Impact of the English Directly Enhanced Service (DES) for Learning Disability

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Abbreviations

AF	Atrial Fibrillation
BMI	Body Mass Index
BP	Blood Pressure
CHD	Coronary Heart Disease
CKD	Chronic Kidney Disease
DES	Directly Enhanced Service
DNA	Did not attend
DM	Diabetes Mellitus
EK	Evangelos Kontopantelis
GP	General Practitioner
IMD	Index of Multiple Deprivation
JR	Joanne Reeve
KF	Karen Flood
LD	Learning disability
NHS	National Health Service
NPT	Normalisation Process Theory
NS	Non significant
PCRN	Primary Care Research Network
PCT	Primary Care Trust
PN	Pauline Nelson
PRIMIS	Primary Care Information Service
PwLD	Person with Learning Disability
QOF	Quality Outcomes Framework

R&D	Research and Development
SH	Susan Hinder
TFT	Thyroid Function Test
UC	Umesh Chauhan

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Easy Read Summary

How are health checks making a difference?

What are health checks?

The government says that all adults with a learning disability who are known to their local Social Services department should be offered a health check every year.

Health checks are usually done at your doctors' surgery.

A health check is a good way to help you stay healthy.

A health check helps you to make sure you are doing the right things to stay healthy.

We wanted to know what doctors and nurses do in a health check.

Where did we go?

We looked at information from over 160 doctor's surgeries.

These surgeries were in 6 different parts of the country

and included surgeries in country areas and big cities.

We looked at the medical records of over 4,000 people with learning disability.

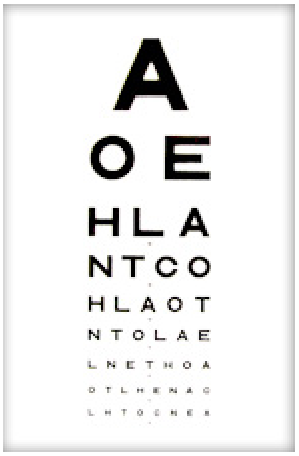
What did we find?

Most doctors' surgeries are doing health checks.

More people with learning disability are having health checks.

Doctors find people with learning disability have health problems like diabetes, asthma and being overweight.

What is wrong with the checks?



Less than half of people with learning disability are getting health checks.

Some parts of the health check are not being done as well as others.

We also wanted to know what it is like for people with learning disability to have a health check.

What we did

32 people with learning disability agreed to take part in the study.

We talked to them about what they thought about health checks.

Some people needed the help of a support worker to talk to us and we also talked to family carers if the person could not talk to us.

What did we find?

Some people with learning disability like seeing the doctor and were happy to have a health check.

Some people would be happy to have a health check again.

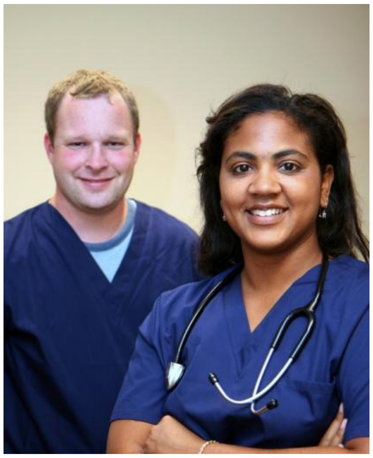
Doctors' surgeries are getting better at doing health checks.

Here are some of the ways they have done that:

Some Doctors' surgeries will phone you to make an appointment for a health check and call again to remind you.

Some doctors' surgeries give you an appointment at a time when it suits you.

Some doctors will come and see you in your home to do a health check.



Nurses with special training who work with you help to make and keep appointments.

They also help to explain what doctors are saying.

Health Action Plans also help doctors to know more about you.

There are some things that doctors and nurses could do better:

It should be easier to make an appointment with a doctor or nurse.

Doctors and nurse should give you more time and listen to you when they see you.

