mental health problem. Hypertension was marginally lower for people with a learning difficulty compared with the remaining population (8% vs 11%).

Figure 7. Test results of health checks in people with a learning difficulty without a major disease



Obesity in all people from the target groups

Given previous evidence of the high proportion of people from the target groups likely to be obese we examined the prevalence of this in all people in the sample. Table 12 lists the figures for obesity according to gender and age group. The overall prevalence of obesity in people with a SMI is 28.5%, which was significantly different from the remaining population (adjusted OR 1.57, 95% CI 1.3 to 1.9, P<0.001). The prevalence

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of obesity for people with depression was lower at 24% but still significantly different from the remaining population (OR 1.26, 95% CI 1.2 to 1.3, $P < 0.001$).

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Table 12. Prevalence of obesity in *all* people in the mental health target groups

	No. of people who are obese	Total no. with SMI	%	No. of people obese	Total no. with depression	%	No. of people obese	Total no. remaining pop	%
Males									
0-17	0	0	0.0	0	2	0.0	24	987	2.4
18-65	75	265	28.3	591	2,804	21.1	4,588	24,033	19.1
65+	5	45	11.1	149	694	21.5	1,606	7,652	21.0
Females									
0-17	0	0	0.0	0	1	0.0	20	934	2.1
18-65	58	198	29.3	1,558	6,195	25.1	5,541	27,599	20.1
65+	31	84	36.9	389	1,506	25.8	2,055	8,754	23.5
Totals	169	592	28.5*	2687	11202	24.0*	13834	69959	19.8

* P<0.001 (adjusted for age, gender and site)

Table 13. Prevalence of obesity in all people with a learning difficulty

	No. of people obese	Total no. with a learning difficulty	%	No. of people obese	Total no. remaining population	%
Males						
0-17	1	20	5.0	23	969	2.4
18-65	33	137	24.1	5,195	26,890	19.3
65+	2	18	11.1	1,756	8,364	21.0
Females						
0-17	0	7	0.0	20	928	2.2
18-65	42	100	42.0	7,090	33,807	21.0
65+	4	8	50.0	2,459	10,302	23.9
Totals	82	290	28.3*	16543	81260	20.4

* P<0.001 (adjusted for age, gender and site)

For people with a learning difficulty the prevalence of obesity was 28.3% and differed significantly from the remaining population (OR 1.69, 95% CI 1.3 to 2.2, P<0.001).

7 Health prevention advice/interventions in the target groups

7.1 Introduction

Here we present the findings on the provision of health prevention or health promotion advice and related interventions in people without one of the four major diseases examined above. We also look at the amount of prevention advice/interventions given to people identified as at increased risk of a major physical health problem. The type of health advice/interventions covered include: flu and tetanus vaccinations; dietary advice; advice on smoking; smoking therapy; and referral to smoking cessation services. We also took into account age, gender and site differences during this analysis.

7.2 SMI and depression

Table 14 shows the percentage of health prevention advice among the mental health target groups without one of the four diseases examined above. Flu vaccination was highest in people with a SMI compared to the remaining population (26.8%, 158/590 vs 12.7%), although after adjusted for age and gender this difference was not significant. Tetanus vaccination featured highly in people with depression, but was not too dissimilar from the remaining population (37.3% vs 34.6%). Dietary advice was identical for both those with a SMI and depression at 32%, but only slightly higher than that of the remaining population (27.1%, 28,780/106,229), and not statistically significant after adjustment for age and gender. Smoking advice was given to 30.2% (178/590) of people with a SMI and a similar proportion of those with depression (29.0%, 3,063/10,580). Both figures were significantly different to that of the remaining population. However, when examined in more detail in terms of the type of smoking advice provided, very little of it involved actual interventions. Here the figures plummet for all groups for the provision of smoking therapy (nicotine therapy) and referral to smoking cessation clinics (see Table 14). No statistical tests were performed with these interventions given the relatively small numbers.

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Table 14. Recorded health prevention advice/interventions¹ in people with a SMI and depression without one of the four diseases

Health advice/ intervention	SMI			Depression ²			Remaining Population ³		
	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%
Flu vaccination	158	590	26.8	2,040	10,580	19.3	13,468	106,229	12.7
Tetanus	160	590	27.1	3,943	10,580	37.3	36,783	106,229	34.6
Dietary advice	191	590	32.4	3,441	10,580	32.5	28,780	106,229	27.1
Smoking advice	178	590	30.2*	3,063	10,580	29.0*	15,429	106,229	14.5
Smoking therapy	37	590	6.3	940	10,580	8.9	2,737	106,229	2.6
Smoking cessation clinic referral	4	590	0.7	77	10,580	0.7	202	106,229	0.2

¹ Based on the latest health advice/intervention and excludes those with the four diseases examined above

* P<0.001 (adjusted for age, gender and site)

² Excludes people with a SMI

³ Excludes people with depression and a SMI

7.3 Learning difficulty

Table 15 shows the number and percentages of people with a learning difficulty (without one of the four diseases) and health prevention advice received. Tetanus vaccination represented the most common health prevention intervention for people with a learning difficulty (31.3%, 181/579); although this percentage was slightly lower than for the remaining population (35.9%, 53,708/149,428). Given the relatively high percentage of obesity in people with a learning difficulty dietary advice was lower than the remaining population (18.7% vs 31.9%). This difference was statistically significant (age, gender and site adjusted OR 0.67, 95% CIs 0.5 to 0.8, P<0.001). Smoking advice was also less likely to be provided to people with a learning difficulty compared with the remaining population (9.0% vs. 18.5%). Again this difference was significant (age, gender and site adjusted OR 0.48, 95% CIs 0.3 to 0.6, P<0.001). Provision of smoking therapy (nicotine therapy) was similarly lower than the remaining population (1.9% vs 3.9%), but of borderline significance.

Table 15. Recorded health prevention/interventions¹ in people with a learning difficulty and without one of the four diseases

Health advice/ intervention	LD			Remaining population		
	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%
Flu vaccination	123	579	21.2	32,334	149,428	21.6
Tetanus	181	579	31.3	53,708	149,428	35.9
Dietary advice	108	579	18.7*	47,648	149,428	31.9
Smoking advice	52	579	9.0*	27,607	149,428	18.5
Smoking therapy	11	579	1.9**	5,899	149,428	3.9
Smoking cessation clinic referral	2	579	0.3	412	149,428	0.3

¹ Based on the latest health advice/intervention and excludes those with the four diseases examined above

* P<0.001 ** P=0.033 (adjusted for age and gender)

7.4 Health prevention/advice and interventions for *all* people in the target groups

Tables 16 and 17 show health prevention advice or interventions recorded for all people in the target groups and the remaining population. People with a SMI were significantly more likely to receive a flu jab, smoking advice and smoking therapy of some kind, but less likely to have a tetanus vaccine (see Table 16). People with depression were more likely to receive flu vaccination, smoking advice and smoking therapy compared to the remaining population. Similar percentages for dietary advice were found among those with a mental health problem and the remaining population.

We examined more closely whether the target groups with a weight problem received dietary advice. There were 192 people with a SMI and overweight (or 22%, 192/864). Of these, 57.3% had received some form of dietary advice. This percentage was very similar to those who were overweight in the remaining population, 56.0% (13,168/23,527). However, people with depression and overweight received significantly less dietary advice compared to the remaining population (adjusted OR 0.82, 95% CIs 0.7 to 0.9, $P < 0.001$). This was also the case for those with depression and obese (adjusted OR 0.88, 95% CIs 0.8 to 0.9, $P = 0.005$). For people with a learning difficulty and a body mass index above 25+ receipt of dietary advice was also lower than the remaining population, but not significantly so. (See Appendix 4, Tables i & ii for the figures).

All those with a learning difficulty generally received less dietary and smoking advice than the remaining population. The percentage of people with a learning difficulty was slightly higher than that of the remaining population but not statistically significant. This was also the case for receiving tetanus vaccination (see Table 17).

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Table 16. Recorded health prevention advice/interventions¹ in *all* people with a SMI and depression

Health advice/ intervention	SMI			Depression ²			Remaining Population ³		
	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%
Flu vaccination	329	864	38.1*	4,875	15,475	31.5*	27,431	134,128	20.4
Tetanus	240	864	27.8*	5,792	15,475	37.4	48,023	134,128	35.8
Dietary advice	344	864	40.0	5,908	15,475	38.2	41,660	134,128	31.0
Smoking advice	296	864	34.2*	4,993	15,475	32.2*	22,506	134,128	16.8
Smoking therapy	69	864	7.9*	1,620	15,475	10.4*	4,260	134,128	3.2
Smoking cessation clinic referral	4	864	0.5	85	15,475	0.5	230	134,128	0.2

¹ Based on the latest health advice/intervention and includes those with the four diseases examined above

* P<0.001 ** P<0.05 (adjusted for age, gender and site)

² Excludes people with a SMI

³ Excludes people with depression and a SMI

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Table 17. Recorded health prevention/interventions¹ in *all* people with a learning difficulty

Health advice/ intervention	LD			Remaining population		
	No. with recorded advice/interv.	Total	%	No. with recorded advice/interv.	Total	%
Flu vaccination	187	753	24.8	32,334	149,428	21.6
Tetanus	247	753	32.8	53,708	149,428	35.9
Dietary advice	149	753	19.8**	47,648	149,428	31.9
Smoking advice	88	753	11.7**	27,607	149,428	18.5
Smoking therapy	18	753	2.4	5,899	149,428	3.9
Smoking cessation clinic referral	3	753	0.4	314	149,428	0.2

¹ Based on the latest health advice/intervention

* P<0.001 ** P=0.05 (adjusted for age, gender and site)

In the next section we examine the findings from the postal survey.

8 Findings from the postal survey

8.1 Introduction

The aims of this part of the study were to:

- identify target groups' experiences of primary care services from within selected GP practices;
- problems encountered and improvements that could be made;
- provision of health promotion, health education or interventions; and
- compliance with Part 3 of the DDA in achieving health targets and in attempts to overcome discriminatory policies, procedures and practices.

A total of 900 questionnaires were sent to users who have a learning difficulty or mental health problem. This was done across 20 practices. Twenty-two completed questionnaires were returned. Seventeen respondents had a mental health problem and 5 a learning difficulty. Twelve were men. In terms of ethnicity, 12 were British, 2 Irish, 1 African-Caribbean, 1 African and 1 Turkish. Responses were roughly equal from three local area sites. There were no responses from the North West site. Ninety-one percent of respondents were working age adults. There were no respondents in the 66 to 80 years' old age group but a couple were over 80 years' old.

Due to the very poor response rate we will provide a simple description of some of the responses covering key issues. However, caution must be used in interpreting the results from this section given the potentially large bias in the number of people responding.

On the whole all respondents were very positive about their experiences of contacting their GP and the care they received. Visits to the GP varied from once or twice a month to once or twice a year. All respondents were content with the building and found access to the surgery easy. None experienced difficulties with waiting to see their GP. Again all respondents reported being treated well by reception staff and their GPs. All respondents reported being involved in decisions about medication, and receiving adequate information about this. Only two respondents required a referral to a specialist. Both reported not having any choice about which hospital they attended but mentioned that the specialist had adequate information about their medical problem.

Issues of registration were minimal. Only one person reported having difficulty registering with a GP but no reason was given. No respondents reported being taken off a GP register.

The postal survey findings presented below cover aspects of access to their GP practice and the quality of care received.

8.2 Access to primary care services

While the majority of respondents, regardless of whether they have a mental health problem or a learning difficulty, are able to make their own appointments a few need the help of a carer whether that be a family member or a professional (Table 18).

Table 18. Who makes your appointments to see the GP?

	myself	relative/ carer	support worker	other
learning difficulty	3	2	0	0
mental health problem	13	1	1	2

Most people also reported that it is easy to get an appointment when they need one (Table 19).

Table 19. Is it easy to get an appointment when you want one?

	no	yes
learning difficulty	1	4
mental health problem	2	15

Despite most people being able to see their GP alone there was a noteworthy number of respondents who needed the assistance of another person (Table 20).

Table 20. Do you see your GP alone?

	yes	no - with spouse	no - with relative	no - with support worker
learning difficulty	3	1	1	0
mental health problem	11	2	2	2

8.3 How were respondents treated by the staff?

Respondents generally mentioned being treated well and with respect by staff at the GP surgery. All people who have a learning difficulty and most with a mental health problem feel listened to by their GP (Table 22). The majority of respondents regardless of diagnosis feel respected by the practice nurse (Table 23). Nearly all respondents

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with a learning difficulty felt they were greeted extremely well by reception staff, and most of those with a mental health problem said they were greeted very well (Table 21).

Table 21. How do the reception staff greet you?

	extremely well, very friendly	very well, quite friendly	good
learning difficulty	4	1	0
mental health problem	5	10	2

Both target groups reported in definite terms that their GP listened to them during their consultation, and that the practice nurse treated them with respect (Tables 22 and 23).

Table 22. Does your GP listen to you?

	yes a little	yes - definitely
learning difficulty	0	5
mental health problem	3	14

Table 23. Did the nurse treat you with respect?

	yes	N/A	maybe
learning difficulty	3	1	0
mental health problem	11	4	1

8.4 How well does the GP communicate with the respondents?

Most people (n=17) felt that they were definitely given enough time to tell their GP about their health condition; although a minority with mental health problems did not feel they did (n=4). Of the respondents who were then prescribed medication for the health condition they described most felt they had been given enough information about the medicine and what it was for (Table 24).

Table 24. Were you given enough information about what the medicine was for?

	No - and I wanted some	yes - some but not enough	yes - enough	N/A
learning difficulty	0	1	3	1
mental health problem	1	2	12	2

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However, nearly half of the respondents who had been prescribed medication felt that they were not given enough information about the possible side effects. One respondent even reported being told to 'read the information leaflet' (see Table 25).

Table 25. Did your GP tell you about the possible side effects?

	no and I wanted some information	yes - some but not enough information	yes - enough information	I didn't want any information	N/A
learning difficulty	1	1	2	0	1
mental health problem	1	5	7	2	2

8.5 Positive reports of the consultation with the GP.

Respondents gave a good many reasons as to why the service provided by their doctor was positive. Most have reported that there is something particularly good about the care they receive (Table 26). A few of the reasons for the positive feedback regarding GPs are shown below.

Table 26. Is there anything particularly good about the care you receive from your GP for any medical problems?

	no	yes	N/A
learning difficulty	1	4	0
mental health problem	3	12	1

The following are quotes gathered from open ended questions about what was considered good about the services received from their GP:

If I'm poorly at night the doctor will come out before sending me to hospital if I need to go.

They are always there for you especially the GP - he is a good listener, time is not an issue, he takes and gives you all the time you need. Excellent practice.

They help in every way possible.

I trust my GP he is ready to spend time with me listening.

My proper GP is very friendly and comforting.

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GP listens and tries to avoid giving prescriptions - counselling is better than antidepressants.

The staff treat me with respect.

They seem to be up to date with the latest information on health and healthy eating, smoking and drinking and other important health issues. They are also very timely in their work.

8.6 Did respondents feel any improvements could be made?

When replying to this question most people felt that no improvements could be made to the care they receive. However, a few people – all with a mental health problem – did feel that there was room for improvement (Table 27). The reasons they gave have been quoted below.

Table 27. Is there anything about the care you receive from you GP that could be improved?

	no	yes	unable to answer
learning difficulty	5	0	0
mental health problem	11	5	1

I wish I could see my own GP when I need to instead of having to see various others at the practice that are less informed of my condition and generally less supportive. I feel that as soon as they know of my mental health problems I am taken less seriously.

Need more information about my medical health condition.

Take time to understand me better by listening to my problems.

9 Findings from focus groups and interviews with people with mental health problems and people with a learning difficulty, and their carers

9.1 Introduction

The remit of this part of the study involved aiming to speak with service users with a range of characteristics across the four local area sites. These included:

- people of adult age, younger people and older people;
- people living independently at home, at home with support, in residential care, nursing care and in medium secure care;
- people with multiple impairments;
- people from Black and minority ethnic communities.

The following two tables (Tables 28 and 29) outline the groups of people that spoke to the researchers in the four different areas. Support workers or advocates were present at some of the focus groups. The suitability of their presence was checked out with participants by the group facilitators prior to the groups commencing.

We spoke to 30 people with learning difficulties and six carers of people with learning difficulties. All of the people with learning difficulties that we spoke to were white British or white European. The people we spoke to lived in a range of accommodation including living:

- a) on their own with no support;
- b) with relatives, usually parents;
- c) on their own with support;
- d) in a supported group home; or
- e) in a residential community for people with learning difficulties.

Both men and women were interviewed. Most of the people were of working age (18-65 years), but the team of researchers with learning difficulties also spoke with a group of young people (16-19 years). Some of the people with learning difficulties were interviewed without support, while others were supported to communicate with the research team with the assistance of a relative or support worker.

The carers of people with learning difficulties were mainly parents who lived with their children. We also spoke to a woman who lived with and cared for her brother.

We spoke to 69 mental health service users and eight carers. The people with mental health problems we spoke to described their ethnicity as follows: white British or European - 77%; Asian (Pakistani, Indian, East African Asian or mixed Mauritian) - 14%; and Black (British, African or Caribbean) - 9%. The people we spoke to lived in a range

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of accommodation ranging from people living on their own with no support, living with relatives, living in a hostel, in warden-sheltered housing, living alone with support, in a group home with support or living in a medium secure unit. Both men and women were interviewed. Most of the people were of adult working age (18-65 years), but the mental health service user research team also spoke with a group of young people (14-17 years) and a small number of people over 65 years. One of the focus groups involved the presence of a support worker who interpreted in Punjabi for some of the participants.

The carers of people with mental health problems we spoke to were mainly partners of a person with a mental health problem. A small number were parents. Most of these carers lived with the person they cared for.

Table 28. People with learning difficulties and their carers

PCT or LHB Area	Organisation through which participants were contacted	Focus group or individual interview	Number of people interviewed	Age range
North West	Self advocacy organisation	Focus group	6 service users	18-65
	Voluntary sector housing project	2 x small focus groups	6 service users	18-65
	Special School (located in a PCT area adjacent to the North West PCT)	Focus group	8 students	16-19
	Local Mencap Society	Telephone interview	1 carer	
Wales	Local county forum	Small focus groups and interviews	7 service users (plus input from 1 carer)	18-65
London	Residential community	Small focus group and interview	3 service users (plus input from 2 support workers)	18-65
	Local carers' organisation	Small focus group	3 carers	18-65
	Local Mencap Society	Telephone interviews	2 carers	
Total			30 service users and 6 carers (plus input from 3 accompanying carers and support workers)	

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Table 29. Mental health service users and their carers

PCT or LHB Area	Organisation through which participants were contacted	Focus group or individual interview	Number of people interviewed	Age range
North West	User led group	Focus group	4 service users	18-65
	Child and Adolescent Mental Health Service	Focus group	4 service users	14-17
	Voluntary sector housing project	Focus group	5 service users	18-65
Wales	Voluntary sector drop-in	Focus group	4 service users, plus input from 1 support worker and 1 advocate	18-65
	Voluntary sector drop-in and statutory housing project	Focus group	11 service users	18-65
	Local Mind	Interview	1 service user	18-65
	Local Hafal (Rethink)	Focus group	4 carers, plus input from 2 support workers	
South East	User led organisation	Focus group	18 service users	18-65
	Local Rethink	Focus group	4 carers, plus input from 1 support worker	18-65
	Via postal questionnaire	Telephone interview	1 service user	18-65
London	Voluntary sector day service	Focus group	5 service users	18-65
	Statutory sector day service	Focus group	9 service users, plus input from support worker	18-65
	Older People's Community Mental Health Team	Interviews (one over the phone and one face-to-face)	2 service users	65+
	Via postal questionnaire	Telephone interview	1 service user	18-65
	Medium secure unit	Focus group	4 service users	18-65
Total			69 service users and 8 carers (plus input from 7 support or advocacy workers)	

Key issues explored in the interviews and focus groups have been examined across each of the different client groups. The words of the participants have been indicated by the use of italics.

9.2 Issues of access to primary care services

Registration

Most people had not experienced any difficulties in registering with a GP. Reasons for re-registering included moving home, the boundaries of their GP surgery changing, in one case a patient being asked to leave a practice, or a patient or carer disliking the way they, or the person they cared for, had been treated by their GP. Some were unaware that re-registration was an option open to them. These people often learnt about the possibility of re-registration for the first time during the focus group or interview they participated in for this study. Most people also felt they lacked knowledge about the process of re-registration. A few people with mental health problems said they had found it difficult to re-register with the same GP if they had moved away from their area for a period of time and then returned.

Those who had re-registered sometimes spoke of the help they had received from relatives or staff members to help them to find lists of GPs in their area or to fill in the required forms. One person with mental health problems recalled how staff at the supported housing project that he lived at had helped him to locate and register with a GP who was known to be understanding of mental health issues.

A woman spoke of how she had intentionally conducted a search of her local GP surgeries prior to deciding which one to join. This woman's active utilisation of choice was very unusual among those we interviewed:

I did a search and went round the surgeries. I saw what the receptionists were like. I went to quite a few. But when I found a surgery it was easy to register. (Mental health service user)

A small number of people had difficult experiences of re-registration. One person spoke of how difficult it was to find a GP surgery in her area that had spaces available.