When you are asked to see a doctor who does not know you, they should know about what you like and dislike.

Doctors and nurses need to make sure that they explain about your learning disability when passing information to each other.

We also wanted to know what it is like for doctors and nurses to try and do health checks.

What we did

We asked doctors and nurses what it was like to do the health checks.

We also asked why some doctors surgeries are not doing health checks.

We talked to them about what they thought about health checks.

What did we find?

The extra money helped doctors and nurses to make time to do the health checks

Doctors and nurses feel they are getting better at doing health checks.

They find this easier when 1 person is in charge of planning the health checks.

What could be better?

Some doctors feel the health check could be made better. So that they can listen more to what people with learning disability want and need.

Doctors would like to offer the best health care to everyone with learning disability. But some do not think the health check is the best way to do this.

To make health checks work better doctors, nurses and people with learning disability need to work together and think about what we can do differently.

Executive Summary and Recommendations

Annual health checks were introduced as a 'reasonable adjustment' to care in 2008 following recommendations by the Disability Rights Commission as a way of addressing the health needs of people with learning disability. General Practices are incentivised by a Directed Enhanced Service (DES) to offer a comprehensive health check including a physical examination, behaviour and mental health assessment for adults with learning disability. This study evaluates the impact of the health check on patients, practitioners and health services by exploring the views of health professionals, people with learning disability and carers, as well as by analysing clinical data recorded in General Practice clinical systems.

Methodology

We addressed the following, broad, research questions:

1. What has been the clinical impact of annual health checks?
2. What are the experiences of people with learning disability and carers of health checks and why do some people with learning disability not have them?
3. Can annual health checks become normalised into General Practice?

Each question was addressed in a different study since different methodological approaches were required for each. Electronic data were collected from 171 practices across 6 PCTS (Blackburn with Darwen, Central Lancashire, Cumbria, East Lancashire, Haringey and Plymouth) and used to assess the impact of health checks. Multi-level linear and logistic regression analyses were used to estimate the effect of health checks on clinical outcomes, information collected and case finding for certain common conditions, whilst controlling for key variables such as age, gender, practice list size, and area deprivation. Views of health professionals and people with learning disability and carers were captured using semi-structured interviews in two Primary Care Trusts (East Lancashire and Haringey). Normalisation Process Theory (NPT) was used as a guiding framework for exploring the barriers and facilitators to introducing health checks.

Results

Clinical Data Analyses

Data were collected over two time periods: April 2009 to March 2010 (designated as 2010) and April 2010 to March 2011 (designated as 2011). The number of practices carrying out health checks increased over the two time periods. The number of people identified as having learning disability increased in the practices during this time period. The number of health checks carried out by practices increased during this time period but less than half the people with learning disability received them and only 20% received a health check in both time periods.

Health checks were also associated with an increased identification of Quality Outcomes Framework (QOF) incentivised diseases, such as diabetes. Most patients with learning disability (over 95%) had one or more disease condition incentivised in some way through the QOF (diabetes, epilepsy, or thyroid disease for example).

Health checks were associated with increased recording of processes which are specific for learning disability but there was considerable variation in recording of such processes (visual assessment>50% to feeding assessment <1% for example).

Views of People with learning disability and carers

A total of 64 people were interviewed in order to capture the experience of 32 people with learning disability. On the whole people with learning disability and carers had a positive view of health checks but they did not see these as being different from usual care provided by their practice.

Non engagement with health checks by participants and carers was not a common theme but poor uptake of health checks in part may be related to problems with access to care (making an appointment with a doctor for example). This is compounded by communication problems which exist at a number of levels:

a. the practice (the way patients are invited for appointments)
b. across services (information is often not shared with other health professionals within the same practice or in other settings)
c. the individual (poor communication skills)

Continuity ('knowing your doctor') was important to both people with learning disability and family carers which health checks helped to improve.

Health Professionals' Views

A total of 40 health professionals were interviewed including General Practitioners (partners, salaried and trainees), nurses (Community Learning Disability Nurse, practice nurses and nurse practitioners), practice managers and health care assistants.

Qualitative interviews with health professionals analysed using NPT identified a number of barriers and promoters to health checks:

- How practices implement health checks depends on the resources available to them and GPs were generally resistant to using structured templates such as the Cardiff template whereas nurses and health care assistants found these useful.
- The financial incentive appeared to be a facilitator for practices in signing up to, and getting started with, the learning disability DES. Practices are also less likely to continue delivering health checks under their current structure if the incentive is stopped, since DES is being treated as an add-on and is not integrated into usual care.
- The way patients are defined as being eligible for a health check does not make clinical sense as this is based on a social assessment and not medical need.
- There are aspects of changes made as a result of the DES being adapted into usual care. For example reasonable adjustments being made to improve access to care, such as approaches to booking appointments, are likely to remain and more likely become part of routine care.
- Health checks, as they are currently structured, are unlikely to lead to sustainable change in practice and lead to health checks becoming normalised into routine practice because of a failure to establish a shared agreement with generalist practitioners about the nature, purpose and value of this approach to care for people with learning disability.

Recommendations

- Funding for health checks should continue as this is leading to increased case finding both in terms of number of people with learning disability and level of comorbidity. Our findings would also suggest that practices are unlikely to continue health checks if the funding is stopped.
- Annual health checks appear to be associated with significant coding activity for QOF incentivised health screening, promotion and disease finding. However, there is considerable variation in coding of the other aspects of the health check, such as hearing assessment and visual assessment, which would suggest there may be resistance in undertaking certain aspects of the health check. We need to know more about the reasons for this. Whether it reflects lack of shared understanding of the value or problems with resources/facilities to conduct the tests or health professionals only undertaking activities they are incentivised for.
- The problems with the current process of checks including the variable uptake of health checks in practices and coding of certain clinical data would suggest a need to revisit the model of learning disability health checks and develop a new approach to learning disability health checks in collaboration with people with learning disability, carers and health professionals.

Contents

Tables

1. Introduction

1.1 Background

People with learning disabilities have significant impairments of intellectual function and social/adaptive functioning present from childhood. There are an estimated 900,000 adults with learning disability in England of whom only 191,000 (21%) were known to learning disability services [1]. People with learning disabilities have a shorter life expectancy, increased risk of early death and poorer health compared with the general population [2, 3]. All cause mortality rates among people with moderate to severe learning disability are three times higher than in the general population, especially among young adults, women, and people with Down's syndrome [4]. Evidence suggests that the health needs of this group are being inadequately addressed and past inquiries into the health care of those with learning disabilities have shown that the level of care provided through Primary Health Care Services is failing to meet the needs of this population [5-7]. Identified problems include lower than expected general practitioner consultation rates, lower uptake of screening activities, and poor access to health promoting activities [8]. They also have more complex health needs and experience higher levels of epilepsy, hearing loss, sight problems, mental ill health, behavioural problems, depression, anxiety, psychosis, sensory impairment and behaviour disorders [9, 10].

1.2 Evidence for health checks

There is increasing evidence that health checks may increase detection of health problems for people with learning disability [11-13]. A recent randomised controlled trial of annual health screening in people with learning disability found increased detection of vision impairment, increase in hearing testing and improvement in women's health screening in the intervention group [14]. A cohort of forty general practices in the UK implemented a health check which identified new health needs in 51% of those who received a health check [15]. However, fewer than 51% of those eligible received a health check [15].

However, research also suggests that people with learning disability have problems accessing primary health care and often fail to attend health screening services that are offered [16, 17].