One carer of a mental health service user spoke of a particularly difficult de-registration and re-registration experience. In the recent past her husband had been placed on the list of violent patients in their local PCT area as a result of a difficult telephone conversation between him and a member of surgery reception staff (see section on reception staff). While on the list of violent patients he was taken off the list of his previous GP and was not permitted to visit a chemist in the area or to join the register of a new GP. During this time this patient was permitted to visit his local general hospital and he also sought the advice of his psychiatrist for his physical health care needs. His carer spoke of how on one occasion her husband's psychiatrist had prescribed him with his urgently needed Ventolin for his asthma but that the psychiatrist should not officially have done this. This situation was particularly difficult as her husband had a fear of hospitals. Eventually this patient was taken off the list of violent patients and he was able to re-register at a new and more sympathetic GP surgery. The process of re-registration took a lot of time,

stress and effort on the part of the patient and his carer, and was enabled through the help of the Independent Complaints and Advocacy Service.

One carer of a person with learning difficulties spoke of how registering his son with a GP surgery in his area had not been difficult, but that he had encountered many difficulties in registering with a dentist. He felt his son had certainly encountered '*discrimination*' at the dental surgeries that he had approached.

The mental health service users who were staying in a medium secure unit said they were automatically patients of the local GP practice that the unit was registered with.

Choosing a GP

While actively choosing a GP practice through re-registration appeared to be rare, people with learning difficulties and people with mental health problems frequently had preferences with regards to which GPs they preferred to see at their surgery if it was a group practice. Many people had a clear preference for a particular GP and this GP was usually a person who was perceived as being '*understanding, empathic*', who took the time to listen to their problems and who was skilled at providing clear information and explanation (see section on staff attitudes). Several people also said that they preferred to have a consultation with a female GP and these patients included mainly women but also some men. When asked, a group of Asian service users explained that the ethnicity of their GP was not a priority. The priority for these people was that their GP was someone who was experienced as being caring and understanding.

Seeing a preferred GP was not always easy. These GPs tended to be the most popular and consequently their appointment spaces were quickly filled or the queues to see them were long '*...he is so popular*'. While some people were prepared to wait to see these GPs, people frequently saw other GPs at the practice, particularly at times of emergencies. Preferred GPs were often discovered through a process of '*trial and error*' - by visiting different GPs within the same practice over time. Some people spoke of having unsatisfactory experiences with particular GPs that had made them actively make an appointment with a different GP on subsequent occasions.

The mental health service users in medium secure care had no choice about which GP they saw. They had a regular visit from the same GP every week to their unit. These mental health service users reflected that they had never considered the option of seeing a different GP.

Making appointments

The process of making appointments was a frustrating experience for most of the people we talked to. A wide range of systems were described. Some people were required to phone in on the morning that they wanted an appointment and had a limited time window within which to do this, such as half an hour in the morning and perhaps also half an hour during the early afternoon. Some surgeries required people to book appointments in advance, while others asked patients to turn up in the morning or afternoon to join a queue to see the GP on that morning or afternoon. People described the advantages and disadvantages of each of these systems.

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Those phoning in to make appointments for that day often found the process extremely stressful. One man with mental health problems spoke of having to continually redial to try to get through to his surgery and of sometimes having to redial up to ten times until he finally spoke with a receptionist. On the other hand many people were glad to be able to see their doctor on the same day and preferred this to making appointments in advance. Some people preferred to turn up at the surgery in the morning rather than trying to get through on the phone. Others spoke of how turning up at the surgery was not allowed. Turning up at a GP surgery and joining a queue for an appointment with a doctor on that same morning or afternoon was also similarly appreciated for providing an opportunity to definitely see the doctor that day. However, long waits were frequently experienced. Booking appointments in advance was a method preferred by some, though those who found it difficult to be organised enough to plan their visits to the doctor in advance found this system very challenging.

People with learning difficulties and mental health service users spoke of the many ways in which carers, support workers, reception staff or even on occasion their GPs supported them to make appointments with the doctor or the nurse. Such help was particularly vital for young people, older people and those who had communication or memory difficulties. Parents of people with learning difficulties or support workers, at the group home at which a person with learning difficulties lived, often made the phone call to a GP surgery to book an appointment. Some of the people with mental health problems spoke of the way in which their nurse or GP took the time at the end of the consultation to ensure that a future appointment was booked in. Such help appeared to be provided to people who found it difficult to plan ahead by themselves and such support was greatly appreciated. Such a service could not be provided at surgeries where the appointments system did not allow for appointments to be booked more than two weeks in advance and several people with mental health problems found these restricted advance booking systems very difficult. People were also helped by their parents, carers or support workers reminding them to phone the GP surgery to make appointments at the appropriate times.

In addition to calling at a surgery in person or talking with reception staff by telephone, one parent of a person with learning difficulties spoke of the useful system by which he could book online on the GP surgery website in order to gain an appointment. Other use of technology included touch screen booking systems which patients were asked to use in the surgeries themselves. The two people with mental health problems who had encountered these systems found them difficult to use, due to a symptom of their mental health problem involving them finding it distressing to touch things. In both cases the partners of these people were instrumental in supporting the person with mental health problems to book a place in the appointments queue using this system.

Home visits were rare though always appreciated. A parent of a person with learning difficulties spoke of how her son could not travel to the GP surgery due to his physical impairments and spoke of how the GP surgery would make home visits at least half of the time that they were requested. An older person with mental health problems spoke of how she was always visited at home by the GPs from her GP practice. She had arthritis and was not able to walk far. When she needed to see a GP she would phone the surgery and the reception staff told her that someone would

come and visit her as soon as they could. No appointment time was given but this was convenient to her as she rarely left her warden-sheltered flat due to her mobility problems.

A woman with mental health problems who spoke little English talked of the way in which her Punjabi speaking GP would set up appointments for her at the end of her consultation time. At other times this woman would take '*all her papers*' to the GP reception staff who knew that she had difficulty communicating in English and they would then help her to book an appointment. If she wasn't able to get an appointment with her Punjabi speaking GP, the reception staff would ensure that an interpreter was booked in for the time of her consultation.

People in rural areas sometimes had a more restricted service than those in a town or city. Several people spoke of their surgeries being open for only 2-3 days a week. Some had to travel on more than one bus to reach their surgery. A few also spoke of the inconvenience they often faced when they were given appointments that did not fit in with their local bus timetable.

Appointments with a nurse were usually much easier to make than those with a GP. The system was often simpler and the waiting times shorter. Generally people either turned up on the day and waited in a queue or made appointments in advance.

For the mental health service users staying in secure care, they could book a slot with their GP on the morning of his weekly visit. An organisational meeting took place each morning at the unit and it was at this meeting that service users could tell unit staff that they wished to see the GP. When people were physically unwell they were usually required to wait for this weekly visit. This group of men told us that currently there were few people with physical health problems staying in their unit and thus needing assistance outside out the weekly visit.

Travel to the surgery and building accessibility

People walked, took the bus, travelled by car or group home minibus or took taxis to reach their GP surgeries. Most people did not have any problems in travelling to their surgery. A large number, particularly people with learning difficulties, were supported by parents, partners or support workers to travel there, and often by car. Those who lived in rural areas spoke of being used to travelling long distances, sometimes by bus, but usually by car. A few people commented that parking near surgeries could often be difficult.

Overall accessibility of buildings was felt to be good. This was particularly the case for modern specifically designed surgeries in comparison to older surgeries that had often been converted from houses. Most of the surgeries were described as being on one level or having ramps to aid wheelchair access. In some cases wheelchair access to consulting rooms was described as being difficult. These rooms were sometimes very small and so provided a rather uncomfortable and cramped space for the wheelchair user and doctor or nurse to meet during a consultation. Room to turn wheelchairs within small consulting rooms was also sometimes difficult. Some surgeries did not have toilets that were accessible to wheelchair users.

Reception staff

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The manner of reception staff was felt to be highly variable. At one extreme reception staff were experienced as being '*smashing*' or '*absolutely brilliant*', while at the other they were described as being '*a bit rough, very abrupt*' or having an '*appalling attitude*'. Generally there was an awareness that receptionists were often under pressure and '*run ragged*' and that sometimes they had to deal with patients who were rough with them. In some surgeries it was noted that there was a high turnover of staff due to these pressures and sometimes low staffing due to illness. A number of people conveyed that they felt the way in which they were treated by reception staff was a reflection of the wider ethos of that GP practice. GP practices with GPs with respectful communication styles were felt to positively influence the way in which reception staff treated patients and their carers.

Those we talked to often felt there was a lack of understanding among reception staff about their needs due to their learning difficulties or mental health problems or the challenges they faced as a carer. People with mental health problems described the difficulties they often experienced in getting up in the morning due to the drowsiness they experienced from their psychiatric medication. These people felt that reception staff often didn't understand their condition and the effect that it had on their lives and functioning. They felt these receptionists didn't take this into account when insisting that people phone early in the morning to book appointments or when they booked individuals into early consultations. The support worker of a person with learning difficulties spoke of how her client would often have to miss the whole of her session at her day centre due to GP appointments being booked at awkward times in the day. It appeared that sometimes little thought was given by reception staff to the wider circumstances and lives of the people with mental health problems or learning difficulties who attended their surgery.

As already mentioned in the section on registration, one man with mental health problems was treated with such a lack of understanding during one phone call to his GP surgery that he was placed on his PCT's list of violent patients following the call. This man had a diagnosis of manic depression and had phoned the surgery at a time of distress wanting an emergency appointment. The receptionist had repeatedly asked him to say what was wrong with him, but he didn't want to say why, as he felt his mental health problem was an issue that he did not wish to share with reception staff. This telephone conversation was perceived as aggressive by the receptionist and as a consequence this patient was placed on the list of violent patients that later caused him and his partner much difficulty and distress. Others with mental health problems also spoke of their reluctance to share their mental health issues and histories with reception staff. Patients presumed that reception staff were not usually privy to this information. Reception staff as well as patients often lived locally to GP surgeries and some of the people we talked to spoke of their concerns about meeting reception staff locally and perhaps even in the supermarket.

People worried about how these people might perceive and treat them if they knew about their diagnosis. *I find it's hard getting past them [receptionists] ... They ask you what's wrong - you shouldn't have to tell them. (Mental health service user)*

Both people with learning difficulties and those with mental health problems often felt upset or annoyed that reception staff would talk to their carer or support worker before talking to them. One person with learning difficulties recalled a receptionist

saying to her support worker *'What's wrong with her, she isn't ill again is she?'* when they entered the GP practice together.

Reception staff were sometimes felt to be in a powerful position with regard to providing access to GPs. One carer of a person with learning difficulties felt that reception staff *'think they are in charge'* and sometimes blocked direct communication between doctor and carer. However there was some acknowledgement that reception staff often had to make judgements about who was a priority to gain a GP consultation that day.

Waiting for a consultation

Most GP practice waiting rooms were felt to be pleasant enough environments. While a few were viewed to be cramped or untidy, most were felt to be comfortable and a few were praised as being *'light and airy'*, improved by the presence of pot plants or for having a corner where children could play with toys. One surgery waiting room doubled as a health resource for the public. There was a toilet that people shopping in town, as well as surgery patients, could use. In addition there was a small library from which written information and videos on physical health conditions could be borrowed.

Posters and information leaflets about physical health conditions were often to be found in waiting rooms. This written information, however, was often felt to be inaccessible to people with learning difficulties. The writing in these leaflets was often small, the language complicated and there were rarely illustrative drawings or photographs that can aid the understanding of such information by people with learning difficulties. Information about learning difficulty and mental health conditions was rarely available in waiting rooms.

Waiting for a consultation was often a real challenge for people with learning difficulties and people with mental health problems. Long waits could often make people feel very agitated or anxious. One woman who had three sons with autism spoke of how long waits in the waiting room could lead to her children becoming hyperactive and difficult to control. She described how long waits could have them *'almost swinging off the ceiling'*. One consequence of this was that her children could be very distracted and challenging to communicate with once in the consultation room with the doctor. This same mother spoke of how the doctor at this surgery used to call her sons *'the little bastards'* due to their behaviour at the surgery. While this woman felt hugely insulted by this comment she never felt able to confront the doctor about it. She felt that the doctor viewed the comment as being amusing. She eventually made a decision to register at a different GP surgery.

A carer of a person with mental health problems spoke of how other patients in the waiting room could often make the experience of attending the GP surgery difficult for her and her partner when he was visibly distressed. She gave the example of how on one occasion someone said *'that f***ing nutter's in again'*. On such occasions she felt she was never given any help by practice staff but was left to deal with the situation alone.

Renewing prescriptions

People had a wide range of experiences of gaining a repeat prescription. Some people preferred to visit their doctor while others would return their signed repeat prescription form in person to their doctor's surgery. The process of gaining a repeat prescription could take several days and, for some, several journeys. People would often be required to take the form to their GP reception, return a day or two later to pick it up and then take it to their pharmacy. Sometimes people then had to make an additional journey to pick up the medication. This process was particularly difficult for those patients and carers who found it difficult to remember to take the form to the surgery prior to medication running out, who on occasion lost their form, or who physically found getting to and from the surgery a challenge.

One carer of a teenage daughter with learning difficulties spoke of her fear of telling reception staff that she had lost her prescription again. She described how the receptionist at her surgery *'always blows her top'* when she mislays her form. This carer spoke of how *'I am always falling apart with my prescription'*. In addition to losing her repeat prescription forms she often did not realise until the last minute that she had run out of her daughter's medication. When this happened it was always very difficult for her as she frequently had to *'dash round London'* attempting to find a chemist that was open. A mother of several children with learning difficulties spoke of the challenge of fitting in travelling to and from the surgery and chemist, to renew prescriptions, with picking up her children from nursery and school. Both these mothers felt that surgery staff were not fully aware of how difficult the process of renewing prescriptions was for them, in the context of their multiple responsibilities as carers. They felt that their surgeries could be more flexible, sympathetic and helpful.

Others spoke of the ways in which surgery and pharmacy staff had been supportive. Two women with mental health problems, and who also had mobility problems, spoke of how their chemists regularly delivered their medication to their home. Another mental health service user spoke of how the reception staff at his surgery sent his signed repeat prescription form directly to the chemist and how he then was only required to go to the chemist in order to pick up his medication 48 hours later.

Telephone services

A few people spoke about their experiences of needing to contact a doctor out-of-hours. While several of the people we spoke to were unaware of how they could contact a doctor at these times, others spoke of visiting their local hospital accident and emergency department or of phoning the practice out-of-hours telephone service. One person had had a positive experience of an out-of-hours helpline through which she then received a home visit. This woman was aware that this service was a limited resource and that they could not visit you twice in a row. However in such circumstances the service would assist you to call an ambulance if required.

Others had less positive contact. One carer of a person with mental health problems spoke of the difficulties she had in finding the right telephone number. This woman's surgery had provided the wrong telephone number on their answer message. Two further carers of people with mental health problems felt that the doctors who worked on these lines often lacked knowledge about mental health issues, indeed one carer

referred to the people who worked in these services as being '*mental health dyslexics*' and the other felt that staff were often wary or '*rude*'.

Only one person spoke of his contact with NHS Direct. This person felt that he had received '*exceptionally good advice*' on his return home from hospital following a foot operation.

Knowing the system

People were not always clear about how different aspects of the health system linked up with one another. This was particularly the case with knowing about how primary care linked up with specialist health services. One mother of children with learning difficulties recalled a time when she had unconventionally accessed a health care specialist via an accident and emergency services department. Prior to this she had contacted both her GP surgery and also NHS Direct. At the time she felt that her concerns about her son – eventually diagnosed with oesophageal reflux – were not taken seriously or helped by either. Her GP had been annoyed at her actions, said that she had '*abused the system*' and had explained that in future she should only access such specialists via a referral from the GP practice. This woman said that at the time she had not known the rules about who you could and could not get access to or how. She explained that at the time she had only been trying to get the best possible help for her child.

Conversely one man spoke of how his doctor had clearly explained to him that if he experienced high blood pressure then he should go directly to his local accident and emergency department. This clear communication was felt to be extremely helpful.

9.3 Experience of the consultation

Communicating with GPs

All of the people we talked to had experience of visiting their GP. Both people with learning difficulties and people with mental health problems were very clear about the way in which they preferred to be treated by their GP. The personal characteristics of their GP appeared to be key in determining how satisfied they were with their experience of primary care.

People valued GPs who had good communication skills, were respectful, were good at listening, had taken the time to get to know them and who appeared to have some understanding about their learning difficulty or mental health problem. Many people with learning difficulties or mental health problems found it helpful to take someone along with them to their consultations.

For people with learning difficulties it was important that their doctor talked to them slowly, clearly and in language without any complicated medical terms which one person with learning difficulties referred to as '*gobbeldy gook*'. It was also important that GPs took the time to communicate directly with the person with learning difficulties who had come to consult them prior to speaking with the person who was accompanying them. GPs who took the time to really hear what the person with learning difficulties had to say, either directly or through the person accompanying them was highly valued.

I understand a little bit, but sometimes it is difficult. (Person with learning

difficulties)

Such communication was felt to be aided by familiarity, an attempt by the GP to get to know them as an individual and through developing rapport:

Yes [you get a good service] when you get to know her [the GP] and when she gets to know you. (Person with learning difficulties)

My doctor talked to me during difficulty week. He tried to understand. (Person with learning difficulties)

Both people with learning difficulties and their carers spoke of the advantages of the person with learning difficulties being accompanied to the GP surgery by their partner, parent or support worker. People commented that if they were accompanied they often felt less anxious and importantly felt they were more likely to be taken seriously. One man with learning difficulties felt that he was less likely to be *fobbed off* by the doctor if someone was with him. Those who accompanied people with learning difficulties were additionally felt to be crucial in helping both the GP understand what the person with learning difficulties had to say as well as often breaking down what the doctor had said to the patient into plainer language.

I need someone to explain things to me. They used to make me go [on my own] but I seized up in the surgery. (Person with learning difficulties)

A respectful attitude from the GP towards people with learning difficulties was also essential. Some people spoke of their doctor as being *'very nice'* with *'a good approach, she talks to me alright'* or as being *'friendly'*. Less positively others described their doctor as being *'indifferent'* or *'not pleasant in the slightest'*, as getting *'very short'* with them or as being *'rather patronising - he talks to me like a five year old'*. Carers of people with learning difficulties also stressed the importance of a good rapport.

One carer with a son with learning difficulties said it was sometimes difficult to get the balance right with regards to encouraging his son to be independent while at the same time ensuring that his son's GP had truly heard his son's physical health concerns. He explained that his son often blamed himself when he was unwell... *'Sorry Dad'* and would not always tell the doctor about all of his symptoms. This carer felt that the GP was not used to communicating with people who were *'more dependent'*.

Overall many people with learning difficulties felt that their GP tried their best to help them and had their best interests at heart:

Yes, he does a lot to help. If there is anything that you need he always makes sure you get your requirements guaranteed to see you through. (Person with learning difficulties)

I think they try their best, if they can, if you are stuck. (Person with learning difficulties)

She smoothes, solves everything, she tries to help you. (Person with learning difficulties)

In addition several of the people with learning difficulties to whom we spoke were aware that the service provided to them was sometimes lacking due to GPs working within a system with many constraints:

I think they do their best with the time and resources. (Person with learning difficulties)

The doctor is sometimes hurried, it's the time factor. He is rushed, he rushes off somewhere else. (Person with learning difficulties)

People with mental health problems also appreciated their doctor speaking to them with respect, without the use of inaccessible medical jargon '*...big words*' and with plenty of explanation. Having enough time in consultations for effective and two-way communication was seen as very important. As with people with learning difficulties they felt that real communication was facilitated by the doctor knowing them and their medical history and ideally through having developed a strong rapport with them over time.

...[for doctors] to understand that if you have a mental health problem that you may need more than five to ten minutes. (Mental health service user)

I feel as if they haven't the time to listen ... You feel sort of rushed in and rushed out as if you've never been which is why I never bother going. (Mental health service user)

Of the people with mental health problems that we spoke to, most went to their GP alone about their physical health problems. This contrasted with occasions when people went to see their doctor about their mental health problems, or when they were feeling psychologically unwell or distressed. On these occasions people with mental health problems often took someone along, often a partner, daughter or support worker, to support them during a GP consultation. Those who found it helpful to take someone along spoke of how the accompanying person helped them to feel less '*stressed*', to remember what had been said after the consultation had ended or indeed in order to be truly heard by their doctor.

One carer spoke of how she felt her relative had been listened to more carefully since he had been regularly accompanied to his GP consultations by a support worker from the residential accommodation that he lived at:

He is listened to a bit more because he has got back up. (Carer of mental health service user)

An advocate who was present at one of the mental health service user focus groups was in agreement and felt that when she accompanied clients she felt that they often got twice the length of consultation - up to 20 minutes - than if they had gone alone and were more likely to be heard with regard to their physical health problems. Another strategy that people with mental health problems utilised in order to fully

convey their difficulties to their GP and to get their physical health needs met involved booking a double appointment or making a decision to go to the GP with one or two issues to focus on specifically, rather than a whole range of issues.

When people with mental health problems spoke about their trips to their GP it was sometimes difficult to disentangle whether they were speaking about their visits to address their physical health needs or their mental health problems. Inevitably their visits to the GP sometimes involved addressing both mental and physical health problems and some people implied that sometimes their physical and mental health issues were intertwined.

Contact with nurses

In the interviews and focus groups people with learning difficulties and people with mental health problems spoke more about their visits to their doctor than to their practice nurse. However people were often in contact with the nurse and frequently so for routine health checks. Several people with mental health problems felt that the quality of the consultations they had with their nurse were better than those with their doctor. They attributed this to the nurse having more time for them than their doctor or to feeling *'more comfortable'* with the nurse than they did with their GP.