An incentive scheme, the Quality Outcomes Framework (QOF) was introduced in the United Kingdom (UK) in 2004. The scheme involves rewarding practices financially for meeting pre-determined targets relating to the management of predominately chronic diseases and practice organisation [18]. Since 2006, practices have been rewarded for maintaining a register of patients with learning disability but there has been no direct reward for reviewing an individual's health within the QOF.

Over the four years (2006 to 2010) the recorded national prevalence of learning disability increased slightly from 0.26% to 0.33% of the total population with a greater percentage increase in 2009 and 2010 [19]. Inclusion in the national QOF data collections is likely both to have improved the overall completeness of identification of people with LD and also to have standardised the recording of learning disability diagnoses in clinical notes.

A recent pilot study assessed the quality of a health check process, prior to the introduction of the Directly Enhanced Service, in a small number of practices in England. Nine practices undertook a health check on 92 of their patients with learning disability [20]. Significant differences were found in the recorded information, between those who underwent a health check and those who did not ($p<0.001$). Processes incentivised through the QOF were more likely to be recorded. However, minimal financial incentive was offered to practices to take part in the pilot study.

Annual health checks for adults with learning disability were introduced in England in primary care as a 'reasonable adjustment' following recommendation by the Disability Rights Commission [21]. A directly enhanced service (DES) was introduced in 2008[22]. This provides a financial incentive of approximately £100 per patient to General GPs to carry out a comprehensive health check including a physical examination, behaviour and mental health assessment, aimed at those with moderate to severe learning disability. Although all primary care trusts (PCTs) have been under an obligation to provide the resources to implement this scheme, participation is voluntary at the practice level [23]. For practices taking part in the DES there are four distinct aspects for achieving payment [22]:

- Practices must liaise with their Local Authority to share and collate information, in order to identify the people on their practice list who are also known to social services primarily because of their learning disabilities

- Practices must include those of its registered patients identified by this liaison in a health check learning disabilities register and ensure that their QOF learning disabilities register includes all patients on the health check register

- Practices providing this service must attend a multi-professional education session. The minimum expectation of staff attending the training is the lead general practitioner (GP), lead practice nurse and practice manager/senior receptionist.

- Practices must use the 'Cardiff' health check protocol (or similar protocol agreed with the PCT) which provides a detailed review of a person's physical and mental health.

Guidance at the time also suggested that 'practices may also wish to involve specialist learning disability staff from the Community Learning Disability team to provide support and advice.'

Evidence suggests wide variability in how health checks are implemented across England. Although PCTs have been obliged to resource the DES, participation is voluntary at practice level. PCT data indicates that only 4 out of 10 adults with learning disability received a health check in 2009/10 which increased to nearly 5 out of 10 in 2010/11 according to the Public Health Observatory for Learning Disabilities with some PCTs providing health checks for fewer than 14% of people with learning disability despite the financial incentive (bottom 10% of PCTs provided health checks for fewer than 25% of those eligible, while the top 10% provided nearly 70%) [24]. (see Table 1, Page 26 for variation in uptake in the areas of the study).

Table 1 Variation in uptake of health checks across England and study sites over time

	2010		2011	
	Number of People with learning disability receiving health checks	Number of People eligible - adults known to both GP and Social Services with LD	Number of People with learning disability receiving health checks	Number of People eligible - adults known to both GP and Social Services with learning disability
England	58,919 (41%)	145,130	72,782 (49%)	149,480
East Lancashire	475 (41%)	1,146	508 (45%)	1,131
Haringey	305 (62%)	490	378 (74%)	513

1.2 Prevalence, management and treatment of other illnesses in people with learning disability

There are a number of clinical conditions which can be easily monitored in primary care information systems because of their inclusion in the QOF. Some are monitored only in prevalence terms (obesity for example), most include management processes (diabetes, hypertension and coronary heart disease for example) and, in some cases outcome indicators are available (e.g. blood pressure control). Some of the conditions included in the QOF are particularly important for people with learning disability, for example diabetes, epilepsy and mental health conditions.

To take one example of a condition included in the QOF, diabetes is more prevalent in people with learning disability than the general population and is also much more common in individuals who are obese. People with learning disabilities are much more likely to be either underweight or obese than the general population [4]. The QOF includes a range of indicators relating to the monitoring and control of diabetes, including a prevalence measure, a range of diabetes related screening tests, and measures relating to control of blood sugar, cholesterol and blood pressure.

1.3 Health Screening and Health Promotion

Certain screening processes are likely to lead to increased identification of medical conditions such as diabetes, hypertension, chronic kidney disease (CKD) and thyroid disease. Studies involving health screening of adults with learning disabilities registered with GPs, prior to the implementation of the learning disability DES have shown high levels of unmet physical and mental health needs [11, 25-28]. The practices were advised to use the 'Cardiff' health check protocol (or similar protocol agreed with the PCT) which provides a detailed review of a person's physical and mental health [22]. There is some evidence from previous studies that repeated health checks can lead to improved case finding for a range of health conditions [27, 29, 30].

1.4 Summary and Study Aims

There has been little research to document the experiences and views of people with learning disability and their family carers about health checks [6] with some evidence to suggest that carers perceive health checks to be useful and effective in improving the health of people with learning disability [31, 32]. Very few studies have explored health professionals' experiences and explanations of the observed variation in uptake of health checks.

This report provides the combined findings from the quantitative study which explored:

1. The uptake of health checks and how this may be related to health care setting (the size of the practice, number of patients with learning disability within a practice and deprivation for example) and the outcomes associated with health checks.

and two qualitative studies which explored:

2. the views and experiences of health checks for people with learning disability and their family carers with the help of support workers.
3. the views of GPs, nurses, practice managers and other health staff within the practice involved in delivering health checks as well as the views of the Community Learning Disability nurses in supporting practices to implement health checks.

The latter was a theoretically informed qualitative study using Normalisation Process Theory[1] as a guiding framework for analysis [33] which explored the barriers and facilitators to the introduction of health checks and aims to inform policy for future development of health checks. Based on our analysis, we have identified a number of barriers and promoters to health checks for people with learning disability and thus make suggestions for further work.

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[1] Not to be confused with Bengt Nirje's Normalization Principle of making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.

2. Project Management

Details of the research team, advisory group and funding are provided in appendix 1 (Page 89).

3. Methodology

The three studies required different methodological approaches to address the questions posed within each study.

3.1 Research Questions

3.1.1 Quantitative Study

The quantitative research study aimed to explore the impact of the DES in terms of data recorded in GP clinical systems as outlined by the following objectives:

1 To determine the uptake of health checks in the participating practices and identify key health parameters recorded as part of the health check.

2 To compare additional information recorded compared to standard care provided through the current QOF structure.

3 To determine the effect of health checks on intermediate outcomes.

4 To determine the effect of health checks in identifying QOF related disease conditions.

3.1.2 People with learning disability and carers study

This qualitative research study aimed to explore the experiences and views of people with learning disability and the family carers with the help of support workers of the health check but included people with learning disability who had not received a health check to explore the reasons why health checks did not happen.

5 What are the experiences of people with a learning disability and their family carers (or Support Workers) of primary care and learning disability health checks?

6 What are the reasons why some individuals with learning disability do not participate in health checks?

3.1.3 Health Professionals' views

This qualitative study aimed to explore reasons for variation in uptake of the learning disability DES through exploring the barriers and facilitators to introducing health checks for people with learning disability in primary care from a health professional's perspective and included practices that were delivering health checks and those that were not. Specific questions which this study wished to address were:

7 How do practices decide whether they want to take part in the Learning Disability DES?

8 Who within the practice is involved in the process of meeting the DES requirements and how do they do this?

9 Who within the practice team is involved in delivering health checks?

10 Can Learning Disability health checks become normalised into general practice?

Questions 7 to 9 describe the variation in provision (or non provision) of learning disability checks at the sample practices. Question 10 allows us to "explore" this descriptive data through the use of Normalisation Process Theory [33] in order to make trustworthy and generalizable statements about facilitators and barriers to introducing learning disability checks through an incentivised process.