Understanding of a person's learning difficulty or mental health problem

People with learning difficulties and people with mental health problems, as well as their carers, often felt that their GP did not know enough about their learning difficulty or mental health problem and how this affected them and their lives. A background or *'broad brush'* understanding of these conditions or difficulties was felt to be essential. This background awareness was felt to aid successful communication with patients, as already discussed, as well as providing a context within which the physical health problems they brought to their GP could be explored. In addition physical health problems and mental health conditions or learning difficulties were felt to overlap in a number of areas. A carer of a person with learning difficulties spoke of how his doctor had not been aware of the link between having a learning difficulty diagnosis and Achilles tendonitis. A further carer spoke of her daughter's learning difficulty that was enmeshed with her experience of epileptic fits. Many people with mental health problems and their carers spoke of the link between diabetes and a mental health diagnosis, particularly a diagnosis of bipolar disorder.

Some of the parents of people with learning difficulties spoke of how they were not in contact with a specific learning difficulty service or specialist. The children of these parents lived with them at home. These parents spoke of having received very little information about the learning difficulty of their child and how they were very reliant on their GP for support with the child(ren) they were caring for. Unfortunately several of these carers felt that their GP had little or no knowledge about their child's condition and felt that their GP was not interested in becoming more aware. One carer with learning difficulties even had lent her GP a book on autism that the GP had subsequently not read.

Many of the mental health service users, and carers, with whom we spoke were in close contact with specialist mental health services and felt secure in this. Most of these people felt that their GP had some knowledge of their mental health condition, though not all felt that their GP had understanding of their situation or true empathy.

Information and involvement in decision-making about treatments

The GP consultation was an opportunity for information about physical health issues to be passed on from the GP or nurse to people with learning difficulties, people with mental health problems and their carers. People often felt that their GP did not pass on adequate information to them. Consultations were short resulting in limited time to pass on verbal information in understandable language. As already highlighted, adequate time for information provision in plain language was particularly important for people with learning difficulties. Few people spoke of receiving information leaflets during consultations and one person with mental health problems said that she sometimes did not even receive verbal information about what medication she had been prescribed.

The main type of information that people received was the written information sheets with medication. This information was often felt to be difficult to use, particularly for people with learning difficulties, due to the small writing. People with learning difficulties and people with mental health problems often required support to use this information.

Some doctors usefully signposted patients and their carers to other organisations for further help. For example it was suggested to a person with mental health problems that she should join Diabetes UK. Other doctors were good at providing advice about how patients should take their medication. One older woman with mental health problems spoke about how her doctor had carefully explained that she should take her diabetic medication with her food. Several people with mental health problems said their doctor or nurse had informed them that they could control their diabetes through diet and were given basic verbal information and often a diet sheet.

Most people with learning difficulties and people with mental health problems felt that their doctor usually made the decisions about the types of health care interventions they received. Many felt comfortable with this. There was generally a feeling that the doctor was the *expert* on physical health matters and these people followed their GP's advice without query.

I don't know how to explain it ...they make the decisions. (Mental health service user)

On the other hand we spoke to a few people with mental health problems and carers of people with learning difficulties who sometimes disputed the expertise of their doctor and requested further explanation and options.

One example involved the experience of a man with mental health problems who was experiencing chronic back pain. His doctor had told him that she didn't know what the cause of the back pain was and had offered him an injection to provide him with a painkiller that would be effective for six months. This man felt very unsatisfied and refused this treatment. Instead he had asked his GP for further explanation and treatment options but was only told that his condition was '*a degenerative problem, old age*'. This man said that he would have liked the option of seeing a physiotherapist, osteopath or bone/joint specialist, but was aware that to get such treatment he would probably have to seek help privately. He was on long term

benefits and said that he could not afford private treatments. He felt that wealthier people had a wider choice of physical health treatment options as they could afford to purchase the ones that were not readily available on the NHS. A different mental health service user spoke of her more positive experience of being offered acupuncture by her GP for treatment for her bad back. Among those we spoke to, the offer of alternatives such as acupuncture was rare.

Two parents of people with learning difficulties spoke about how they felt as if they were more expert, with regards to the learning difficulty condition that their children experienced, than their GP. These parents often gained information about their child(ren)'s condition from websites or in one case an internet discussion forum for parents. One carer had even attended a professional conference in order to gain further knowledge. These two parents were not currently in contact with a learning difficulty specialist and subsequently felt that they had to provide the expertise to their doctor. One parent was pleased that her doctor would receive suggestions from her, for example regarding prescriptions of special foods for her sons to improve their behaviour. However overall this woman felt that this lack of knowledge by her GP about her sons' conditions was frustrating and worrying. She often felt that she was the expert in their health care. Suggestions for treatment or referrals were usually initiated by her and not by her GP.

A woman with mental health problems spoke of how in the past she hadn't felt involved in her care, but how this had changed over the past two years because she had made a conscious effort to be more involved in any decision-making about her health at her GP surgery:

They can just palm you off with anything so now I tend to ask questions.
(Mental health service user)

There was acknowledgement among mental health service users, their carers and the carers of people with learning difficulties that it was helpful when doctors were honest and said that they didn't know enough about a particular condition or medication. People were often reassured when GPs needed to look up medication contra-indications, side effects or dosages in books such as the *BNF* (British National Formulary).

Diagnostic overshadowing

A number of the people to whom we spoke recalled incidents in which they felt that their physical health problems, or those of the person they cared for, had not been believed, identified or fully taken on board due to their learning difficulty or mental health diagnosis. People spoke of being '*fobbed off, ignored, dismissed*' and of '*not being believed*'. People with mental health problems and their carers gave the most examples of this. These people felt that GPs would sometimes '*link it*' or '*blame it all on your mental health*'.

I don't feel that I am listened to. They link it with the mental health. Everyone is entitled to be treated for physical problems. (Mental health service user)

We know when we are physically unwell. It's dismissed in most cases.
(Mental health service user)

I find that if you go with a physical complaint it is dismissed. It is not seen as serious. You put off making an appointment, but when you do, if it's not serious, you feel silly. You don't feel [as if you are treated] like other people, who if they have a physical problem, they just go to the doctor. (Mental health service user)

I would like my GP to view me as a whole person and not just as a mental illness – to see [my] physical illness in the same way as for everyone else. (Mental health service user)

An example of a person with learning difficulties' physical health problems being consistently overshadowed by their learning difficulty includes the experience of the following carer. This carer, who had lived with and supported her brother for many years, spoke of how his hernia, long term migraines and a minor stroke were never given adequate attention despite her advocating on his behalf. She spoke of how his migraines were finally, after eight years, addressed when she had caused a big fuss at her GP surgery that led to him finally being referred for a scan.

One woman with a mental health problem spoke of how she had received a diagnosis for a kidney problem in Africa and had then been treated for this condition at a GP surgery in a previous part of the UK she had lived in. She spoke of how her current doctor had tried to simplify her symptoms by expressing them as not being serious. She felt that her doctor had not treated her as an equal and that she had not been respected as an individual in need of health care. She said that she would like to find a new GP but said that she did not know how to go about doing this.

Another example involved the experience of a man with mental health problems who was staying in a medium secure hospital. This man spoke of a time when he had felt nauseous due to what he felt were side effects of the psychiatric medication he was taking. He described how he had phoned 999 that day and was asked by the emergency services staff member to fetch a member of staff working at the unit. This member of staff had said to emergency services '*...don't listen to him he is mentally ill*'.

A person with mental health problems spoke of how it had taken over three years for him to be diagnosed with diabetes:

The doctor told me I was wasting his time. I was diabetic and it took three years to diagnose it. And it wasn't them in the end [who made the diagnosis], it was the optician. My condition is [now] worse than it would have been. (Mental health service user)

A final story involved a woman with mental health problems who went to see her doctor regarding alopecia (hair loss). The response from the GP was to place this woman on a six month waiting list to see a specialist. This woman felt that this length of wait was unacceptable. She returned to her GP supported by an advocate and the result was that an appointment with a dermatologist was arranged to take place within a fortnight.

Some people with mental health problems, or their carers, reported that the consequence of their not being believed, or their condition not being seen as important, by their GP was that it led to them feeling reluctant to return to their GP surgery for further consultations and health checks.

I didn't ring them because I dread it. They say it is all in the mind. (Mental health service user)

9.4 Services and treatments

Health checks

Those people who had been diagnosed with a health condition such as a heart problem, high blood pressure, diabetes, a liver problem, a chest problem or asthma were offered regular health checks with their nurse, with a specialist nurse at a visiting clinic, their GP, or a specialist doctor at a clinic or hospital. Some people were supported by staff, carers or support workers to make appointments for these checks, while others were able to remember and book for themselves. People with learning difficulties were particularly reliant on those who cared for them to support them to receive regular health checks. A small number of people received reminder letters from their GP surgeries to make appointments for these regular checks. At one surgery patients were reminded to attend their regular checks through a reminder note being printed on their repeat prescription forms.

Few people however spoke of being offered preventative health checks, apart from the people with mental health problems that we spoke to in medium secure care and some of the older people with mental health problems. The men in the secure unit told us that within a few months of being admitted to the unit they had received a health check from the visiting GP. They also spoke of the drug and alcohol checks that took place for all inpatients at the unit, from time to time, when staff were suspicious of drugs being present on the ward. Some of these men were also regularly weighed by their unit primary care nurse and also had their blood pressure taken. The older people we spoke to said that every time they saw a GP or nurse, or they were visited in their home by practice staff, they would have their blood pressure checked at the very least. One woman with mental health problems said that she had only ever received a urine test at the surgery with which she had registered four months previously.

Women with mental health problems, and some with learning difficulties, spoke of receiving and going for regular smear tests or breast checks or attending well women clinics. One young woman with mental health problems spoke of a positive experience of attending a GP surgery for a smear to test for a sexually transmitted disease. Well men clinics appeared to be less well known by men with learning difficulties or those with mental health problems. One carer of a man with learning difficulties spoke of how a local health activist had suggested that she take the person she cared for to the doctor to be checked for testicular cancer. This carer had said that the female doctor had refused and had referred her back to the volunteer health activist. She said that she felt this was an example of health professionals '*passing the buck*'.

The people we spoke to often felt frustrated about the ways in which the results of health checks were communicated to them. While some were unclear about the mechanisms by which they were required to collect this information, others spoke of results going missing or of finding it difficult to contact staff on the phone to ask them about the results. Some people with mental health problems explained that they sometimes found it difficult to remember to phone up the surgery, following tests, to find out their results.

Health promotion

A minority of people with mental health problems or learning difficulties had received advice on health promotion or had been offered an intervention. Sometimes advice was offered by GPs or nurses and sometimes by specialists. GPs would often suggest to people that they stop smoking, should lose weight or should exercise more. Several people, including an older woman with mental health problems, had been encouraged to walk more. Specialists would also often suggest health promotion measures. For example a hepatologist had suggested to one man that he should give up drinking. More advice appeared to have been provided to people with mental health problems than people with learning difficulties.

Most health promotion advice from GPs was not followed up with more practical help. Only a few spoke of being actively supported to take up more healthy lifestyles. A couple of carers of people with learning difficulties had received nutritional advice from dietary specialists. While one person had found the advice provided to her sons incredibly helpful and the service supportive, another felt that the advice was *'as much use as a chocolate fireguard'*.

A couple of people with mental health problems who felt they were overweight because of the psychiatric medication they were taking had asked their doctor for a prescription for exercise. However all of these people had been refused and told that they weren't overweight enough. They felt that the message that their GPs had provided them with was that *'you have to do it yourself'* or that the doctor did not really care if they were overweight.

Many people with mental health problems, including the younger people interviewed, were aware of basic health promotion advice. Many felt that they had gained this information from places outside their GP surgery. Some people with mental health problems, their carers and carers of people with learning difficulties felt that they were offered more support with health promotion issues from local day services or voluntary sector organisations than they were from their GP or nurse. For example one carer of a man with learning difficulties said that his day centre supported him to exercise and people with mental health problems mentioned the importance of day centres and voluntary sector organisations in providing health promotion literature or offering opportunities to take part in exercise, yoga or relaxation classes.

A few people with mental health problems spoke about how ultimately the responsibility for giving up smoking, taking more exercise or eating more healthily was down to the individual. They felt that people knew about healthier ways of living and that it is up to individuals to apply their own willpower.

The people we talked to in secure care appeared to have many challenges in their pursuit of a healthier lifestyle. These men were restricted to being inside for much of the day. They spoke of how they did have an opportunity once a day to play volleyball in the compound, but that they were not able to go for walks outside in the fresh air and could not currently get access to a gym. There was a gym on site and in the past a gym instructor had been employed. However the gym had been under-used by patients and had been subsequently closed. One man spoke of how it was very easy to put on weight while living in secure care as they were provided with three big meals a day and little opportunity to exercise. Another felt that it was also difficult to give up smoking in the unit. This man spoke of how he had found it possible to give up smoking when he was in prison, but was smoking again now he was in secure care. In prison he hadn't had access to tobacco. These men spoke about how much healthier they had felt at times that they had lost weight or had given up smoking.

Medication side effects, review and contra-indications

Both people with learning difficulties and people with mental health problems experienced side effects from the medications they were taking. However this appeared to be a particular issue for people with mental health problems.

One parent of a daughter with learning difficulties recalled the time that she had spoken with her daughter's specialist regarding the night time dribbling on her pillow that her daughter was experiencing. This woman was pleased to have raised this issue as her concerns were taken on board and the medication was adjusted.

As already mentioned, many people with mental health problems were upset by weight gain or loss they had experienced. Many of these people attributed their weight change to the psychiatric medication they were taking. They frequently felt unheard and uncared for by their GP with regard to their changes in weight. Weight gain was common and appeared to be distressing to people as it led to them feeling unattractive and unfit and they were aware that being overweight meant they were more susceptible to other health problems. Losing weight was also very worrying. The following woman felt that she was not taken seriously by her doctor when she had rapidly lost weight in the past:

I lost five and a half stone due to depression in a period of eight months. I went to the doctor. She said 'Oh no, it's just anxiety'. She [the doctor] pulled out a roll of fat on her stomach and said 'How would you like that then, and all I have had today is a banana'. I got Ensure [a nutritional supplement] in the end but that was from the hospital. (Mental health service user)

Other people with mental health problems complained of psychiatric medication leading to a wide range of other side effects including shivering, night time pillow dribbling, not being able to think properly, feeling drowsy, bowel problems, muscle gain, sexual dysfunction, wanting to smoke more and distressing physical and psychological symptoms experienced when withdrawing from a particular anti-depressant.

A few people with learning difficulties and mental health problems had been asked by their GP about side effects, but the majority felt they had to raise the issue

proactively themselves with their GP. As already mentioned people usually could get information about possible side effects from the information leaflets supplied with medication but this was often difficult to read and one person with mental health problems commented that reading such leaflets was not always enough: *'You don't know what to expect. You just don't get told.'* [Mental health service user]

Some people had received support with side effects. For example a man with mental health problems, who had spoken with his GP about the drowsiness he was experiencing, spoke of how he had received the helpful advice of taking his tablets in the evening so that he would be more alert during the day. Side effects from physical medication had also been experienced. One carer of a person with mental health problems spoke of the side effects her husband had experienced while taking insulin that had led to his skin resembling that *'of a tiger'*. His insulin dose was later adjusted. Medication side effects appeared to be an issue that was addressed by GPs when difficulties arose, and when brought up by a patient or their carer, rather than as a regular matter of course.

People on the whole were keen to receive information, though one woman commented that the information on medication side effects could sometimes *'scare you to death'*. People with mental health problems and their carers spoke of the internet, local voluntary sector organisations and the BNF as being very useful sources of information about side effects.

People had mixed views and experiences about their physical health medication being reviewed. Some people with mental health problems felt that little real care was taken when repeat prescription forms were signed by doctors and a person with learning difficulties recalled an occasion when she was deflected with the comment *'Don't worry'* from her doctor when she asked her to review her medication. Others had more positive experiences. A carer of a person with learning difficulties and a mental health service user both spoke of careful monitoring and mutual decision-making regarding sleeping tablets *'...We decided on other tablets instead'*. One carer said her husband tested himself for his diabetes and directly liaised with the hospital regarding his insulin dose.

Long-term use of psychiatric medication was also mentioned. One man who had been on procyclidine for many years spoke of how he was changed to a different drug, despite his preferring the side effects of the old to the new drug. Other people with mental health problems stressed the importance of long-term psychiatric medications being regularly reviewed.

Many of those we spoke to were taking a combination of both physical health and/or psychiatric drugs. One man with mental health problems spoke of the 22 tablets that he took each day. Some of the people we spoke to told us about the difficulties they experienced when some of these medications interacted. A woman with learning difficulties spoke of her experience of taking medication that cancelled out her contraceptive pill. The result of this was that the woman became pregnant and later miscarried. A person with mental health problems had experienced difficulties as a result of his asthma and mental health medications interacting. A further mental health service user had fallen asleep at work as a result of an interaction between her diabetic and her mental health medication.

Some patients and/or their GPs were proactive about addressing any potentially conflicts between different medications:

If I'm unhappy I phone them up and check why I've been give something when I have deep vein thrombosis. (Mental health service user)

Whenever the psychiatrist or hospital doctors give me anything I check it with the GP. I took a tub of tablets to the GP and she threw it in the bin. (Mental health service user)

However other GPs were dismissive of their role in keeping an eye on the multiple medications that people were taking. These doctors felt that knowledge about the many and complex interactions was beyond their remit: *'My doctor said "I can't know everything about pharmaceuticals"'. (Mental health service user)*

Two people with mental health problems also spoke of the potentially dangerous situations they had been put in with regards to medication they had been wrongly prescribed:

There was once when I was supposed to be given 50 Cocodomol and the locum GP gave me 500. (Mental health service user)

I was given Ventolin all the time and then my doctor change it to Salbutamol. I was given a prescription for both and I was taking both for quite a long while - a double dose which is dangerous. (Mental health service user)

A mental health service user spoke positively about the joint decision-making he had made with his doctor regarding changing to an anti-depressant medication that might interact with another medication he was taking and cause stomach bleeding. This person's GP had informed him about this possibility, but this service user had chosen to go ahead with taking the new medication anyway. He made the decision to change to a new anti-depressant as the previous anti-depressant had impaired his sexual functioning.

Referrals to physical health specialists

Most referrals were suggested by GPs though a few carers of people with learning difficulties and people with mental health problems spoke about the way in which they were sometimes active in requesting a referral from their GP. Researching options beforehand, developing a trusting relationship with your doctor, being assertive and having someone to support or advocate for you, all appeared to be helpful ways of proactively gaining a referral.

You do your homework and then you know what you want. You self-diagnose. You have rapport. (Carer of person with mental health problems)

While most people were satisfied with the quality of their consultations with specialists there was often dissatisfaction with the way in which they found out about tests that were undertaken during these consultations. This reflects the experience of gaining information about the results of health tests (see section on health

checks). People were also sometimes confused about what would happen following the consultation with the specialist. It seemed that it was sometimes up to the patient to actively ask what the next steps would be.

Physical health specialists were often felt to provide useful written and verbal information about particular treatments and conditions.

9.5 Emerging issues for specific groups of people

This section highlights the key topic areas arising for the specific groups of people whose views we were asked to gain.

Young people

The young people with learning difficulties and mental health problems that we spoke to were usually reliant on their parents to help them to make appointments and travel to their GP surgery. This was particularly the case as most of the younger people we spoke to lived in rural communities '*...Where I live my mum has to take me*'.

Some of the young people with mental health problems liked the fact that their GP lived locally to them and was a familiar face, while others felt they would prefer greater anonymity. One young woman said that she wouldn't be surprised if what she told her GP was then passed onto her parents. This same young woman spoke of how she had on occasions approached a GP local to her school rather than her home in order to achieve anonymity. She had been told that she could only attend that surgery if she was staying with someone who lived in that area. One time she had successfully got into this surgery by saying that she was staying with her aunt. One young woman also spoke of the lack of anonymity she experienced when she was referred by the school nurse to her local CAMHS (Child and Adolescent Mental Health Service). She was reassured at the time that her parents would not be informed, but then a letter was sent to them.

Some saw the GP alone, while others were accompanied by their parents. One young woman with mental health problems spoke of how when she was younger her mother had accompanied her, but that now she was older her parents had given her a choice about this. Several of the young people with mental health problems found the language used by their doctor difficult to understand. One young woman said that it was often hard to pluck up the courage to ask a doctor to explain what he or she had just said. Some of the young women with mental health problems said that they found it most comfortable to visit a female doctor or nurse at their practice.

The young people with mental health problems also spoke about the lack of knowledge their GP had about mental health problems. They had mostly been referred on to their local CAMHS service by their GP but had been provided with little information about it by their doctor. These young people spoke of how useful and unusual the focus group for this study was as they had rarely had the opportunity before to speak with other young people with mental health problems. Several of these young people swapped phone numbers at the end of the focus group.

Some of the young people we spoke to felt that they did not get enough information about either their psychiatric medication or side effects. One young woman said:

I'm not even told exactly what I am supposed to be on. [They just say] 'Here you are, just take that for however long'. (Young person with mental health problems)

Older people

While we only spoke to two people over 65, we spoke to many more in their 50s and 60s. These older people often had numerous physical complaints in addition to their learning difficulty or mental health problem. Overall they appeared to receive good physical health care. One older woman with mental health problems who had reduced mobility due to arthritis and who lived in warden-sheltered housing, was always visited by doctors from her GP surgery when a consultation was required. A small number of older people received their medication by their chemist dropping off their prescription to them at home. Older people, particularly if they already had identified physical health problems, regularly received health checks – often every time they had a nurse or doctor consultation. Checks for high blood pressure were very common.

Some older people often found travelling to their GP surgery a challenge. One woman said she did not live far from the GP surgery but would always take the bus two stops to get there. She also spoke of how trips to the chemist, in addition to the GP, took a lot of her time and energy. People with mental health problems and learning difficulties, and particularly those who were older, were frequently taking numerous medications that required renewal by the doctor and picking up from the chemist.