3.2 Ethical Approval

Ethical Approval for the three studies was sought separately due to varying degrees of complexity related to the recruitment process.

For the quantitative study (REC reference number 10/H1003/41) favourable ethical opinion (June 2010) and Research and Development (R&D) approval were received from the six National Health Service (NHS) and Local Authority areas in which we conducted the quantitative study: Blackburn with Darwen, Central Lancashire, Cumbria, East Lancashire, Haringey and Plymouth.

Favourable ethical opinion was also received for the qualitative study with health professional (REC reference number 10/H1015/81 in November 2010) and R&D approval was received from the two NHS and Local Authority areas in which we conducted the study: East Lancashire and Haringey.

Getting approval for the qualitative study with people with learning disability and family carers (REC reference number 10/H1003/39) was slightly protracted but granted in June 2010. Appendix 2 (Page 91) provides some further detail of the ethical issues raised and how these were addressed in this study.

3.2 Research Methods

3.2.1 Quantitative Study Design

A cohort observational study design with follow up over two years was used to address the objectives outlined above.

3.2.2 Recruitment of practices for the quantitative study

Participating practices were recruited from six English NHS Primary Care Trusts (PCTs). Practices in East Lancashire and Blackburn with Darwen were recruited directly through the support of the local PRIMIS team to take part in the research. Practices in Haringey were approached through the PCRN as were practices in Plymouth and Cumbria. Practices in Central Lancashire were also approached directly through the support of the PCT and local PRIMIS team. Practices were provided information leaflet and expression of interest form.

3.2.3 Extraction query development

A pilot study was undertaken prior to the introduction of the DES to see how health checks might work. This allowed a number of processes to be validated including Read Codes used in different clinical systems to identify patients who may have learning disability based, data extraction using MIQUEST and methods for analysis of the data [20].

Data extraction from clinical systems was carried out using MIQUEST queries. These queries were initially developed with the support of the PRIMIS team in Nottinghamshire for the pilot study and were updated to include revisions to the QOF in April 2009 (there were no major changes to the QOF clinical indicators in April 2010). Queries were modified and tested to ensure they worked in different clinical systems.

3.2.4 Data extraction process

Anonymised data were extracted for all patients with learning disability (as defined by Read Codes listed under QOF business rules as being diagnostic of learning disability) from all practices who agreed to participate. It was possible to extract data at two time points in East Lancashire after April 2010 (for data related to health checks carried out between 1st of April 2009 and March 31st 2010) and from April 2011 (for data related to health checks between 1st of April 2010 and March 31st 2011)[2]. In the other PCTs, due to time constraints, data for both time points were collected at the same time. This approach would only include patients registered at the time the query was run and not those who have left the practice or died. The clinical systems generated a unique identifier for individual patients which was used to link data across the two time points. Practices were directed in the DES guidance to use an administrative Read Code (Read code 69DB for example) to identify those patients who received a health check. Each practice also had to submit the number of patients eligible for a health check and the number of health checks completed to the PCTs for payment purposes, thus it was possible to validate the extraction process.

3.2.5 Deprivation

In order to ensure anonymity, it was not possible to extract post code data at the patient level which could be used for meaningful analysis. Deprivation scores were therefore uniformly assigned to all patients in each practice on the basis of the Index of

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[2] PCTs incentivised practices from 1/4/2009 to 31/3/2011 to complete this DES.

Multiple Deprivation (IMD) score at the practice location. The IMD differs from other deprivation measures as it uses a range of information from local government and other agencies to create a measure of deprivation comprising of seven weighted themes or domains (income, employment, health and disability, education skills and training, barriers to housing services, crime and living environment) which are combined to create an overall score.

3.2.6 Practice List size

As part of the extraction process, the practice list size (total number of registered patients) and practice population over the age of 18 years were also extracted.

3.2.7 Power Calculation

We estimated the sample size required to address the question of whether there was a difference in the information collected from the group that had a health check compared to the group that did not; a minimum of 60 practices (approximately 1,500 patients with learning disability in total) would be required to detect a 5% difference in most situations. As the structure of the data is multi-levelled, the power calculations were based on a multi-level linear regression approach, treating patient and practice as random effects.

It became clear in the early phase of the study that recruiting practices to take part in the study would be difficult in Haringey, despite the support of the research network. The research was opened to other sites through the research network and 4 other PCTs were recruited (Blackburn with Darwen, Central Lancashire, Cumbria and Plymouth) within the time framework of the study.

3.2.8 Prevalence, management and treatment of other illnesses in people with learning disability

The QOF includes a range of indicators for various conditions. Variation in recording of measurable parameters (Table 2, Page 33) was compared between those who undergo a health check and those who do not.

Sub analyses took account of the presence of comorbidity. Individual patients were considered to have a comorbidity if they had Read Coded data for one or more of the following clinical conditions; coronary heart disease (CHD), heart failure (HF), hypertension, diabetes, CKD, asthma, chronic obstructive pulmonary disease (COPD), stroke, atrial fibrillation (AF), epilepsy, thyroid, mental health, depression, dementia, palliative care or cancer. Obesity was omitted as payment to practices under the QOF for this condition is for the maintenance of a register only, and prevalence is not recorded.

Sub analyses also included the use of exception reporting. Exception reporting can be used by practices to exclude patients from an indicator if it is not considered appropriate. Patients can be exception coded for clinical reasons for a particular indicator, for example: not attending for review, or where a medication cannot be prescribed due to a contraindication or side-effect. There is great variation in exception rates across indicators. In general, the lowest exception rates relate to indicators that measure a process, and the highest exception rates relate to indicators that measure the provision of treatments.

Table 2 Examples of processes incentivised under the QOF

	Condition			
	CHD	Diabetes	Hypertension	Epilepsy
Blood Pressure (BP) record (in previous 15 months	Yes	Yes	Yes (9months)	±
BP <150/90*	Yes	Yes	Yes	-
Cholesterol Record (<15 months)	Yes	Yes	Yes (newly diagnosed through PP1∞)	-
Total cholesterol <5mmol/l	Yes	Yes	-	-
Influenza immunisation+	Yes	Yes	-	-
CVD risk Assessment	-	-	Yes	-
Body mass Index (BMI) record (<15 months)	-	Yes	-	-
Smoking status for smokers (<15 months)	Yes	Yes	Yes	≠
Smoking advice, referral, Rx (<15 months)	Yes	Yes	Yes	-
Medication Review	Yes	Yes	Yes	Yes

*< 145/85 DM and CKD
± recorded in preceding 5 years if over 45 years
≠ Preceding 27 months (except non-smokers)
+ Patients aged over 65 years also eligible
∞ PP1- QOF indicator Primary prevention 1.

We have attempted to review outcomes for certain common comorbid conditions (Coronary Heart Disease (CHD), diabetes and hypertension) using the blood pressure, HbA1c, BMI and cholesterol level control (Table 3, Page 34).

Table 3 Intermediate Outcomes incentivised through QOF

	QOF Registers		
	CHD	Diabetes	Hypertension
BP <150/90	Yes	Yes (145/85)	Yes
BMI		Yes	
Total cholesterol <5mmol/l	Yes	Yes	-
HbA1c (record and level <7)	-	Yes	-

3.2.9 Data analysis

Analyses were conducted using STATA v11.2. We examined the effect of the health assessment on a) information domains; b) referrals; c) intermediate outcomes and d) case finding. For all analyses we only included the 160 practices for which we had collected data across years, 2009-10 and 2010-11. Analyses a and b used all available patients across both years. Analysis c used all available patients with the relevant conditions (diabetes for example), across both years. For analysis d, since we did not have the earliest recording of diagnoses, we had to examine only patients for which we had information across both year and did not have the respective condition(s) in 2009-10.