It is worth mentioning that the older people we contacted through the CMHT for people over 65 did not readily identify themselves as having a mental health problem. In fact one of the interviews did not take place because the older person the interviewer visited said that her mental health issues were all in the past and so that her current dealings with her GP practice were purely to do with her physical health problems. In the small number of interviews with these service users it was harder to gain a feel for any issues emerging from the interaction of visiting a GP (or being visited by a GP at home) for both mental health and physical health problems.

People living in supported accommodation

In this study we mainly spoke to people living at home independently, people living at home with support from family, partners or support workers or people living in supported accommodation. The latter included a community for people with learning difficulties. Those living in supported accommodation were often helped in many ways to receive care from their GP surgery. People spoke of the help they gained from support workers in finding and registering with a sympathetic GP, identifying that something was wrong with them and thus needing to go to their GP surgery, making an appointment with their GP or nurse, travelling to the surgery and in attending consultation appointments. In consultation sessions support staff were able to help people to communicate more effectively with their GP or nurse (particularly those with learning difficulties) and to speak up more confidently and assertively for themselves. Support workers attending consultations with clients with

learning difficulties or mental health problems often appeared to lead to their clients' issues being more comprehensively heard and taken seriously by GP staff. In a few cases it was apparent that the presence of a support worker led to more appropriate and swift referrals being offered.

Parents and partners, living with people with learning difficulties and people with mental health problems, also appeared to provide people with similar advantages at the GP surgery. The importance of supporters enabling their relative, partner or client to make decisions about how much help they required from them during visits to the GP was also highlighted by many support workers, parents and partners.

People living in medium secure care

We spoke to four men with mental health problems staying in a medium secure unit. They had all received a thorough medical check on arrival at the unit and regular health checks since, particularly for weight and blood pressure. These men had regular and weekly access to a local GP with whom the unit was registered. There was no choice with regard to the GP they saw.

Health promotion on the unit was poor and people felt that it was very easy to put on weight and smoke. There was little opportunity to exercise or be outside and motivation to be active was felt to be low among those staying on the ward. This could perhaps partly be due to the medication that people on the unit were taking. One man felt that the meals provided on the ward were too big and he said that in the past they had led him to put on too much weight. Several men felt that the lack of activities on the ward and the ready availability of tobacco meant that it was difficult to give up smoking on the unit or to want to give up smoking.

One man also spoke of how he needed new reading glasses but was unsure of how to go about obtaining them while staying on the unit.

People from Black and minority ethnic communities

Most of the people from Black and minority ethnic communities that we talked to were mental health service users and lived in London. Overall most of these people felt they received a good service from their GP practice. Some of those we talked to were asked if they preferred to see a GP with a similar ethnic background to them. Most people felt that more important than their GP sharing a similar ethnic background was that their GP had good listening skills, understood their mental health problems, had good medical knowledge and was respectful:

It doesn't matter as long as they are good, as long as they know what they are doing. (Asian mental health service user.)

Another person pointed out that if you were registered with a group practice and wanted a particular GP, perhaps one of a similar ethnic background, then you would often have to wait a long time to get an appointment.

Being registered with a GP who spoke the same first language was incredibly useful for some of the people we spoke to. Two of the women we talked with spoke Punjabi as their first language and did not feel confident communicating in English. One of these women spoke of the usefulness of her GP speaking the same

language. During her consultations she could speak with ease with the doctor. This woman was also helped to make future appointments by this doctor with reception staff. If this woman could not make an appointment with this GP for any reason then reception staff would ensure that an interpreter was booked in advance. The awareness of this Punjabi speaking GP about the needs of her Punjabi speaking patients appeared to influence the awareness, helpfulness and respect of reception staff at the practice.

We spoke to one woman who had either refugee or asylum status and was living in one of the PCT areas outside of London. This woman spoke of the better health services she had received previously both in London and in her country of origin. She hinted that she had experienced stigma and perhaps poorer services within her current GP practice due to a combination of being a mental health service user, being Black and having refugee or asylum seeker status. She spoke of how she felt her doctor had been more interested in her asylum status rather than her physical health problems during her consultations.

People living in rural communities

People living in rural communities sometimes had to travel long distances to reach their GP practice and were often reliant on others such as parents, partners or support workers to transport them there. Many travelled by car, but some of those who travelled by bus spoke of the lack of flexibility shown by reception staff in fitting appointments in with bus timetables. Some bus routes in rural areas had very few buses running during the day. Those living in rural communities sometimes also had fewer options with regard to the days which they could visit their GP practice. A small number of people spoke of their practices only being open 3 days a week rather than 5 days.

People living with multiple impairments

Some of the people we spoke to had physical and sensory impairments in addition to their learning difficulty or mental health problem. This was more often the case for people with learning difficulties. For example people spoke about the additional challenges they faced at their GP surgery due to having a speech difficulty or due to having mobility problems. One person spoke positively about the system in their GP surgery that alerted patients that the doctor or nurse was ready to see them by the use of a buzzer and light. This person felt that this would be useful for people with either hearing or visual impairments.

Many surgeries were accessible by wheelchair through the use of ramps, though some of the consulting rooms were reported to be too small to comfortably accommodate a wheelchair during a consultation and to be difficult to turn a wheelchair in. One carer who was a wheelchair user spoke of the lack of a disabled toilet at her partner's GP practice. A woman with a speech impairment spoke of the frustration she experienced, during consultations, when her doctor would finish her sentences for her:

That's one of the worst things someone can do. It's as though I am rushed.
(Mental health service user)

9.6 Key Themes

A number of key issues arose from the discussions with people with mental health problems, people with learning difficulties and their carers. These are highlighted below:

- There appears to be a lack of knowledge and awareness among reception staff, GPs and physical health specialists about the needs of people with learning difficulties, people with mental health problems and their carers when using their GP surgery. Staff often seem to lack the willingness or time to get to know patients and carers well enough in order to find out how they can help them to access the surgery more easily and how to make the experience a more pleasant one. Among reception staff there frequently appears to be lack of flexibility regarding making appointments and waiting times. Lack of skilled communication, particularly in interactions with people with learning difficulties, was apparent among practice staff.
- The diagnosis of a learning difficulty and particularly a mental health problem often appears to overshadow a person's physical health issues. People with mental health problems frequently spoke of being seen as a person with a mental health problem first when they walked into a GP surgery rather than being seen as someone with holistic mental and physical health care needs.
- People with mental health problems often feel that they are treated with less respect than other people at their GP surgery due to having a label of a mental health diagnosis. This experience of feeling stigmatised is sometimes felt to lead to reluctance among mental health service users to visit their surgery for their physical health needs and thus perhaps increasing their chances of becoming physically unwell. Difficult responses from GP practice staff often occurred at times when people visited the surgery when unwell with their mental health problems.
- The current way in which primary care operates, particularly with regards to the lack of time that can be spent with each patient and the financial implications of each referral or service provided, appears to have led to a culture in which those who 'shout the loudest' appear to get the most out of the system. People with learning difficulties often have difficulties in communicating their needs to others. People with mental health problems frequently have low self esteem and sometimes find it difficult to be assertive in GP consultations. Carers of people with learning difficulties spoke of how they sometimes felt that they were *bothering* the practice yet again with the problems of the person they cared for. Moreover, people with learning difficulties and mental health service users often appeared to receive a better service when they were encouraged to attend their practice, or were accompanied by a parent, partner, support worker or advocate to a GP consultation. As a consequence GP practices need to be much more active in supporting people with learning difficulties and people with mental health problems to promote their physical well being and to identify, treat and regularly monitor any physical health problems they might have. People with

learning difficulties and mental health problems may also be less likely to have access to information sources such as the internet and so may not be as aware of different treatment options as other patients.

- People with learning difficulties and mental health problems are often on many types of medication. In addition, many of these individuals are often taking medications on a long-term basis. It is essential that the complex interactions of drugs are always considered in prescribing decisions and that long-term medications are comprehensively reviewed in order to prevent physical damage to patients. People with learning difficulties and people with mental health problems also often experience distressing side effects of these medications. Individuals experiencing these symptoms need to be actively supported by GPs to identify these side effects and to explore different dosages or alternative medications or treatments, in order to reduce these symptoms.
- People with learning difficulties and people with mental health problems often are on benefits and so have less financial resources with which to choose and pay for alternative health care interventions such as osteopathy or acupuncture. These groups of people also have less money to spend on healthy eating and on opportunities to exercise.
- The GP is the practitioner who links a person's practice-based health interventions with specialist health interventions and learning difficulty or mental health specialists. It is important that GPs effectively communicate with and link up with all of the specialists involved in their patients' care, so that their patient can be treated as a whole person without their mental and physical health being fragmented and treated separately.
- Due to the constraints experienced by GP surgeries, practices appear to work within a culture of crisis management rather than active health promotion. The consequence of this appears to be that patients only approach their GP surgery when they are unwell, rather than having ongoing and regular contact which could support them to maintain their physical well being and prevent people developing physical health problems.
- The voices of people with learning difficulties are often hard to reach as they frequently require substantial time and skilled support to enable them to fully communicate their needs. As well as hearing this message through what people with learning difficulties said in the focus groups about their experience of primary care, this was also apparent in the process of this study. In this research project it was easier to set up interviews and focus groups with people with mental health problems than people with learning difficulties and as a consequence we spoke to a larger number of people with mental health problems. In addition, people with mental health problems are usually more able to express themselves in words than people with learning difficulties. As a result a higher proportion of this section of the report feeds back the issues experienced by mental health service users than those of people with learning

difficulties. Great effort and care needs to be taken in the future to ensure that the views of people with learning difficulties are elicited, heard and taken into account regarding primary care. Only in this way can their needs begin to be fully met when they are visiting their GP practice.

10 Findings from Interviews with Health Professionals and Senior Managers

10.1 Introduction

The remit of this part of the study involved interviewing key stakeholders in the four geographical areas in order to explore the context for primary care in that area.

Interviews included:

- managers in primary care;
- practitioners and staff in primary care;
- managers in specialist secondary care services;
- managers in specialist advocacy services.

We wanted to get a sense of what was happening of relevance to our service users alongside primary care and what key managers from within and outside of primary care had to say about crucial service issues.

10.2 Site 1 – South East

Seven interviews were conducted from this site.

Access issues

What is service users' experience of accessing primary care services in this locality?

A GP and a practice manager, from different practices, were interviewed. Both indicated that people with mental health problems and also those with learning difficulties were easily identified, but in different ways.

The practice manager relied on local knowledge of patients' conditions. So for those with mental ill health:

Yes because I know them from being here so long. I have become aware over time of patients that have a mental health problem.

And similarly with people with learning difficulties:

I can only identify those known over time and through correspondence/notes.

There were issues with new patients and the practice manager said that until the doctor had seen a person for the first time, a mental health diagnosis would not be evident. She seemed to indicate that with learning difficulty it was more straightforward as issues were in general picked up in infancy.

The GP, meanwhile, used Read Codes and the Quality and Outcome Framework (QOF) to identify these groups of patients.

The Sainsbury Centre for Mental Health

The GP conveyed a view that people with mental health problems might have difficulty in identifying when they might need to visit their GP and the practice addressed this by:

... using a follow up appointment system - especially useful for difficult patients...

The practice manager indicated that people with mental health problems would get special treatment because the staff were aware that they had problems:

We would generally get them seen straightaway - don't mess around with them - so they would if possible be put in instantly. In some cases they have a priority over other patients because of their mental health.

For people with learning difficulties, practices seemed to rely on carers to decide when people should visit the surgery and to make appointments.

The GP stated that:

For those living in residential accommodation their carer/admin staff manage appointments, so generally that's quite smooth.

The practice manager also said that:

Most people have a carer who would help access.

Long waits did not seem to pose any sort of problem in either of these two practices. Both had ad hoc arrangements in place so that issues could be handled immediately.

The practice manager indicated that for both groups of patients:

Privacy is not an issue because if people do get upset we take them into the office to give them some space. Our timekeeping is generally very good so our patients don't have to wait long – if they had to wait 15 minutes that would be a long time for us.

However a Learning Disability Support Manager said that there were quite a few cases where his clients didn't get the support they need to get access to primary care services, there are waiting issues, and accommodating special needs i.e. wheelchair users, is difficult in an area where practice accommodation is unsuitable.

A carer advocate confirmed this perception and said that:

Certain problems can crop up for people with learning difficulties, severe anxiety in waiting rooms with the general patient population, it's very stressful for everyone. Currently there are inadequate premises, a lot of single-handed GPs. This is a big issue locally, and there's a big drive on to improve the fabric of establishments.

Staff attitudes

Once service users - and their carers - arrive in primary care services, what kind of experience do they have? From the perspective of those who work in primary care, the experience is made as easy and accessible as possible.

The GP interviewed said that his staff were wonderful and there were no particular problems. But '*...frequent attendees are noted...*' He went on to say that:

There is some form of positive discrimination, in that people with Severe LD are often placed in a side room, and got in quickly to see the doctor.

A similar practice was utilised for people with mental health problems.

The practice manager was similarly positive about staff attitudes, but she did concede that sometimes there were challenges:

I do find some people can be aggressive towards reception staff if they don't get what they want straight away. There is one gentleman who always insists he can reorder his medication over phone and he gets threatening towards reception staff when we explain it is policy that patients come in to fill in a repeat prescription slip. He is more aggressive than mentally ill, although he is under the mental health team due to a previous overdose attempt.

How would staff handle this situation?

There are no raised voices from us we let him have his say and then he will calm down and apologise.

In essence, this practice manager asserted that people with learning difficulties and mental health problems got a better deal from reception staff because of their condition:

Generally though I don't think they have a problem with the attitude of reception staff. We tend to be more sympathetic towards them because of their problems. We go out of our way to help because of their problems. We try to make their life easier instead of harder.

Communication was not perceived as a problem for either group of service users:

I don't really know why they [people with mental health problems] would have a problem. I guess it depends on how bad they are. Those who are severe have carers though. We have a very sympathetic and understanding nurse. And the doctor is lovely. He is too good really. We have people queuing up to join this surgery. All our patients have good communication with him. And the doctor knows all the learning disabled patients himself, he has been here over 20 years so he knows people inside out. He is a father of four himself, and he is brilliant with them. He has the old values.

The GP put it more succinctly and said that communication was: '*...no different to any other patient group...*'

But what does it look like from outside primary care? For people with learning difficulties and their carers there was a strong sense that GPs lack the confidence and training to interact effectively with this group of service users. Time was also an issue.

...lack of time to see people properly, too rushed...

An interviewee from the Community LD Team thought that:

GPs don't listen, their training in chromosomal disorders is inadequate, they offload responsibility to secondary care and specialist services.

Diagnostic overshadowing - where a learning difficulty or mental health diagnosis dominates a consultation and impedes a holistic view of the patient - was identified as a key issue. A primary care commissioner for people with learning difficulties said:

...the 'Does he take sugar syndrome' operates here, GPs tend only to see labels. They don't think of how to maximise a person's potential.

Similar obstacles existed for mental health and the same commissioner said that:

GPs encounter complex issues less often, mental health problems operate almost at a semi exclusion level in the minds of many GPs – these problems belong elsewhere. For example, the director of the on-call service identified unusual demands as those from PwLD and PwMH problems. I need one telephone number we can call if we get these kinds of people.

A different senior manager in the PCT also described the impact of diagnostic overshadowing:

There is still however a tendency to leap to solutions. My mother has been taking anti-depressants for a while. When she presented to primary care with a specific problem, the fact that she had had a stroke was missed by services. Her usage of anti-depressants meant that services had leapt to certain conclusions...

But there was acknowledgement that communication was a two-way issue:

...mental health service users' ability to articulate their needs is an issue and as a consequence their rights can easily be ignored.

For people with learning difficulties the role of carers and advocates was central and several interviewees mentioned the vital part they played in ensuring communication was clear. But this raised issues of providing carers with the requisite skills to identify when there were physical health problems.

Physical health issues

What physical health issues do people bring to primary care and are their concerns being taken seriously? Most respondents to this question stated that in the majority

of cases, physical health concerns are the same as for everybody else. However, there particular areas of concern for the different groups.

People with learning difficulties have a range of very specific health issues, such as increased incidence of cardiac problems associated with Downs Syndrome. An interviewee for a carers organisation mentioned that *'LD goes hand in hand with physical health problems such as mobility, obesity'*. There were also potential problems connected to reactions to medication.

An emerging issue for people with learning difficulties was ageing - this group of people is living longer and this demographic trend is throwing up issues for service providers and commissioners.

For mental health service users, dominant physical health concerns were connected to lifestyle behaviours, especially smoking, and its effects:

Usually unhealthy lifestyle - smoking, diet, exercise - it's accepted that people with mental health problems smoke more. Also generally issues of control and addiction.

A community mental health nurse said that the most pressing physical health concern was:

Side effects of medication – in depot clinics there is no time to discuss physical health issues or side effects of medication.

And in purely practical terms, there can be a lot of liaison with primary care for individuals that have several, related complaints:

A man with asthma, apnoea and obesity has complex needs. As care co-ordinator for such a person, these issues are all linked together. It can feel like they are all treated separately.

Services and treatments for physical health issues

What sort of physical health services and treatments are on offer from primary care for these groups of service users? The GP said that most physical health problems such as diabetes, cardiac or gastric problems had worse outcomes for people from these service user groups. For people with mental health problems, he said that smoking outcomes were worse because:

... they understand their symptoms less, their lifestyle, impact of medication, as being less important...

The practice manager thought that health outcomes for patients from both groups of service users were no worse than for anyone because of their difficulties:

Patients' treatment and care is very good. Side effect of medication may mean they increase in size, but from a health point of view all our patients are very healthy. Patients with learning difficulties get all the treatment they need and are not treated any differently.

The example was given of a young girl with Downs Syndrome who had had kidney failure:

She has been in surgery for it. All patients get appropriate treatment if necessary regardless of their problem.

But among those who work with service users the view is different. Even basic physical health problems could become more complicated because of the context of a person's life and condition.

Issues arise because of a lack of communication skills, i.e. a person with Downs Syndrome may be acting up because they are in pain with an ear infection but they don't get the access to ENT services that they need.

There was a perception that for people with learning difficulties:

...local GPs won't take responsibility for medication contra-indications.

Accurate diagnoses of physical health problems were described by the GP as 'very time dependent'. But even if a problem was identified there was a sense that service users might not be compliant. People not attending for appointments or not following health promotion advice were mentioned by both the GP and the practice manager.

The practice manager expanded on this theme.

We don't push it onto them. If they ask for it, it is available. They can talk to the nurse about it. But we don't promote it as such, they have access to the services if they wish.

The view from this one practice was that neither group of service users asked for much health promotion advice. The one thing that the practice would press on a service user, especially with a mental health problem, was medication.

Nine out of ten times they just don't turn up to an appointment because of memory problems - which can be problematic if they need to get medication. Without their medication they tend to wander off a bit - so we wouldn't put that on hold. I think the majority of them come here to get medication - they don't see us as anything else.

But from service users' point of view, chronic, debilitating problems can be missed, in part because of this passivity by practices. A community mental health nurse described one such account:

For example a woman of 64 years had not had a smear and had never gone to the dentist. Within the CMHT at least she had an opportunity to discuss her fear and start to address the obstacles.

A senior manager in the PCT mentioned a range of targeted and more generic health promotion initiatives for mental health service users.

There is a smoking cessation service and user advocates have pushed this service. There is the Bridge Builder scheme, funded by the PCT, that helps to get service users back into work or meaningful occupation. There are no special physical health check-ups in place as yet for service users, but they are offered flu injections along with the whole patient population.

Interface between primary and secondary care

Whose responsibility is the physical health care of these groups of service users? All respondents said without hesitation that the first port of call for both groups of service users should be primary care.

A learning support manager said:

It should be GPs, this should never even be an issue, they are legally responsible for their patients' health care, it depends on how involved they want to get.

A learning difficulties carers' advocate agreed with this view:

Primary care services should be first port of call for physical health care. I have a strong sense that these services are offered primarily via secondary care. Specialist services also play a significant role.

A community mental health nurse said that:

...it should be primary care - but in reality this doesn't always happen.

And a senior PCT manager said that, although all services have a responsibility:

... GPs need to be more sensitive to mental health issues. They need to look beyond, at what's generating a problem rather than only at the problem itself.

There was acknowledgement of the diverse demands on GPs' time and skills.

There is so much pressure on GPs to deliver so many different things.

And there was a strong sense that the extent to which service users received a good service was very much down to individual GPs and their commitment and willingness.

Really depends on the GP, their interest and experience, but there is no formal sharing between individual GPs.

Some GPs are committed and go the extra mile. Some GPs will come out and do home visits where a person might not want to or be fit to visit the surgery.

Primary care services are so dependent on individual GPs, some are excellent but it's the luck of the draw.

Some GP practices are very good and are better than others at identifying the problems.

But from primary care staff perceptions, specialist services should play a bigger role. For example the practice manager said that for mental health service users:

Other agencies could push more information their way. CMHT/consultants could encourage them to take it up. They tend to see more of them than we do.

And the GP thought that the local mental health trust should be providing mental health awareness training for primary care services.

What's not going so well

What were the gaps and deficiencies in current practice and services that our sample identified?

For people with learning difficulties there are a range of quite specific issues, many of them related to practitioners' nominal levels of knowledge and skills for this group.

For example, a big issue is epilepsy control, as people with learning difficulties are over-represented among those with this disorder.

Furthermore, services find it difficult to differentiate between psychosis and challenging behaviour.

A big issue is one of ageing: people with learning difficulties are living longer and local social services have to cope with this group of older people, but they are being treated as if they have dementia in residential homes for older people.

More proactivity by GPs towards the physical health care of people with learning difficulties, such as annual health checks, were seen as one way of addressing any deficit in care.

There is a major issue on combined mental health and learning difficulty diagnoses that are not yet being addressed by either commissioners or providers. It remains unclear how these groups of people are served by either primary or secondary care.

For mental health service users an issue identified was dual diagnosis; the focus has tended to be on illicit drugs whereas alcohol misuse can be far more serious.

And in terms of the structure and ordering of local services, all Community Psychiatric Nurses wanted links back into practices, because it gave them the opportunity to 'hold' the system. However government policy that aims for 24 hour access, assertive outreach etc had created a layer outside the community mental health team, an additional layer to negotiate. As a consequence there is a huge waiting list to see people who are inappropriately referred. It raises issues of how best to take back access into primary care.

What can we learn from?

The situation is never all bleak and there were examples of practice that addressed concerns and that are worth sharing.

The PCT had done significant work on de-stigmatising mental health and this has had an impact: people in primary care have been asking for information, and there has been a recent push on self-harm. This normalisation message communicates to practitioners that help is at hand, it's not yet another huge new burden on services.

A clinical network for key practitioners and advocates has been established on self-harm. The network provides peer support - say a new NICE guideline emerges, there can be a discussion to address delivery. The network provides slots of up to one hour on the telephone for peer support and the organisation allows its employees the time to do it and also to receive it. This process will hopefully create a resource that's embedded and sustainable.

There is a lifestyle adviser employed at the PCT, and the community mental health nurse is meeting with her to ensure mental health issues are taken into account. A GP has now put forward their name as mental health lead for the PCT.

There will be two graduate primary care mental health workers in post shortly, both permanent appointments, and they will work across the whole PCT area. GPs are resourcing the posts with underspend from secondary care.

For learning difficulties, initiatives are developing outside primary care but could be utilised by those services. For example the community learning difficulty team is developing Health Action Plans for service users (a requirement in *Valuing People*), as well as an accessible Health Booklet (imminent like the Health Passport). And there is a county-wide LD Partnership Group that encourages carer involvement, which is very important.

10.3 Site 2 - London

Eight interviews were conducted on this site.

Access issues

What is service users' experience of accessing primary care services in this locality? Two GPs and one practice manager were interviewed, all from different practices.

All three of these primary care staff said that identification of the target groups of service users were via mechanisms such as Read Codes, practice registers or QOF data analysis. In addition information in recording systems were supplemented by the data recorded for each consultation.

For mental health service users, one of the GPs said that:

...we undertook an audit in the practice three years ago that identified that particular patients with psychosis did not receive the same interventions and care as other groups.

Making appointments could pose problems in certain circumstances:

The more severely mentally ill are put off by the appointment system, and it puts off those with mental health and learning difficulties more than others.

This view was corroborated by the other GP interviewee:

Appointment systems are difficult for all patients, which means for those who have mental health or learning difficulty problems, it is even harder – really a case of ‘survival of the fittest’.

The practice manager gave a similar view about making appointments.

This is a bit tricky - issues of dual diagnosis especially, some of the people with enduring mental health problems who live in private residential homes have good carers and so they can act as advocates.

Getting an appointment was not perceived to be too difficult, largely because of special arrangements. The practice manager said that:

Waits aren't too long, we have been trying to run the new appointments system which says no more than 48 hour wait, but we always keep a few appointments that can be booked in advance. We accommodate the needs of the patients.

A senior manager from the PCT emphasised that:

Registration is NOT a problem in this area for mental health service users.

However, a learning difficulty advocate had a different perspective.

Improved awareness and attitudes of practitioners is essential. If a person is not welcomed into a service they won't make use of it. For example, it took a whole year to get a learning disabled person registered at a particular practice locally. It seems hard for practitioners to get past the learning difficulty diagnosis.

Staff attitudes

Once service users and their carers arrive in primary care services, what kind of experience do they have? The practice manager said that due to the long history with these groups of patients, services were at least as good as the rest and sometimes better.

Patients from these groups are treated exactly the same and sometimes receive enhanced care. We have a huge number of patients that have been looked after ever since the Community Care Act in the 1990s, the practice has really known some of these people for years. Most of the reception staff know these people, most staff have been at the practice for a long time so continuity

exists. They know how to handle people, they know the homes where people live, they know the problems that exist across the patch.

One of the GPs said that his reception staff could be better trained, but that their communication skills were good, especially in the face of perceived adversity. Waiting arrangements posed no problem ‘...except if a patient is drunk...’, and communication between patients and practitioners was generally good ‘... but for those patients who are particularly demanding (more than 10 contacts per week) patience wears thin...’

The second GP, from a different practice, said that:

Reception staff are wonderful. The EMIS system [a computing system for medical records] is useful, as it can attach warning flags to highlight to receptionists that patients have particular problems. But very frequently that knowledge is there already, because of local and prior knowledge.

This same surgery also had a private area for conversations that could be considered confidential. Staff had been trained by the PCT and the practice to understand and identify situations as to when a conversation should be handled as though it is confidential.

A senior manager from the PCT said that despite progress, people with learning difficulties still faced issues getting their physical health looked after in primary care.

For people with complex needs, there are issues of access, being listened to, waiting times.

A community development worker said that:

Practitioners will ignore what they are unfamiliar with. Labelling does take place and a diagnosis can overshadow physical health needs. However the QOF will encourage check ups on e.g. smoking status, flu jabs etc.

Physical health issues

What physical health issues do people bring to primary care and are their concerns being taken seriously? In addition to the usual health concerns of the general population, specific issues were highlighted for each group of service users.

For example there is a lot of concern about the amount of physiotherapy available for people with learning difficulties as there is only one specialist post in the area. Getting access to chiropody services is also a problem.

Issues have also been identified with dentistry, especially for people with high support needs.

Finding a dentist that can communicate well and can accommodate someone in a wheelchair is not easy, but these are very practical problems. Many local service users and their carers end up going to the dentistry department at the

general hospital, as they can accommodate a person who might need general anaesthetic for their treatment.

A learning difficulty manager identified significant problems with:

...awareness of screening, hearing, eyesight. Communicating problems and solutions is an issue. Also health problems on obesity, healthy eating – all these issues cut across choice.

In addition there are basic issues of inequalities, obesity, early mortality, general poor health, although these issues are being tackled, especially via the Health & Social Care Partnership Board. And here, as in other sites, ageing among this group of service users is emerging as a vital issue.

For mental health service users, the main concern seemed to be about engagement with clinicians. Clients feel they are not getting beyond mental health issues when they go to primary care.

One of the GPs said that:

Diabetes and schizophrenia a particular problem, due to lifestyle and compliance and denial of disorder; the only way of managing them is to treat them as though they are housebound with home visits....

Services & treatments for physical health issues

What sort of physical health services and treatments are on offer from primary care in this locality for these groups of service users?

One GP found it difficult as there are '*...no blood tests*'. He is aware of the two question screening/case finding system recommended in the NICE guidelines, but they are not using it. Interestingly the practice had had a half day away day (regular event) and the most recent training had been on primary care mental health. They had not discussed the screening and better identification, but had talked about QOF, and primary to secondary care interface issues

The other GP said that diagnosis was not a big problem for target groups generally, but they needed better access to specialist consultant advice. However, he also said that service users from both groups were less likely to be screened for risk factors.

One practice undertook an audit three years ago, which identified that patients with psychosis in particular did not receive the same interventions and care as other groups.

The audit exercise was useful; identified that only 15% responded to invitations to attend for screening. Therefore we respond now by offering the interventions opportunistically. The audit demonstrated that uptake was less than other groups.

Regarding health promotion advice, one GP said that:

Compliance is poor, hypertension, and poor support at home, and socially isolated. If a patient is anxious they are more likely to take up interventions, otherwise less so.

New arrangements for measuring performance were seen as helpful.

QOF is really helpful in ensuring people get access to the treatments they need, although it is quite prescriptive. Why is there a LES for [people with learning difficulties] but no QOF – this smacks of discrimination [QOF encourages excellent essential care, LES encourages excellence in care intermediate between primary and secondary care services – they are not the same] Appropriate patient leaflets would be helpful.

The practice manager said that it was very easy to make a diagnosis but that:

We keep a close eye on people when they go into secondary care for physical health problems as it's there that their diagnosis can overshadow their physical health problems.

However a local learning difficulty advocate was not so sure about how good the service was for people's physical health.

It's very hit and miss, there are examples of really good stuff going on, but also really bad things as well. One recent example was of a person who had an eye problem and was fobbed off by the GP. The person ended up going to the hospital where the consultants discovered some serious eye problems that hadn't been detected. This was in a practice that in fact was part of the Locally Enhanced Service scheme for learning difficulty! The receptionist at the practice claimed to have no knowledge of the practice's involvement in the scheme.

But there were more examples of positive services locally, especially through the agency of a specialist post.

We have invested in a Community Learning Disability Nurse, who has been in post since January 2005. She is doing all the work on Health Action Plans for these groups of service users, working with GPs, and also provider elements and exploring enhanced contracts for services for people with learning difficulties. She is also working with the local People First and users and carers.

Interface between primary and secondary care

Respondents identified the main responsibility for the physical health care of these groups of service users as primary care. For example one senior manager in the PCT said:

Specialist services should be there only to support users, carers and primary care practitioners.

Another said:

Primary care has the main responsibility for providing the physical health care for these groups and then where necessary referral to secondary mainstream health services. For us accountability is with primary care and is the ideal setting for this care.

A PCT manager said that:

Mainstream health services often say they are not equipped to deal with those who display bizarre or challenging behaviour. Where communication difficulties are severe, advocacy is key. In primary care there are issues of time restrictions when seeing patients. There is a need for practices to increase the time available for seeing these groups. Also the interface between primary and secondary mental health care needs to be improved. Named workers are key.

What's not going so well

What were the gaps and deficiencies in current practice and services that our sample identified? Training to improve attitudes of all staff was identified as a need. However one GP said:

These areas are not 'fashionable', at present, so there is little training for registrars and the areas are not covered in the VTS[?] schemes curricula.

The practice manager took a broader view and said that, pragmatically,

This is an incremental process, it won't all happen overnight. What and how we are offering physical health checks - CHD, asthma etc, - is a long job. We won't get through to all relevant patients in a few weeks.

Inaccessible information for people with learning difficulties was identified as a deficit. The local advocacy service said:

There have been a few referrals for exercise on prescription, but often there is no allowance made for the learning difficulty, so the information remains inaccessible.

The same person posed a query for the service:

People with high support needs and their carers both are in need of support. E.g. getting a multiply disabled person to the GP for an appointment seems to be asking a lot. Why can't there be home visits for this group? Or what about allowing District Nurses to provide a home visit for injections of medication?

Accuracy of information on patient groups was highlighted as something still in development. The community development worker said that:

Levels of difficulty differ, as does accuracy of information about these groups of users. For example Social Services has a register, but people don't have

to go onto it. People from other Boroughs can get treatment in this Borough and so they might not be on the registers either. An awareness raising event to share good practice on Learning Disability will precede a big push to get accurate registers. The hope is that this will encourage Learning Disability involvement in patient participation groups.

What can we learn from?

There were examples of practices that addressed identified concerns in this locality. The one mentioned most frequently, for people with learning difficulties, was the appointment of a specialist learning disability nurse. Almost everyone interviewed mentioned this person by name and it demonstrated the importance of resourcing specialist services.

A GP practice in the area is initiating the Health Plans with its learning difficulty patients so that when a person comes into surgery, the GP is proactively helping to establish plans. This investment and commitment is particularly telling as, on a population basis, there isn't a big issue with learning difficulty, only about 4/1000 head of population. GPs with a practice list of 2,000 people won't see many of these service users, so it can feel like an unimportant issue.

For mental health service users, the PCT has made a commitment to invest more in anxiety and depression and provide more talking therapies. They also have the resource to recruit several graduate primary mental health care workers.

Additionally, work is going on with practice staff to train them to recognise more common mental health problems such as depression associated with chronic physical health problems such as CHD or diabetes. This is being driven and monitored under the aegis of clinical governance in the PCT.

10.4 Site 3 – North West

Five interviews were conducted from this site.

Access issues

Uniquely for this locality we secured an interview with a GP and also a receptionist from the same practice. The GP said that identifying service users from our groups of interest was easily achieved.

Yes, for both MH and LD patients. Would do this by searching using a search system using 'medication' and 'diagnosis' and also brainstorming with the district nurse.

The receptionist however was not as confident. For people with mental health problems she said:

By talking at the desk - people are willing to give information at the desk when making an appointment. Also when I give out medication for a particular illness I can identify that it may be a mental health problem. We do have counsellors here so we do get people coming to see them. If people are disabled you see that.

She did not think she could identify people with a learning difficulty that easily.

Patients are very good at saying they can't write though. I would then make a mental note that that person can't write and wouldn't ask them in the future to write something down. Other than that I wouldn't be able to identify these patients unless I was told by other staff that the patient had a learning difficulty.

In terms of making an appointment, the GP said that he felt sure there are difficulties for people in deciding when to approach a primary care professional.

It depends on carers – this is more of an issue for people with LD – and on how familiar patients are with their primary care practitioners, how comfortable they feel approaching the surgery and how patients perceive the service.

The receptionist conveyed a sense of caring and compassion when she said that mental health service users didn't experience any difficulties in making appointments because of her patience.

I just bear with them if they break down which sometimes they do. If they do break down I will listen to them and give them comfort. I would try to make them feel at ease and then they feel they can carry on. I would reassure them that they are not being any trouble.

She added that learning disability patients sometimes ask friends or carers to make appointments for them or some people might ask for dialling help.

Once connected they will speak to the receptionist themselves. I am not aware of any other difficulties they may have.

The doctor said that he couldn't comment on people who did not make appointments and why there might have been problems, but the practice was exploring the possibility of an online booking system. But as he himself pointed out:

It does mean patients have to be reasonably computer literate to make an appointment via the web.

Getting to the surgery need not pose a challenge either. The receptionist mentioned that there was:

... a bus service to help people in rural areas. It brings people to appointments and takes them here or to the hospital. It is a good help to patients.

Once at the surgery for an appointment, waiting can be problematic. The GP acknowledged that due to the nature of this community where everyone knew everyone else, privacy and confidentiality were issues.

The receptionist was sensitive to these concerns.

I provide reassurance. I might take them into another room away from the front desk so they can have some space and not feel under pressure. Sometimes they find it easier to talk face to face away from everyone. I would ask if there was anyone else that I could contact for them to help but obviously would get their permission before ringing – confidentiality. I would also aim to get those patients seen as soon as possible so they don't have to wait around in the waiting room.

The practice manager from the second surgery indicated that identifying patients from these groups was unevenly developed.

We have a register set up for people with mental health problems using our system, but not for people with LD. We are however seeking to set up a register for the latter group. It shouldn't be difficult to set up. We can do this by altering our templates.

She also said that making an appointment was straightforward for both groups:

No problem with this - staff are trained to do this. They usually spend more time making an appointment for someone with a mental health problem or LD.

And she said that waiting times posed no identified problems.

What was the view from services outside primary care? A learning disability consultant psychologist had a mixed view.

About 10 out of 55 practices in this locality are working well with patients with LD, so still a minority. What makes a difference is a combination of local GPs who are champions, who might have had personal experience of LD, and good liaison between primary care and the local Liaison Nurse. She has acted as a catalyst locally.

A manager from a provider of supported mental health housing said:

The way GP services are structured make it difficult to communicate and share information with GPs or form relationships with them because of their perceptions of people with mental health problems. Our client group have a high incidence and prevalence of physical health problems. We see this through our outreach service - people live in poor housing which then impacts on their physical health. There are also lifestyle issues, like drug and alcohol that also contribute to poor health.

Staff attitudes

Once service users – and their carers – arrive in primary care services, what kind of experience do they have? As described earlier, the receptionist in one of the participating surgeries ensured that a person's experience was as helpful as possible. For people with learning difficulties:

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I would make sure to write everything down – for carers as well as ensuring verbal confirmation of next appointment etc is clear.

The doctor from this same surgery acknowledged that people's experiences while at the surgery could be challenging.

There can be difficulties in communication between the two groups. We have considered allocating times for specific groups - mainly for younger patients. However, this is difficult to do with people with these issues as it could be quite stigmatising for them to come.

He then provided a useful description of the local context and offered a broader view of communication issues.

You need to understand the area. The population is very homogenous, there are no ethnic groups. There is a very strong sense of community here. We are better able to meet the needs of these groups of people. It's not unusual to receive informal calls from a neighbour of someone with a mental health problem who might be unwell. We would act on these calls.

The practice manager from the second surgery said that communication with both groups of service users was good, no problems had been identified and that attitudes of clinical staff were not an issue.

The learning disability psychologist gave an overview of the local situation and said he thought that:

Basic access issues don't get addressed, primary care is quite passive, it is secondary care that makes the running. The PCT is only just getting to the point of identifying that learning disability is their business. Reliable identification of people with learning difficulties does not exist yet. There are no incentives via government and too much reliance on local knowledge of the population.

The mental health manager provided a different view of the impact of the local context on the experience of primary care.

We have people who self harm. GPs in our area (very rural) have a very traditional view of this. Self-harm is not viewed by the GP as a way of coping. Also, I have come across cases where people with borderline personality disorder are usually excluded or might be withdrawn from primary care services due to a lack of understanding by the GP about this condition.

Physical health issues

What physical health issues do people bring to primary care and are their concerns being taken seriously? A range of issues specific to either mental health or learning difficulty were identified by respondents, in addition to the usual complaints that anyone would ring to their GP.

For learning difficulty, distinct health concerns included:

... conditions like Prader-Willi [syndrome], a metabolic disorder that is associated with uncontrolled eating because the person never feels full. This condition leads to obesity and people have died from it due to lack of understanding of the processes and treatments involved. Incidence is about 1 or 2 people per 100k of the population. This condition can occur at any age, usually present early on in life, picked up in paediatric services but it is a lifelong disorder. Another condition is tuberous sclerosis and epilepsy are also common among certain learning disabled people and there are particular neurological events that can be observed.

More particularly, the learning disability psychologist thought that '*...there has been an underplaying of sexuality for people with learning difficulties*'. He also said that at both ends of the life course new physical health issues were emerging for these groups.

There are now more young people with complex needs, but at the other end of the life cycle there are more older people with learning difficulties. Until fairly recently learning disabled people in their 50s were seen as unusual, but no longer. People with Downs Syndrome are living longer, the implications for primary care services are immense.

The percentage of Black and minority ethnic people is low in this area and the learning disability consultant pointed out that:

Local services are not good at catering for these groups, they need to be sensitive to the specific physical health issues for different groups, to treat each person as an individual.

The mental health advocacy manager said that for his client group discrete physical health concerns included:

Long term health conditions that are disabling like diabetes, epilepsy, eye sight, teeth and feet - conditions that are a result of certain lifestyles that get exacerbated. There is also a degree of secondary infection among people who self harm.

He added that:

The area is geared up for older people as a lot of people come to retire in this area. So this social trend could have a positive impact on services.

Services & treatments for physical health issues

What sort of physical health services and treatments are on offer from primary care for these groups of service users? The GP discussed how a diagnosis might be made:

Depends on knowledge and skills of the GP. We have very good support from secondary mental health and learning disability services. We have a

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clinical psychologist who comes into the service on a regular basis as well as informal access to secondary services and specialists to talk to for advice.

He felt that diagnostic overshadowing was not a problem, but said that access to appropriate treatment for a physical health problem could in some cases be an issue.

For example, if someone has claustrophobia it may be difficult to send them for a CT scan. They probably wouldn't get into a scanner. Or a patient from one of these groups may decline referral for further tests or to see a specialist. Despite reassurances these patients don't easily 'submit' themselves for further treatment. Sometimes we even try to facilitate this to ensure that people go to their referral or have a test done.

The receptionist at this surgery said that there was limited health promotion information for either group of patients at the surgery, but they did refer people on to other appropriate services as necessary. For people with learning difficulties there is a specialist nurse who will see patients either at the surgery or at home, as required.

The GP added that the difficulty for patients was not about access to health promotion services, rather it is in:

...the uptake and in people with mental health problems and learning difficulties, understanding the full implications of what's involved.

Proper adherence to health promotion regimes meant more support for these groups and he acknowledged that more needed to be done.

The practice manager from the second surgery said that any problems with a diagnosis would lead to discussions with specialist services and that access to appropriate treatments was not a problem.

From outside primary care, the view on treatments and services available to these populations was quite negative. The learning disability consultant said that:

Specific projects have been set up e.g. breast screening, making accessible information available. However in things like smoking cessation and weight management, GP services are lagging behind in making accessible services available. People with milder LD may be able to access information and help.

He felt this was due to the PCT not prioritising or understanding LD issues.

The mental health advocate felt that his clients were not getting the physical health services to which they were entitled in primary care but they did receive them elsewhere.

The 'Health Action Zone' locally is doing lots of good work and a lot of health promotion. This ranges from smoking cessation to exercise etc. It actively involves local communities from the bottom upwards and has proved successful.

His service also supported clients in getting access to primary care.

He felt that this deficit had several causes.

Where signs and symptoms of physical health problems are hidden or less obvious GPs are not so good at detection. The system of access breaks down where GPs rely on patients to give an indication of their health problems. Lots of our clients use NHS Direct. The 24/7 cover makes a difference.

Interface between primary and secondary care

There were mixed views on where the prime responsibility for the physical health care of these groups of service users should lie. The learning disability consultant said that:

The majority of physical health needs of this group of service users are entirely the same as everybody else and primary care should be able to care for them directly.

However he went on to point out that:

What would be helpful for adults however would be a service more akin to that which exists for children with learning difficulties, i.e. a first step health service. These children are better catered for because primary care knows exactly who to turn to if there are problems or concerns, they have a better sense of where to refer with children.

He said that lack of knowledge and confidence about presenting issues and problems were the main obstacles to primary care fulfilling this role.

The mental health advocate thought that it wasn't clear that primary care was the main area where service users could get their physical health problems treated.

Some SHOs in the mental health system take an active interest in physical health checks and tests. GPs tend to see this as a mental health trust responsibility and vice versa. Physical health problems don't always feature in people's minds and a person's mental health is the primary focus. GPs don't take an active role in identifying physical health problems in people with mental health problems. Mental health services have a more active role in caring for people's mental health problems. There is no system in place that promotes healthy living.

What's not going so well

What were the gaps and deficiencies in current practice and services that our sample identified? The GP conveyed a sense that in general, the service offered by his practice was accessible and equitable. He did acknowledge that more could always be done to improve services. But he pointed out that half a day a month was allocated to training and that they had had an outside speaker come in to talk about mental health issues, but not yet learning difficulties.

The receptionist from this practice echoed these sentiments.

We supply quite a good service here. We try to remember people are ill, and we have to treat each person as an individual and take on board what they are trying to get across. Listening to what people have to say is important. Not interrupting them and putting your point forward.

The practice manager from the other surgery, who had consulted her colleagues before completing the interview, conveyed a sense that the difficulties in service provision were associated with the challenges of working with these client groups. However, there was no indication of whether or how the practice had tried to address these issues.

These groups have problems with taking medication, with understanding what to do and following the treatment regime. Often the practice professionals don't know if the person has followed the treatment.

The learning disability consultant felt that:

Valuing People was very weak, there is nothing in the GP Contract for people with learning difficulties, quite different from what's there on mental health. Have to rely on culture change, good will, education ... up to a point. There must be core health information, there is a need for a structural requirement, i.e. in the contract, to have input from specialist services etc.

However current reconfiguration plans in the locality could undermine progress that had been made in recent years, especially the establishment of good working links with the Primary Care Trust.

The mental health advocate said that:

The response from GPs differs according to their perception of the person's mental health problem. For example, they will respond differently to someone who self-harms or who has a diagnosis of personality disorder. It's largely because GPs lack an understanding of mental health and often form an opinion about that individual.

He went on to say that what would help is GPs acquiring

... a basic understanding of mental health problems not seen through diagnostic manuals (such as ICD 10) but based on people's experiences of having a mental health problem.

What can we learn from?

There was little sense from any of the primary care staff interviews of initiatives that were particularly targeted at our groups of interest.

In contrast, the learning disability consultant mentioned the excellent work done by the specialist breast screening nurse and said that there:

...is a need to be proactive with other nurses i.e. cardiac, cancer, so that they can replicate the breast screening model in other specialisms. The nurses are very 'can do'.

He also mentioned the impending co-terminosity of the PCT and Social Services which would make joint working easier and the good working links with the Director of Public Health at the PCT.

The mental health advocate had several illustrations of current and possible future practice that would enhance services for people with mental health problems.

The networks among GPs in the area are very good and the best way to change practice is through them rather than writing to GPs and asking them to change.

Impending improvements locally included:

[The Emergency Doctors on Call service] is being discussed. This will provide access to primary care services (duty GP) that is out of hours. Graduate mental health workers will be a good but a small resource. There will be a need to target staff in the practice (i.e. practice nurses) to have better training in using a more holistic approach to mental health.

He concluded by saying:

Mental health is never going to be a big agenda for primary care. Responsibility for the physical health care of these groups needs to be joint between primary care, mental health secondary care and other specialist health care services.

10.5 Site 4 - Wales

Six interviews were conducted from this site.

Access issues

What is service users' experience of accessing primary care services in this locality? The one GP interviewed in this locality said that identifying people with a mental health problem or learning difficulty was problematical because they did not have accurate ways to do so. In terms of making appointments, he thought people would be likely to have a problem in deciding 'Am I ill enough to see the doctor?' But there were no specific policies in place in this practice for mental health or learning difficulty.

He said that in terms of length of waits people from these groups were treated no differently from anyone else.

A local mental health service advocate said that accessing GP appointments was a problem for mental health service users. And a learning disability manager at the local council said

The 'Hearts & Minds' campaign was a pilot scheme that found vast undiagnosed need, but currently there is no facility to be proactive with these groups of service users.

A mental health advocate said that problems in accessing primary care and having one's problems taken seriously had resulted in some service users attending for appointments in England.

Staff attitudes

Once service users - and their carers - arrive in primary care services, what kind of experience do they have? The GP stated that

Previous knowledge of the reception staff, ... allows them to make allowances" [for these groups of service users but that clinical staff had] "...no specific training...

He added that diagnostic overshadowing was '...very common...'

A mental health community development worker corroborated this view.

People with anxieties in particular get dismissed. Once the GP identifies that the patient has a mental health problem their physical health is not taken as seriously. Sometimes this can result in referrals to secondary mental health care, to get them screened for any mental health issues before their physical health is taken on board.

A joint commissioner added:

Mental health is not 'core business', GP trainees do not take up rotations in psychiatry in very large numbers, GPs are anxious about dealing with mental health problems. These patients are perceived as 'heartsink' people.

For people with learning difficulties, the perception was similarly downbeat.

A cardiac problem would probably be treated the same, but a person with learning disability might not even get to the hospital for treatment – they would be very reliant on a carer. If that person doesn't recognise the symptoms, then the service user is in a very vulnerable position. The GP or other primary care practitioner can only work with what they are being told. If a carer doesn't recognise symptoms etc then it's hard. A nurse might pick up on things but again it's hit or miss.

A learning disability manager from the local council said that:

People with learning difficulties get a raw deal, there is lack of understanding and communication with these groups of people is poor and under-developed.

Physical health issues

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What physical health issues do people bring to primary care and are their concerns being taken seriously? The GP said that all the chronic health complaints with which a person might present to primary care, such as diabetes, obesity, cardiovascular or respiratory problems all had worse outcomes amongst these groups of service users, and thought this was due to '*...lifestyle and perhaps biochemical...*'.

A community learning disability manager had more specific views on this topic.

Service users are more prone to health problems across the board and this is partly the nature of having a LD and partly lifestyle issues. E.g. epilepsy is more common in this group of service users...

A council LD manager said that alongside the usual physical health complaints anyone would bring to primary care,

Additional issues are e.g. Downs Syndrome has increased incidence of heart disease; Atlantoaxial instability (first two vertebrae); early onset Alzheimer's (late 40s, early 50s); non-ambulant people get constipation more readily.

A manager from the learning disability team added that there were specific gender issues for people with learning difficulties:

Breast and cervical screening don't offer adequate services, service users don't understand the procedures, health screening, Well Man clinics, information that is provided isn't appropriate. LD services are perceived as whole person care - all singing, all dancing - preferable to enable service users so that they can access the services they need and establish systems to identify problems.

For mental health service users, additional physical health concerns included:

Anything from the side effects of new drugs such as Olanzapine through to comfort eating and links with diabetes. Smoking, healthy living, lack of exercise - how do you tackle all these issues when there is a dominant issue with e.g. depression?

The mental health nurse expanded on specific areas of concern:

In this locality Black and minority ethnic groups are widely dispersed and there is no cultural mix. Hence understanding of the needs of asylum seekers or refugees is very low and there are no discreet services for these groups. However, there are pockets of people from these groups clustered around certain primary care services. There are no interpreters or translation services available. Where these services are available they are expensive and have to be brought in from England most of the time.

He went on to describe what for him was one of the most pressing local issues:

The worst access problems to primary care are for Travellers. There is a good outreach scheme locally to try and engage Travellers, for mental health

problems. The LHB has recognised that Travellers have the highest risk for a range of both physical and mental health problems - mostly because of the high rates of alcohol and drug use. Travellers have a real dislike for authority and there are big problems where letting health professionals on site are concerned. Needs long term working to get them to engage.

Services & treatments for physical health issues

What sort of physical health services and treatments are on offer from primary care for these groups of service users? Several respondents mentioned the 'Hearts & Minds' initiative from the Welsh Assembly Government, but the view was not always positive.

Some elements have been implemented, mainly those with soft targets like dance classes or exercise. And allowances are not always made for different groups, i.e. accessible information.

A local mental health advocate was more critical.

It has been very difficult to engage local GPs with the 'Hearts & Minds' campaign, there was an expectation that the Local Health Partnership would spearhead the work and they could play a more passive role

Health promotion advice does not seem to be available for these groups of service users and this was a view shared by all respondents. The GP said that advice was '*... offered less or the same, but patients need it more, so relatively offered it much less...*'. He went on to say that '*Interventions are offered opportunistically, and when written to and invited, they rarely attend*'.

A manager from the community LD team said that, as regards health promotion advice,

It depends - a service user who is a heavy smoker may receive advice - but the information will not be tailored to be accessible - mainly written information which is not helpful for these groups of users.

He went on to say that:

Unmet health needs continue to be a problem, i.e. people who have not had a hearing test for 20 years, no blood pressure or weight checks, no health screening of any kind, no medication reviews

A joint mental health commissioner painted a similar picture for these groups of service users. He had:

'... the impression that local primary care services are not really engaged with health promotion for mental health service users'.

A mental health nurse added:

I think that for primary care, the priority is with their mental health, particularly with such limited time available. Their physical health would be overlooked in this situation. Stigma also plays a part in this too. When I was a student I read that 90% of people with mental health problems smoked, but this doesn't seem to be an issue for primary care.

From the one GP interview, diagnosis of physical health problems seemed to be deficient. For mental health service users he said:

I forget to use screening questionnaires, although I am aware of them.

And for LD he stated it was:

Difficult to make diagnosis, and I am unclear as to the various diagnostic sub groups - there is an enormous range in variation of learning disability.

He claimed that access to appropriate treatment for a physical health problem was less than the rest of the population as mental health service users were usually seen in secondary care and added:

Seeing psychiatrists on a regular basis jeopardises their physical health, as the psychiatrists are less likely to be able to manage successfully their physical health needs.

He said he was unable to generalise about referrals to specialist services for physical health treatments as each patient had very individual needs.

The mental health advocate gave examples of local service users who had had physical health problems ignored by primary care because of diagnostic overshadowing. In one case this had resulted in the person suffering a heart attack for which they were rushed to hospital and finally received treatment.

Similarly, diagnostic overshadowing for people with learning difficulties could result in sometimes quite straightforward problems could be missed.

A person who had wax in their ears finally got them syringed and they didn't need either eyeglasses (kept falling over because loss of balance) or hearing aid (couldn't hear because of blockage). He might have ended up being labelled non-compliant and having challenging behaviour when in fact it was a physical health complaint.

Interface between primary and secondary care

Not all respondents in this locality thought it was clear that primary care should be the first port of call for service users in these groups. Some were. For example a manager from the community LD team said '*It should always be primary care services*', but he went on to say '*...it's not happening either because of poor access or poor communication skills by service user and also practitioners.*

A mental health commissioner echoed these views.

It should absolutely be primary care. So what if a person has a mental health diagnosis?

But he added:

The twin issues are the difficulty in engaging by GPs and the fact that some mental health service users are not easy people to deal with.

A mental health nurse however felt that primary care itself was not clear that theirs was the main responsibility for physical health care for these groups.

Less clear with the NICE guidelines where physical health care is meant to be addressed within secondary care services. There was an assumption in primary care that it was their responsibility, but the views are mixed.

Several respondents mentioned a pilot scheme that employed a specialist LD liaison nurse who:

...acted as a link between primary and secondary care. There were no diagnostic codes so she went through the caseload manually, got to know the population, knew who was registered where and started pulling people in for health checks.

That post had now ended but a bid was up before the LHB to extend and maintain such a role.

What's not going so well

Respondents mentioned a number of the gaps and deficiencies in current practice and services in their locality. The manager from the Community LD Team said that:

A particular issue is the treatment of epilepsy. This is a chronic condition for PWLD, there is high mortality rate attached, and provision of local resources is poor. Epilepsy care is a postcode lottery. Up to half the population has epilepsy; one in five people with MILD LD has epilepsy and it is of the refractory type i.e. it doesn't respond to treatment; six in ten people with SEVERE LD also has epilepsy and less than 10% respond to current treatment. The key treatment options are surgery (vagal nerve stimulation reduces fits by half) or removing tumours. PWLD aren't even assessed for surgical options.

He added,

Another issue is combined MH + LD, very complex conditions and there are no local services, people get sent a long way away with all the implications for continuity of care and getting support from family and friends.

Within mental health a number of gaps had been recognised.

There is a need for primary mental health services, with graduate workers who are qualified psychology or psychiatry professionals - CPNs, ASWs,

Psychologists. Locally Enhanced Services might have a role to play, but such a development also sends out a signal that mental health is not core business.

A mental health commissioner said that:

GPs and other primary care practitioners can be facilitated to 'hold' people by having primary mental health care teams that can run clinics, supervise primary care practitioners and support patients to recover. For example people with OCD can work with a psychologist and can improve and be helped to recover.

The mental health nurse talked about the structures that can impede effective and timely physical health care for service users.

There is still a fair gap between secondary mental health services and primary care. No partnership exists and there is a lack of willingness to work together on matters relating to mental and physical health. There have been services where nurses from secondary care have been allocated to practices. This link person did attempt to make contact with GPs but very few invited them to be involved in the practice. In this sort of situation the GPs usually want to 'own' such staff and manage them and secure these sorts of resources for themselves. GPs prefer in-house CPNs or OTs etc. Trying to get a room in the practice to do liaison work is very difficult. There is a political disincentive for psychiatric staff to work in primary care because GPs want to manage/own them.

The GP interviewed remarked that he needed '*... more time with patients...*' and added that '*A nurse practitioner for patients in the community would be very helpful.*'

What can we learn from?

There is some good practice in this locality and, even if it is underdeveloped, it has created a basis from which to move forward. For example, the specialist nurse was cited in several instances as a '*can do*' sort of person who made a significant difference to PWLD care and treatment.

The nurse pilot scheme had a significant positive impact and undiagnosed chronic conditions were successfully treated.

Currently the Local Health Board is considering a proposal to reinstitute this scheme.

By March 2006 there will be Section 31 arrangements in place between health and social care in this locality [two local health boards and two councils]. These arrangements allow for joint appointments and budgets between the NHS and local government. The LD commissioner said:

There is optimism that the S31 arrangements will provide the opportunity for more open communication between health and social care. There will be unified assessments and the best person for the role will be appointed as key

worker and will be tasked with sharing information with all key practitioners for each person.

A mental health commissioner said that:

The GMS contract has introduced incentives for primary care to introduce physical health checks for people with mental health problems; it has made this work core business for GPs.

And the mental health advocate said that user and carer involvement on the Local Health Partnership Board had had an impact on a range of issues associated with mental health problems.

10.6 Key themes

The data from these interviews were collected and analysed within the framework of a series of themes that also informed the interview schedules. These were drawn from a framework - Stages of the Journey - that the Disability Rights Commission suggested to us. Certain themes, common to both people with mental health problems and also those with learning difficulties, emerged from the interviews in all the sites. There were also matters specific to each discrete group. Both these sets of issues are detailed below.

What becomes clear looking through the data is that the view of all these areas differs depending on whether you are answering as a primary care practitioner or staff member, or as a *'fellow traveller'* in commissioning, advocacy or secondary services. There is no one truth, but the reality of service users' lived experience lies somewhere between these differing perspectives.

Access issues

Information systems to identify both groups of service users accurately are extremely variable. There seems no one reliable way of doing this and we had examples that ranged from utilising Read Codes by GPs to *'just knowing when someone is disabled'* from practice staff. Specialist staff from both learning disability and also mental health services described how they manually matched GP records against people registered with their services in order to build an accurate picture of the population of interest.

There was a clear reliance on carers - both formal and informal - as primary care access enablers for people with learning difficulties and also for people with enduring mental health problems who lived in supported housing. A need that emerged from the interviews is training for carers so that they can recognise when someone they are supporting needs to see the GP for physical health problems.

The physical fabric of buildings was clearly an issue for both groups of service users. Some GP practices are in buildings which do not allow for disabled access, or within the surgery itself consulting rooms are situated up flights of stairs. There is often insufficient space to allow for the privacy that some service users would value. Many of the primary care managers with whom we spoke were aware of these issues as presenting obstacles to equitable access.

Specialist health staff such as learning disability (LD) nurses or Community Psychiatric Nurses (CPN) also played significant roles in enabling access for these groups of service users. The Specialist LD posts tended to be short-term contracts or funded through non-recurring monies such as Health Action Zones, whereas the CPN posts are integral to and embedded within psychiatric services. The disparity between these two services demonstrated the need for the extension of specialist learning disability expertise within service delivery in localities.

Staff attitudes

The subtext from the interviews with primary care staff and practitioners was a mix of fear, anxiety and some impatience combined with paternalism and kindness. Even though some of the interviews described the provision of awareness training in both mental health and learning difficulty, there was still a sense that patients from these groups were like time bombs ready to go off at any moment '*... get people in quickly...*'

Time available to see patients once they had an appointment was a recurring issue. Carers and advocates mentioned the speed with which people were seen and treated, which did not allow for proper understanding or getting to the root cause of a physical health problem.

Doctors talked about 'heartsink patients' from these groups, but there were also compassionate comments that acknowledged that people attending primary care should not have their lives made more difficult by that experience.

Some practice staff expressed bewilderment as to why there should be any issues for people with mental health problems or learning difficulties getting their needs understood. This view came from staff who are doing their best to be kind and considerate, but it could create problems for people trying to make an appointment or getting their needs met once they are attending for an appointment.

The lack of understanding of the fundamental problems some service users might face is not an implicit criticism of values; rather it illustrates the need for regular, relevant, timely awareness training for all primary care staff so that the stigma surrounding the treatment of these groups of patients, and perhaps unwitting discriminatory behaviour, could be eliminated.

On a more positive note, it was clear from the interviews that there are many champions among GPs and other primary care staff, who are prepared to 'go the extra mile' for patients from these groups. In the main, these champions have one common trait – they all seem to have personal experience of either mental health problems or learning difficulties in their families or from within their social networks. They are a vast untapped source of expertise and they convey credibility as they work within primary care.

Physical health issues

In the view of those outside primary care services, diagnostic overshadowing was a significant obstacle to people with learning difficulties and also to those with mental health problems in getting their physical health concerns taken seriously in primary

care. A person's mental health or learning disability diagnosis often impeded a determined effort to explore and address a physical health complaint. We heard many stories of a range of conditions being missed or overlooked, often with profoundly negative consequences.

There seems to be a self-fulfilling prophecy on the physical health care of these groups of people and to a certain extent it is associated with accuracy of identification. We heard from practice staff that detection of these groups of people relied on a mixture of local knowledge and use of coding systems. However the precision of these methods was in doubt; particularly we heard from secondary care and advocacy agencies that they had service users on their books who were not so identified within primary care.

All of this would have no more than academic interest if it were not for the implications. Poor identification results in assumptions of low prevalence of people with certain conditions. Assumed low prevalence translates into no investment of either time or finance in making a service more user-friendly for these groups.

Most of the discussions about people with learning difficulties were skewed towards more severe or complex needs. It was acknowledged that people with more mild learning difficulties might be able to access services, for example health promotion information. But as practices' abilities to identify this group were so under developed, it was difficult to know if and when the practice would know they had such a person attending for care.

There was a realisation among primary care practitioners that they did not have specialist skills in learning difficulties or enduring mental health problems. However in the former instance, low prevalence was given as a reason for not acquiring the knowledge and skills – they might never be used.

The most recurrent theme to emerge in learning difficulties is the demographic trend toward this population living on into later life. In the view of many of our sample, the social and service implications of this trend have not even begun to be addressed.

Services & treatments for physical health issues

The nature of primary care, with its emphasis on limited time available for appointments, combined with the paucity of specialist skills in mental health and also learning difficulty, militate in many instances against a satisfactory outcome for these groups of people. Even though medical practitioners are aware that health outcomes are worse across a range of indicators for both groups, there is a very passive attitude to health promotion.

In almost all interviews with primary care staff we heard about patients from these groups who don't follow advice as given, don't attend for appointments and who can't cope with the implications of the advice they have been given. There did not seem to be any strategies in place to support these groups to follow any advice or guidance they might have been given.

More than once the ad hoc nature of care was drawn to our attention and we heard about very good practice as well as practice that left much to be desired. People talked about '*...the luck of the draw...*' with their GP.

Even with the development of primary care organisations - trusts in England and local health boards in Wales - individual practitioners tend still to have an individual, client-centred approach. Although this is perfectly logical - after all the GP-patient relationship is an individual one and can span many years - it may not take into account the broader contextual picture in a given locality.

Some of the good practice described to us was taking place beyond individual practices. For example clinical support networks on relevant themes or Local Strategic Partnerships that included active service user involvement or drop-in centres run by local voluntary organisations seemed not to make as much of an impact on individual practitioners as discrete clinicians like specialist nurses.

Interface between primary and secondary care

By far the majority of interviewees said quite categorically that primary care should be first port of call for these groups of people when they have concerns about their physical health. But there was also an understanding that primary care is faced with a plethora of demands from all of its patients. That, combined with lack of specialist skills and confidence working with these groups, meant that in many cases primary care was quick to offload people onto specialist services.

From their perspective both specialist mental health and learning disability services were happy to both provide services and also to enable their clients to get access to primary care. In addition we heard about partnerships between specialist statutory and voluntary services, both to provide services and actively to enable service users to use primary care. The alternative was that clients did not receive the care they required.

However, structural change within primary care was perceived both as undermining good practice and as threatening established links. We heard examples of CPNs being allocated to primary care practices and then being removed when PCTs were established - thus breaking effective contacts. We also heard of developing associations between PCTs and specialist learning disability trusts that could be undermined by imminent changes to the configuration of PCTs in the next year.

Closing the gap

There is a clear-cut perception gap between primary care practitioners and staff and not only people with mental health problems and learning difficulties who use services, but also a range of key stakeholders in primary, secondary and voluntary sectors. The former have a sense from their individual interactions with their patients that they are providing as good a service as possible, but the latter think that services could be much improved, even allowing for multiple demands on primary care.

Communication was one of the most significant issues for care and treatment in this area. GPs and practice staff do not always have the skills or time to find out what

people's needs and concerns are. We heard from more than one practitioner that service users from these groups are hard to communicate with. Even if that is the case - and there were managers from advocacy agencies who said this could well be true - it is the role of practitioners to ensure that they can really engage with all of their patients.

At the very least it is incumbent that primary care acquires the specialist knowledge on specific health conditions for these groups, i.e. epilepsy, heart disease and Downs Syndrome etc for people with learning difficulties; and especially about physical side effects of long-term medication and effective lifestyle advice for mental health service users.

The implication here is not that every primary care practitioner should become a specialist in learning disability or mental health. Rather there should be more emphasis on partnerships that work to the benefit of these groups of service users, at individual clinical network level right through to the range of strategic groups that exist in all areas to improve the commissioning and delivery of services.

At the very least primary care practices should avail themselves of local knowledge on good practice in mental health and learning difficulty through their own management structures such as Professional Executive Committees. On a national level websites such as www.networks.nhs.uk exist to provide easy access to online discussion groups on a range of topics with relevance to these groups of users.

What emerged clearly from the data was the importance of local champions - specialist LD nurses, GPs with experience of mental health issues, service user involvement on partnership groupings. Change will not all occur at once, but there is much good practice to build on. There is also an immense commitment to providing a good service by primary care and it is because of this that there are so many examples of innovative service delivery for both groups.

Champions can lead by example, not only in their own localities but nationally. Publicising good practice through relevant local arrangements and sharing process, input and outcomes can go some way towards alleviating understandable concerns about overload.

Primary care managers also have an important commissioning role for services for these groups of service users. They are in a position to look more broadly for examples of interesting and effective practice. Partnerships between primary care practitioners and their own colleagues, for example in public health or social inclusion, have the potential to not only improve service design and delivery but also to enhance the interface between practitioners and their patients who use mental health or learning disability services.

More than once we heard that perhaps there is a need for a new GP contract with incentives for learning difficulties similar to those for mental health. Certainly the requirement in the GP contract to establish registers of people with enduring mental health problems and offer these groups health screening and special physical health checks could perhaps already be bearing fruit.

11 Discussion

11.1 Overview of the study

This study makes an important contribution to the debate on the physical health care of people with a mental health problem and people with learning difficulties. Its strength lies in the use of a multi-method approach and different data sources, to cover a broad range of groups and key issues. We have confirmed some of the health inequalities that currently exist and evidenced in previous work. We have also shown some encouraging results that point to positive changes in primary health care for people with a mental health problem. No doubt the nGMS contract has in part led to these changes. However, there are still considerable improvements to be made in access to primary care services for people with learning difficulties. Health prevention advice/intervention is a key factor for both target groups which needs further emphasis and development. The solutions found in good practice examples emphasise the need to champion the cause of the target groups whose role is focused on meeting their physical health needs.

11.2 Limitations of the study

It is important to be aware of the limitations of the study when interpreting the findings presented. GP datasets, although they provide a wealth of information concerning the amount of primary care services delivered, can also raise concerns about its accuracy. For example, identifying the target groups was difficult and it is uncertain as to the numbers of people that were not picked up and probably registered elsewhere, particularly for people with a SMI. Due to the poor recording of ethnicity within GP datasets we were unable to report differences according to these groups. Including two diagnostic groups (i.e. people with psychosis and people with bipolar disorder) to form the SMI category is problematic in terms of generalisability. However, we restricted both our mental health groups to those with a psychiatric diagnosis and not all those receiving psychotropic medication. A great number of statistical tests were performed where the number of people being examined was small. Caution needs to be exercised when making decisions about the significance of some findings. However, we were able to account for any differences that could be explained by age, gender and in some analyses locality. Although where relevant we performed separate analyses to identify any notable age and gender differences in the provision of primary care services for physical health problems in the target groups.

Findings from the qualitative part of the study also need to be interpreted carefully. Our mental health service user consultants and researchers with a learning difficulty encountered many difficulties in identifying and organising focus groups and interviews. Covering the broad range of groups (i.e. different age groups, Black and minority ethnic groups, people in forensic settings etc.) was problematic and exacerbated by current research governance rules and regulations when accessing vulnerable groups for research purposes. The selection of practitioners and senior managers was constrained by time and was subject to those who agreed to be interviewed.

11.3 Conclusion

A focused approach leads to positive results. This is no less true for addressing physical health problems among people with a learning difficulty and those with a mental health problem. Good communication skills, the provision of appropriately formatted and accessible information, taking the time to understand the person's requirements, listening, and exercising sensitivity are especially important for these groups. Good practice examples show how championing the cause of people with a mental health problem or a learning difficulty can have an enormously beneficial impact on the physical health needs of these groups. Making these positive examples both permanent and widespread is the next challenge.

11.4 Further research

There are at least two key areas that would benefit from further research. These include:

- a longitudinal study to examine the physical health outcomes of the target groups for specific health problems presenting to primary care; and
- to identify and evaluate appropriate primary care health promotion advice and in particular interventions to improve the lifestyle of people in the target groups at greater risk of developing a major disease.

12 Recommendations

We suggest a number of recommendations based on our findings and suggestions from focus group and interviewee participants.

12.1 For GP practices

- GP practices should consider developing a **protocol** for supporting people with learning difficulties and people with mental health problems to get the most from their GP practice. This might include:
 - for people with learning difficulties and mental health problems to be treated with respect by all GP practice staff and by other patients using the practice;
 - to provide information about people's right to re-register at a different practice and about how they can go about doing this;
 - to provide people with clear information about what they should do if they need to contact a medical practitioner out-of-hours.
- Ensure that people with learning difficulties and people with mental health problems are encouraged to attend regular preventative health checks, perhaps every six months or yearly.
- For GP practices to move away from crisis intervention towards promoting physical well being and disease prevention. In addition people should be encouraged to visit the GP to discuss health questions prior to them becoming unwell to move away from only visiting GP practices at times of ill health or physical health crisis.
- Flexibility and support with booking appointments. Support for people with learning difficulties to be as independent as possible and make their own appointments, e.g. providing people with one number or one contact name.
- Awareness that some people with mental health problems might not want to explain their mental health difficulty to reception staff or in front of other patients sitting in a waiting room.
- Reduced waiting times for those who find it distressing. In addition a system by which reception staff regularly inform patients about the length of time they are likely to have to wait.
- Simplification of the repeat prescription process. To reduce length of time waiting and number of journeys.

- Posters and leaflets about physical health conditions provided in accessible formats including the illustrative use of pictures and photographs. For medications to be labelled in an accessible way so that people with learning difficulties can understand them.
- For GP surgeries to develop so that they are seen as a resource i.e. a place where people can borrow books or videos on health issues, pick up relevant and accessible leaflets and find out information about other related local services such as those providing support with health promotion activities.
- Ensure there are good links with PCT/LHB initiatives such as clinical networks.
- Ensure that there is well-developed knowledge of and links with the specialist secondary sector in health and social care and also with the voluntary and community sectors.

12.2 For primary care practice staff

- GP practice staff, including reception staff, GPs and nurses should receive **learning difficulty and mental health awareness training**, ideally from trainers who have learning difficulties themselves, mental health service user trainers and carer trainers.
- This training should provide GP staff with an opportunity to gain a broader awareness of what it is like to live with a learning difficulty or mental health problem, or to support someone who does. In this way GP staff can be encouraged to consider how they might more easily support people to use their surgery and to get the most from consultations.
- A large component of this training would focus on the need for practice staff to get to know patients on an individual basis and to develop their communication skills. Skilled communication is particularly important for effective and respectful communication with people with learning difficulties.
- Staff should also be made aware of the ways in which the physical health problems of these two groups of people are frequently overshadowed by their learning difficulty or mental health diagnosis.
- Staff should be encouraged to actively support their patients to identify and express their physical health care needs and to be involved in decisions about their treatment options.
- For GP practice staff to support people to access their test results and to be clear about what the next steps are following referrals to specialists.

12.3 For primary care practitioners

- For primary care practitioners to continue monitoring the health of people with a mental health problem, but to also focus efforts on those with a learning difficulty.
- To consider more effective health promotion advice and seek appropriate interventions to improve dietary habits and encourage smoking cessation.
- More awareness of weight gain in people receiving atypical antipsychotic medication.
- For doctors to be aware that people with learning difficulties and mental health problems sometimes find it difficult to advocate for their own physical well being due to communication difficulties or lack of self esteem and confidence.
- Ensuring that medications are reviewed regularly and thoroughly and that doctors are vigilant when signing repeat prescriptions.
- Raising awareness that these groups of people are often taking numerous medications for different conditions and that these medications can negatively interact or be contra-indicated for other conditions they might have.
- For doctors regularly and proactively to ask patients about any side effects they might be experiencing and to explore lower doses or alternatives.
- For GPs to signpost patients and their carers to appropriate health and social care services.
- For doctors to actively support people with learning difficulties and mental health problems to quit smoking, eat more healthily, lose weight and take up exercise.
- For doctors to actively monitor the health of their patients. To find out whether the treatments or interventions, including health promotion advice or interventions, that have been offered or prescribed have been helpful or not.
- Take advantage of existing pools of knowledge on good practice available electronically such as those on www.networks.nhs.uk.

12.4 For people with learning difficulties and with mental health problems

- For **guidance** to be provided to people with learning difficulties and people with mental health problems, and those who accompany them, to enable them

to get the most out of their visits to their GP practice. This might include the following suggestions:

- people with learning difficulties, people with mental health problems and their carers should consider ways in which they can be more active and assertive in ensuring that their GP practice meets their health needs or those of the person they are caring for;
- greater active engagement with GP practices might involve taking time before a visit to the GP to think through what issues they would like to raise and what types of treatments they would like to be offered;
- that people with learning difficulties or mental health problems consider taking someone along with them to support them during their consultations if they feel they are not getting what they require from their GP practice;
- the people accompanying them should always ensure that prior to a visit, a full explanation and discussion takes place so that the person knows what is going to happen, who is going to talk and that both people are aware of the issues and questions that need to be raised.

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14 Appendix 1. Read Codes used for GP Dataset

Patient identifiers

- MIQUEST unique identifiers
- Year of birth
- Gender
- First part postcode
- Ethnicity

Read coded variables

1. Diagnoses

- Ischaemic heart disease (earliest date recorded)
- COPD – respiratory disease (earliest date recorded)
- Cerebrovascular disease – stroke (earliest date recorded)
- Psychiatric disorders (earliest date recorded)
- Learning difficulties (earliest date recorded)
- HIV/AIDS (earliest date recorded)
- Hepatitis (earliest date recorded)

2. Psychotropic medication

- Antipsychotics, depot and non depot treatments (latest, date and value)
- Antidepressants (latest, date and value)

3. Screening and prevention

- Systolic blood pressure (latest, value and date recorded)
- Diastolic blood pressure (latest, value and date recorded)
- Height, weight and body mass index (latest, value and date recorded)
- Viral hepatitis and HIV (latest and date recorded)
- Tetanus and flu vaccination (latest and date recorded)
- Cervical smear and mammogram (latest and date recorded)
- Urine analysis (latest and date recorded)
- Statins (latest date and value)
- Serum cholesterol (total and LDL) (latest date and value)
- Smoking code that implies current smoker (date given)
- Smoking code that implies non-smoker (date given)
- Diet and smoking advice (date recorded)

A full list of the Read Codes used is available upon request.

15 Appendix 2. Report by Central England People First for the Sainsbury Centre for Mental Health

“A look at the physical health problems in people with learning difficulties and people with mental health problems and the service we receive from their General Practitioner (or doctor).”

15.1 Introduction

Central England People First were asked by the Sainsbury Centre for Mental Health to do some research on their behalf, on the above project.

We have experience in this area and thought that our role would be quite straight forward.

The time that the project had to be completed in did seem short. As people with learning difficulties ourselves, we know that people with learning difficulties need more time to understand things. However, we did feel we could do the research within the time given.

15.2 Our brief

- We were to hold a small focus group to help identify good questions for the research.
- We were to have a say in the questions and the postal questionnaire.
- We were to receive names of places to hold focus groups and do the research.
- We were to have a say in the final report.

15.3 How we got on

The first part went very well. We held a focus group and had a say in the questions in the time allowed.

However, we then had several hurdles to overcome.

The first of these was the red tape involved. Having to have honorary contracts and even a second police check, in one area, meant that we had to wait to arrange the focus groups.

The next problem was that we were to contact people ourselves to find focus groups. We found this difficult because

- i. As in other research projects we have done, we sometimes are not taken seriously because we have learning difficulties.
- ii. The short amount of time meant that our contacts found it difficult to get in touch with enough people to form a focus group. This was because they were busy themselves.
- iii. In one area a similar project had held a focus group recently and people did not want to do the same thing twice.

- iv. Our time input in the project grew and grew. This was because of the problems we were having getting the groups together meant that we spent a lot of our time chasing up people on the phone, by e-mail and by fax.
- v. We also had a problem with the consent form when we went to a sixth form school. We were delayed as we sent ahead the consent forms. But these had to be redone to suit younger adults. This was not difficult but caused a time delay.
- vi. Because of the difficulty in getting groups together we found that we could not organise focus groups in the same area at the same time. This meant going to the same areas in different weeks. This caused more time to be used.

However, we did find some contacts who went all out to help us and make things happen.

All the people who took part in the research were very helpful.

The Sainsbury Centre for Mental Health were very supportive.

15.4 How we did the research

We started by chatting to people and putting them at ease.

We always went through the information again to make sure that everybody understood everything. Where this was not possible we all ways made sure that the parent or carer were clear on our approach about talking to the individual.

We always went through the consent forms. On two occasions we were asked not to use a tape recorder.

The questions were directed at the people with learning difficulties even when the parent or carer was going to answer.

We did finish early on a couple of occasions as people had had enough.

We always checked to see if people had had their say.

When we had finished we made sure that people were comfortable with the experience before giving them their money.

For some people it was a large amount of money for them to get. Most people were very pleased with the amount.

However, on some occasions we got the feeling that some people were there just because of the money.

Ian Davies
Supported by Joan Walker
October 2005

16 Appendix 3. Tools used in focus groups, interviews, and the postal survey

16.1 Topic guide for focus groups/interviews with people with mental health problems

AIMS

Examine service users' experiences of accessing help with their physical health problems from their GP surgeries:

- *What have they found helpful?*
- *What have they found difficult?*
- *In what ways could primary care services better meet their needs?*

TOPIC AREAS (Brief topic guide)

We are interested in hearing about people's **positive and difficult** experiences.

We are interested in finding out if people feel they are **treated differently** to those without a mental health problem.

1. When accessing your GP practice, what is your experience of:

- making appointments
- travelling to GP practice
- accessing the building
- reception
- the waiting room

2. What is your experience of getting help from your GP or nurse about your physical health problems?

- support to attend
- *talking with doctor or nurse
- info received
- review of medication – drugs for physical health problems
- review of medication – side effects of psychiatric drugs
- referral to specialists

3. What is your experience of being supported by your GP practice to attend health checks?

egg blood pressure, urine tests, breathing / peak flow tests, smear tests, checks of lumps on breasts, pre-natal checks (last 3 – women only)

4. What is your experience of receiving health promotion advice or interventions?

egg for smoking, healthy diet, weight loss, alcohol consumption, exercise

5. What was your experience of registering with your GP?

- including any experience of attempting to change GP or being taken off GP list

6. Do you have any suggestions for ways in which your GP practice could help you more in the future?

MORE DETAILED TOPIC GUIDE

1. Accessing GP practices

- **Making appointments:** phoning GP practice; who makes phone call; how quickly get appointment (nurse and doctor); how easy to make appointment with particular doctor or nurse prefer to see
- **Travelling to GP practice:** own transport; public transport; rely on someone else – who
- **Accessing the building:** any adaptations to building for people with physical impairments or difficulties
- **Reception and waiting room:** reception staff; posters displayed / leaflets available; length of waiting time; environment

2. Consultation

- **Support to attend:** see Dr or nurse alone or accompanied by someone else
- **Communication with Dr or nurse:** listened to; respected; heard; adequate length of time; language used; involvement in decision making; any differences between way treated by Dr and nurse
- **Information provided:** leaflets about condition; leaflets about medication and side effects
- **Review of medication for physical health problems:** how often; involvement in decision making
- **Referrals to specialists** egg hospital consultant or specialist clinic: length of wait until appointment with specialist; communication about appointment with Dr or nurse; any information provided about referral

3. Health checks

egg blood pressure, urine tests, breathing / peak flow tests (for chronic obstructive pulmonary disease or asthma), smear tests, checks for lumps on breasts and pre-natal checks (last 3 – women only)

- **Checks undertaken during routine visits** to Dr or nurse
- **Reminder letters:** letters received; language used; your response to letters; support to respond to letters from anyone else egg mental health workers, friends or family

4. Health Promotion

egg smoking, healthy diet, weight loss, alcohol consumption, exercise

- **Information and advice:** verbal / written; you ask for it; it given to you by Dr or nurse; language used
- **Interventions offered** egg prescription for exercise, appointment with nutritionist, smoking cessation groups or advisors: experience of these interventions

5. Registering with GP

- Any difficulties encountered when attempting to register with GP practice or change GP practice

6. Suggestions for improvements

- Any aspect of their contact with their GP practice

16.2 Focus group questions for people with learning difficulties - compiled by Central England People First

1. Do you have a doctor that you see?
2. How many times have you seen your doctor in the last year?
3. Who makes your appointments when you want to see a doctor?
4. Is it easy to get an appointment when you want one?
5. How do you get to your doctors when you need to go?
6. Is it easy to get to your doctors?
7. What is the building like that you see your doctor in?
8. Is the building easy to use?
9. Can you understand any of the posters or leaflets in the waiting room?
10. Do the reception staff talk to you in a good way?
11. Do you have to wait for a long time in the waiting room?
12. Do you see your doctor on your own?
13. Does your doctor talk to you?
14. Does your doctor listen to you carefully and take your views seriously?
15. Does your doctor talk to you in a good way?
16. Does your doctor tell you things in a way you understand?
17. Does your doctor tell you about the “side effects” of any medication you have?
18. If you are on medication does your doctor “review” your medication?
19. Do you have any check ups like
 - Blood pressure
 - Checks for lumps
 - Cervical smear
 - Well woman or man clinic

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20. Do you think your doctor does their best to look after your health?
21. Do you think you are treated worse because you have a learning difficulty?
22. Do you think that your doctor and other staff try especially hard to help you because you have a learning difficulty?
23. Is there anything else you want to tell us about your doctor?

16.3 Telephone interview for primary care practitioners and other practice staff

1. Can you tell me a bit about your job/role?

(Describe and include: length of time in current job, training if relevant)

Identifying the target groups

2. Are you able to identify those people registered at the practice that have:-

2a. a MH problem?

If so, how do you know?

2b. a LD?

If so, how do you know?

Access to primary care services

'I'd like to ask some questions about access to primary care services for these groups'

3. Do you think people with a MH problem or a LD have any difficulties accessing primary care services in terms of:

a) deciding at which point to make initial contact with their primary care professional (GP, practice nurse etc);

b) making an appointment;

c) the attitude and helpfulness of reception staff;

d) the waiting arrangements at a practice (length of wait, crowded waiting room, privacy etc)

e) communication between MH/LD patients and the primary care professional;

f) attitude of clinical staff;

g) how easy it is to make diagnosis;

h) diagnostic overshadowing (i.e. where physical health problems/symptoms are misinterpreted as being part of a person's mental health problem/learning difficulty);

i) access to appropriate treatment for a physical health problem

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- j) access to health promotion advice (i.e. smoking cessation, dietary advice, exercise advice etc)
 - k) referrals to specialist services for a physical health problem
 - l) the need for support in adhering to any treatment or health promotion/prevention advice.
4. Do you think access to primary care services could be *improved* for these groups?

Health outcomes

'I'd like to ask you a couple of questions about health outcomes for these groups'

5. Do you think people with MH problems/LD have similar, better or worse outcomes compared to those without MH/LD for particular physical health conditions such as:
- Respiratory problems
 - Cardiovascular problems
 - Diabetes
 - Obesity
 - Gastric problems
 - Or any other physical health problems
- a) If 'better' or 'worse' health outcomes why do you think that is?

Health promotion advice/services/interventions

'I'd like to ask about health promotion advice, services or interventions for these groups'

6. Are people with a MH problem/LD *offered* health promotion advice, services or interventions?
- a) If so, are they more likely, less likely or equally likely to take up any health promotion advice, services or interventions?
- b) If less likely, what **support** might be needed to help them take up such advice, service or intervention?

Specific practices for the groups

7. Have you or your colleagues designed any practices or implemented any policies that are intended to improve physical health outcomes for people with mental health problems or learning difficulties?
- a) If so, can you provide a few examples?

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8. Do you require any additional training to meet the physical health needs of:-
 - a. People with a MH problem
 - b. If so, what should this include?
 - c. If not, why is that?
 - d. People with a LD
 - e. If so, what should this include?
 - f. If not, why is that?
9. Do you have any other comments you'd like to make?

END OF INTERVIEW FOR PRACTITIONERS AND PRACTICE MANAGERS
THANK YOU FOR TAKING PART

Questions for reception staff only

10. Are you able to identify those people registered at the practice that have a MH/LD?
 - a) If so, how do you know?
11. Do people with a MH problem/LD experience any particular difficulties booking or arranging appointments?
 - a) If so, what are these?
12. What are you able to do to help overcome these difficulties?
 - a) For people with MH problems
 - b) For people with LD
13. Do you provide health information that is specifically targeted at these groups of patients at the practice?
14. Do you think this information is:-
 - a. Seen and taken by people in these groups? (Please describe)
 - b. Available in appropriate formats for these groups of people?
15. Do you require any additional training to meet the needs of these particular groups? (Please probe)

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- a. MH problem
If so, what should this include?
If not, why is that?
- b. LD
If so, what should this include?
If not, why is that?

16. Do you have any other comments?

END OF RECEPTION STAFF INTERVIEW
THANK YOU FOR TAKING PART

Interviewer notes

(please note down any interesting points that emerged from the interview)

16.4 Telephone interview for commissioners, secondary care staff, voluntary sector and advocates

1. Can you tell me a bit about your job/role and that of your organisation/agency? (*Describe and include: length of time in current job, training if relevant*)
2. Do you think the physical health concerns of people with mental health problems/learning difficulties are taken seriously in primary care? (*Prompt: side-effects of medication*)
 - a. If you think they are not, why is that?
 - 2b. What do you think the physical health concerns of these groups of people are?
3. Do you think it is clear who should provide physical health care for these groups of people?
 - a. If it is not clear in your view, why is that?
1. Do you think people with mental health problems/learning difficulties receive helpful advice on how to promote their physical health? (*Prompt: smoking cessation or reduction, exercise, nutrition*)
 - a. If not, why is this?
5. Do you think there are any specific problems with reference to gender, or age, or ethnicity and the physical health care of these groups of people? (*Prompt: impact of long-term medication, interaction of medication with hormonal cycles, impact of medication with other meds for e.g. high blood pressure*)
 - a. Can you give any examples?
6. What do you think would help primary care practitioners to improve or enhance the physical health care of these groups of people? (*Prompt: stigma awareness training, user involvement, physical health skills training*)
7. Do you know of any interesting current practice in primary care that addresses meeting the physical health care needs of these groups of people? (*Prompt: Any structures in place? Any incentives from Government?*)
8. Any other comments? Have you had the opportunity to say all that you want on this topic?

EXPLAIN NEXT STEPS & COURSE OF INVESTIGATION

16.5 Postal Survey Questionnaire



GP QUESTIONNAIRE Physical Health Project

A. Visiting your doctor/GP

1. Do you have a doctor/GP/practice nurse that you can see if you have a **medical problem** or need a **health check**?

- Yes, I go to the local health centre/GP practice
- Yes, someone comes to see me at home
- Yes, but I have not seen anyone from my GP practice in the last 12 months
- No

a) If 'No', please tell us why (for example, 'did not need to'; 'had problems getting to see my GP'; not registered with a GP)

2. If you live in any sort of supported accommodation do you get to see a doctor/GP/practice nurse when you need to?

- Yes
- No

a) If 'No', could you tell us why (for example, 'could not arrange an appointment'; 'had problems getting to see my GP')

3. How often have you seen your **GP/doctor** in the last 12 months?

- Once or twice in the past year
- Once every 3 months
- Once or twice a month
- Every week or more
- Not seen a GP in the past 12 months

4. How often have you seen your **practice nurse** in the last 12 months?

- Once or twice in the past year
- Once every 3 months
- Once or twice a month
- Every week or more
- Not seen a practice nurse in the past 12 months

5. Who makes your appointments when you want to see a GP?

- Myself
- Relative/carer
- Support worker
- Friend/Neighbour
- Other – (Please say who) _____

6. Is it easy to get an appointment when you want one?

- Yes

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No

a) If 'No', please tell us why

7. How do you get to your doctors when you need to go?

Public transport

Car

Walk

Other (Please describe) _____

8. Is it easy to get to your GP surgery?

Yes

No

9. Is the building at your GP surgery easy to use?

Yes

No

a) If 'No', please tell us why

10. When you go to your GP surgery how do the reception staff usually greet you?

Extremely well, they are very friendly

Very well, quite friendly

Good

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- Not well, quite unfriendly
- Not very well, very unfriendly

11. Do you usually have to wait a long time in the waiting room?

- Seen on time or early
- Waited up to 15 minutes
- Waited 16-30 minutes
- Waited 31 minutes to 1 hour
- Waited longer than 1 hour
- Can't remember

12. Do you find it difficult to wait?

- Yes
- No

a) If Yes, please tell us why

B. Seeing your doctor/GP

13. Do you see your GP on your own?

Yes

No

a) If you answered NO, please tell us who goes with you (for example, relative or parent, support worker, friend, neighbour, etc)

14. Did your GP **listen** to what you have to say?

Yes, definitely

Yes, a little

No

15. Does your GP give you enough time to tell him or her about your medical problem?

Yes, definitely

Yes, a little

No

I did not need to discuss anything

a) If 'Yes, a little' or 'No', tell us why (for example, your GP thought your medical problem was to do with your mental health or learning difficulty).

16. Does your GP tell you things in a way you understand?

Yes, definitely

Yes, a little

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No

17. Does your GP treat you with **respect**?

Yes, all of the time

Yes, some of the time

No

18. Do you think that your GP does their best to look after your medical health?

Yes, all of the time

Yes, some of the time

No

C. Medicines you have

19. In the last 12 months, have you had any new medicine(s) (like tablets, injections, ointment, oral contraceptives, etc) that your GP has prescribed for you?

- Yes
- No
- Can't remember

If yes, where you involved in deciding your medicine or treatment?

- Yes, completely
- Yes, to some extent
- No
- I did not need to be involved
- No treatment or action was needed

20. Where you given enough information about what the medicine was for?

- Yes, enough information
- Some, but not enough information
- No information at all, and I wanted some
- I did not want any information

21. Did your GP tell you about any "side effects" the medicines might have?

- Yes, enough information
- Some, but not enough information
- No information at all, and I wanted some
- I did not want any information

22. Do you take any medication for a mental health problem?

- Yes
- No

a) If 'Yes', have you noticed any physical "side effects" or changes in your body from this medication?

- Yes
- No

b) If 'Yes', please tell us what those "side effects" or changes are? (For example, putting on weight, headaches, other physical changes)

23. Have you talked about any physical "side effects" with your GP?

- Yes
- No

a) If 'No', please tell us why?

24. Has your GP told you enough about how to use the medicine(s) (e.g. when to take it, how long you should take it for; whether it should be taken with food)?

- Yes, enough information
- Some, but not enough
- No information at all, and I wanted some
- I did not want any information

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25. If you are on medication all the time does your GP “review” your medicine?

Yes

No

Don't know / Not sure

D. Referrals to a specialist

26. In the past 12 months has your GP referred you for a medical problem to a specialist doctor or other professional (like a hospital consultant, physiotherapist, dietician or smoking cessation nurse)?

Yes

No

Don't know / can't remember

a) If 'Yes', please tell us what type of specialist or professional?

27. Did you have a choice about which hospital or specialist to go to?

Yes

No

Don't know / can't remember

28. Where you able to see this specialist or go to the hospital?

Yes

No

a) If 'No', please tell us why (e.g. no one to go with, difficulties in using public transport etc)

If 'Yes', did the person you see have enough information about you, your medical problem, or treatment?

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- Yes, completely
- Yes, to some extent
- No
- I have not been yet
- Don't know / can't remember

E. Health checks / tests

29. In the last 12 months, tell us if you have had any of these checks/tests at your GP surgery:

a) Blood pressure check

- Yes
- No
- Not sure / can't remember

b) Blood test

- Yes
- No
- Not sure / can't remember

c) Urine test

- Yes
- No
- Not sure / can't remember

d) Breathing test (Peak Flow)

- Yes
- No
- Not sure / can't remember

e) Check for lumps

- Yes
- No
- Not sure / can't remember

f) Smear test (to check the cervix – for women only)

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Yes

No

Not sure / can't remember

g) Visited a well woman or mans clinic

Yes

No

Not sure / can't remember

h) If you had any of the above checks or tests were they done by a practice nurse at your GP surgery?

Yes

No

Not sure / can't remember

i) If 'Yes', did the practice nurse treat you with **respect**?

Yes

No

j) If 'No', please tell us why not?

30. Did the person doing the check or test tell you what it was for in a way you could understand?

Yes, for all tests or checks

Yes, for some tests or checks

No

Not sure / can't remember

31. Did someone explain the results in a way you could understand?

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- Yes, for all tests or checks
- Yes, for some tests or checks
- No
- Not sure / can't remember

F. Health Promotion

32. Do you smoke cigarettes at all nowadays?

Yes

No

33. Have you ever been offered advice or help from your GP or nurse to **give up smoking**?

Yes, and I was given the help I needed

Yes, I have tried, but I was not given the help I needed

No, I have not tried to get this type of help

No, I have not been offered this advice

34. Have you ever been offered advice or help from your GP or nurse on **eating a healthy diet**?

Yes, and I was given the help I needed

Yes, I have tried but I was not given the help I needed

No, I have not tried to get this kind of help

No, I have not been offered this advice

35. Have you ever been offered advice or help from your GP or nurse on **getting enough exercise**?

Yes and I was given the help I needed

Yes, I have tried but I was not given the help I needed

No, I have not tried to get this type of help

No, I have not been offered this advice

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36. Have you ever been offered advice or help from your GP or nurse on **healthy alcohol intake**?

- Yes, and I was given the help I needed
- Yes, I have tried but I was not given the help I needed
- No, I have not tried to get this kind of help
- No, I have not been offered this advice
- I do not drink alcohol

G. Other Issues

37. Have you changed your GP (family doctor) within the last 12 months?

Yes

No

38. What was the reason for this change?

I moved house

I was unhappy with my previous GP

My previous GP retired / moved away

The previous practice / health centre closed down

Other

39. How easy was it to register with another GP (family doctor)?

Very easy

Fairly easy

Fairly difficult

Very difficult

a) If it was 'fairly difficult' or 'very difficult' to register with a GP please tell us why?

40. Have you ever had problems registering or staying registered with a GP?

Yes

No

a) If Yes, please tell us why?

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41. Have you ever been taken off a GP register?

Yes

No

Not sure / can't remember

b) If Yes, please tell us why?

H. Other Comments

42. Is there anything particularly **good** about the care you receive from your GP practice for any medical problems?

Yes

No

a) If YES, please tell us what that is:

43. Is there anything about the care you receive from your GP practice for any medical problems that **could be improved**?

Yes

No

a) If 'Yes', please tell us what that is:

b) If there anything else you want to tell us about your GP please tell us here?

44. Who filled in this questionnaire?

- Person addressed to?
- Parent or guardian (if person under 16)
- Carer (relative or friend)
- Neighbour
- Researcher
- Support worker or professional carer

I. About you

45. Are you male or female?

Male

Female

46. What was your year of birth?

(Please write in)

e.g.

1

9

6

3

47. Do you have a mental health problem?

Yes

No

a) If 'Yes', please tell us what your diagnosis or mental health problem is.

48. Do you have a learning difficulty?

Yes

No

a) If 'Yes', please tell us what your type of learning difficulty you have.

49. Do you have any other difficulties or impairments?

Yes

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No

a) If Yes, please tell us what this is. (For example, hard of hearing, visual impairment, physical difficulty, etc)

50. To which of these ethnic groups would you say you belong? **(Tick one only)**

a. WHITE

British

Irish

Any other White background
(Please write in box)

b. MIXED

White and Black Caribbean

White & Black African

White & Asian

Any other Mixed background
(Please write in box)

c. ASIAN OR ASIAN BRITISH

Indian

Pakistani

Bangladeshi

Any other Asian background
(Please write in box)

d. BLACK OR BLACK BRITISH

- Caribbean
- African
- Any other Black background
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

- Chinese
- Any other ethnic group
(Please write in box)

51. Where do you live?

- South East
- London
- North West
- Wales

52. What type of accommodation do you live in?

- Independent accommodation (i.e. without any support)
- Nursing home
- Day support housing
- Residential care home
- Supporting People Programme housing
- Hostel (with support)
- Homeless

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- Secure unit (forensic setting)
 - Other (please tell us what this is)
-

J. Contact Information

53. Would you like to tell us more about your experiences of seeing your doctor/GP?

Yes

No

a) If 'Yes', you can take part in an interview. Please provide us with your contact details if you would like to take part:

What is your full name?

What is your telephone number?

What is your address?

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you have answered all the questions that apply to you.

Please return this Questionnaire and the signed Consent Form in the stamped addressed envelope provided.

17 Appendix 4. Tables of additional analyses

Table 30. Receipt of dietary advice for people overweight or obese and with a mental health problem

	SMI			Depression			Remaining Population		
	No. with received advice	Total no.	%	No. with received advice	Total no.	%	No. with received advice	Total no.	%
Weight group									
overweight (BMI 25+)	110	192	57.3	1819	3571	50.9***	13168	23527	56.0
obese (BMI 30+)	108	169	63.9	1638	2687	61.0*	8855	13834	64.0

***P<0.001 **P<0.005 *P<0.05
Adjusted for age, gender and site

Table 31. Receipt of dietary advice for people overweight or obese with a learning difficulty

	LD			Remaining population		
	No. with received advice	Total no. with LD	%	No. with received advice	Total no.	%
Weight group						
overweight (BMI 25+)	35	70	50.0	15030	27166	55.3
obese (BMI 30+)	43	82	52.4	10522	16543	63.6

Adjusted for age, gender and site

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Table 32. Mammography & cervical screening according to age (years) in people with a SMI or depression

(women only)

	SMI			Depression*			Remaining Population**		
	No. with recorded check	Total no. with SMI	%	No. with recorded check	Total no. with depression	%	No. with recorded check	Total no.	%
Mammography									
0-49	1	145	0.7	58	5567	1.0	225	42344	0.5
50+	67	246	27.2***	1701	4538	37.5	9192	22777	40.4
Cervical screening									
0-24	2	10	20.0	258	636	40.6	1654	20337	8.1
25-64	205	245	83.7	6881	7505	91.7	29452	33213	88.7
65+	61	136	44.9	1090	1964	55.5	6150	11571	53.2

* Excludes people with SMI

** Excludes people with SMI and depression

***P<0.001

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Table 33. Mammography & cervical screening according to age in people with a LD

(women only)

	LD			Remaining population		
	No. with recorded check	Total no. with LD	%	No. with recorded check	Total no.	%
Mammography						
0-49 years	1	199	0.5	283	47789	0.6
50+ years	19	55	34.5	10921	27417	39.8
Cervical screening						
0-24	7	116	6.0	1907	20864	9.1
25-64	56	119	47.1***	36394	40742	89.3
65+	4	19	21.1***	7267	13600	53.4

***P<0.001

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Table 34. Recorded health checks in people with a SMI or depression and IHD by gender

	SMI			Depression			Remaining Population		
	No. with recorded check	Total no. with IHD	%	No. with recorded check	Total no. with IHD	%	No. with recorded check	Total no. with IHD	%
Type of health check¹									
Total cholesterol									
male	25	25	100.0	445	455	97.8	3150	3245	97.1
female	17	22	77.3*	503	546	92.1	1864	2006	92.9
LDL cholesterol									
male	4	25	16.0	170	455	37.4	1249	3245	38.5
female	7	22	31.8	203	546	37.2	732	2006	36.5
Body mass index									
male	24	25	96.0	417	455	91.6	3010	3245	92.8
female	17	22	77.3	481	546	88.1	1773	2006	88.4
BP - systolic									
male	25	25	100.0	452	455	99.3	3222	3245	99.3
female	20	22	90.9	542	546	99.3	1990	2006	99.2
BP - diastolic									
male	25	25	100.0	451	455	99.1	3217	3245	99.1
female	20	22	90.9	542	546	99.3	1988	2006	99.1
Current smoker									
male	20	25	80.0	208	455	45.7	1067	3245	32.9
female	11	22	50.0*	183	546	33.5	445	2006	22.2

¹ Based on latest recorded health check

*P<0.05

The Sainsbury Centre for Mental Health

Table 35. Recorded health advice/intervention for the mental health target groups with IHD by gender

	SMI			Depression*			Remaining Population**		
	No. with recorded advice	Total no. with IHD	%	No. with recorded advice	Total no. with IHD	%	No. with recorded advice	Total no. with IHD	%
Type of advice/interv.¹									
Smoking advice									
male	18	25	72.0	210	455	46.2	1206	3245	17.1
female	9	22	40.9	176	546	32.2	554	2006	27.6
Lipid lowering therapy									
male	19	25	76.0	380	455	83.5	2688	3245	46.4
female	11	22	50.0	403	546	73.8***	1505	2006	75.0

¹ Based on latest recorded health check

***P<0.001

* Excludes people with SMI

** Excludes people with SMI and depression

The Sainsbury Centre for Mental Health

Table 36. Recorded health checks in people with a SMI or depression and stroke by gender

Type of health check ¹	SMI			Depression*			Remaining Population**		
	No. with recorded	Total no.	%	No. with recorded	Total no.	%	No. with recorded	Total no. with stroke	%
	check	with stroke		check	with stroke		check	stroke	
BP - systolic									
male	21	21	100.0	221	223	99.1	1294	1307	99.0
female	23	23	100.0	312	318	98.1	1162	1190	97.6
BP - diastolic									
male	21	21	100.0	220	223	98.7	1290	1307	98.7
female	23	23	100.0	313	318	98.4	1160	1190	97.5
Current smoker									
male	13	21	61.9	96	223	43.0	426	1307	32.6
female	7	23	30.4	118	318	37.1	292	1190	24.5

¹ Based on latest recorded health check

The Sainsbury Centre for Mental Health

Table 37. Recorded health checks in people with a SMI or depression and diabetes mellitus by gender

	SMI			Depression*			Remaining Population**		
	No. with recorded check	Total no. with diabetes	%	No. with recorded check	Total no. with diabetes	%	No. with recorded check	Total no. with diabetes	%
Type of health check¹									
BP - systolic									
male	36	36	100	306	307	99.7	2358	2409	97.9
female	39	40	97.5	438	439	99.8	1868	1904	98.1
BP - diastolic									
male	36	36	100	306	307	99.7	2353	2409	97.7
female	39	40	97.5	438	439	99.8	1863	1904	97.8
Urine analysis									
male	21	36	58.3	220	307	71.7	1818	2409	75.5
female	25	40	62.5	345	439	78.6	1485	1904	78.0
Body mass index									
male	34	36	94.4	297	307	96.7	2288	2409	95.0
female	32	40	80.0	418	439	95.2	1781	1904	93.5

¹ Based on latest recorded health check

* Excludes people with SMI

** Excludes people with SMI and depression

The Sainsbury Centre for Mental Health

Table 38. Recorded health checks in people with a SMI or depression and COPD by gender

	SMI			Depression*		
	No. with recorded check	Total no. with COPD	%	No. with recorded check	Total no. with COPD	%
Type of health check¹						
Current smoker						
male	62	100	62.0	581	1155	50.3
female	38	74	51.4	1232	2404	51.2

¹ Based on latest recorded health check

* Excludes people with SMI

** Excludes people with SMI and depression

Table x Recorded health checks in people with a LD and COPD by gender

	SMI		
	No. with recorded check	Total no. with COPD	%
Type of health check¹			
Current smoker			
male	22	104	21.2
female	9	45	20.0

The Sainsbury Centre for Mental Health

Table 39. Recorded health checks in all people with a SMI or depression by gender

Type of health check ¹	SMI			Depression*			Remaining Population**				
	No. with recorded check	Total no.	%	No. with recorded check	Total no.	%	No. with recorded check	Total No.	%		
Total cholesterol											
male	165	473	34.9	3886	5370	72.4	*	16589	69007	24.0	
female	161	391	41.2	2172	10105	21.5		17246	65121	26.5	
Urine analysis											
male	127	473	26.8	1658	5370	30.9		16687	69007	24.2	
female	160	391	40.9	***	4111	10105	40.7	***	21761	65121	33.4
Body mass index											
male	310	473	65.5	3500	5370	65.2		32672	69007	47.3	
female	282	391	72.1	*	7702	10105	76.2	***	37287	65121	57.3
BP - systolic											
male	389	473	82.2	4587	5370	85.4		40524	69007	58.7	
female	351	391	89.8	**	9592	10105	94.9	***	46586	65121	71.5
BP - diastolic											
male	389	473	82.2	4560	5370	84.9		40057	69007	58.0	
female	349	391	89.3	**	9557	10105	94.6	***	46175	65121	70.9
Current smoker											
male	264	473	55.8	2490	5370	46.4		15771	69007	22.9	
female	165	391	42.2	***	4478	10105	44.3	*	14192	65121	21.8

¹ Based on latest recorded health check

***P<0.001

**P<0.005

*P<0.05

The Sainsbury Centre for Mental Health

Table 40. Recorded health checks in all people with a LD by gender

Type of health check ¹	LD			Remaining population		
	No. with recorded check	Total no. with LD	%	No. with recorded check	Total no.	%
Total cholesterol						
male	49	499	9.8	19482	74222	26.2
female	31	254	12.2	20535	75206	27.3
Urine analysis						
male	100	499	20.0	18338	74222	24.7
female	79	254	31.1	25894	75206	34.4
Body mass index						
male	175	499	35.1	36223	74222	48.8
female	115	254	45.3 **	45037	75206	59.9
BP - systolic						
male	205	499	41.1	45182	74222	60.9
female	151	254	59.4 ***	56232	75206	74.8
BP - diastolic						
male	205	499	41.1	44687	74222	60.2
female	153	254	60.2 ***	55788	75206	74.2
Current smoker						
male	78	499	15.6	18370	74222	24.8
female	33	254	13.0	18731	75206	24.9

¹ Based on latest recorded health check

***P<0.001

**P<0.005

*P<0.05

The Sainsbury Centre for Mental Health