Two informational domains were created ('LD (learning disability) specific', and 'QOF targets') and for each domain the relevant available variables were aggregated into scores, on a 0-100 scale. There are certain aspects of care within the health check which are already incentivised (blood pressure, smoking status, body mass index for example) through the QOF and already attract payment [34] whilst others attract payments through other enhanced services (use of Choose and Book as a referral process for example). The 'LD specific' domain (Table 5, Page 35) contained information that related to data on Health Action Plan, visual assessment, hearing assessment, behaviour assessment, self-neglect assessment and bowel function assessment. The 'QOF targets' domain (Table 4, Page 35) aggregated information measures which related to QOF targets and thus attracted direct payment for achievement [22]: blood pressure, smoking status, ethnicity, body mass index, medication review and influenza vaccination. Although cervical cytology is an incentivised processes, this was excluded from the QOF target domain as it only applies to a subset of participants in England (women aged 25-64 years) with complicated rules sets for achievement (smear performed within the last 5 years) [35]. Data for smoking was expected to be updated annually if the patient was a smoker and influenza vaccination is recommended for those who meet the following criteria: presence of an underlying serious medical condition (such as CHD and diabetes), over 65 years of age, pregnant and those living in a residential home.

An additional outcome domain relating to health checks was created from the following referrals: Choose and Book, audiology, occupational therapy, orthotics, chiropodist, speech therapy and learning disability team (Table 6, Page 35).

Table 4 'QOF targets' processes

Coded Data
Blood Pressure (annual)
Smoking Status (annual)
Ethnicity (ever)
Body Mass Index (annual)
Medication Review (annual)
Flu vaccination (annual)

Table 5 'LD specific' health check processes

Coded Data
Health Action Plan (annual)
Visual Assessment (annual)
Hearing Assessment (annual)
Bowel Assessment (annual)
Behaviour Assessment (ever)
Self-neglect Assessment (ever)

Table 6 Outcomes related to referrals

Coded Data
Choose and Book (annual)
Audiology (annual)
Orthotics (annual)
Chiropodist (annual)
Speech therapy (annual)
Learning disability (annual)

For each binary outcome we report crosstabs with health assessment and the associated significance using Fisher's exact test.

For the outcomes outlined in a-d we also used multi-level linear or logistic regressions to estimate the effect of health assessment, while controlling for key variables (age, gender, practice list size, learning disability register size, Super Output Area Index of

Multiple Deprivation, presence of one or more QOF comorbidity and time). We took into account the three-level structure of the data (patients nested within practices nested within PCTs) to accurately model the uncertainty in the estimates due to the fact that items at all levels are samples of much larger populations. An alpha level of 5% was used in all analyses.

3.2.10 Qualitative Studies Design

There are a variety of methods of data collection used in qualitative research such as one to one interviews, focus groups and observation. Semi-structured interviews were chosen as they are a good method for collecting in-depth information on participants' views and experiences of the research issue under consideration [36].

The semi-structured interview uses a framework of clear topics to be discussed and specific questions to be asked, but with the flexibility in the order of discussion of these topics, and a freedom for the interviewer to probe deeper and allow the development of ideas and discussion of wider issues. It was recognised that individuals with learning or communication difficulties may require highly structured support in giving their views, but such support can distort views through the nature and phrasing of questions [37], thus prompt cards were used as part of the interview schedule to address this problem.

3.2.11 Interview Schedule for people with learning and carers

Estimates suggest that 50% to 90% of people with learning disabilities have communication difficulties [38]. About 60% of people with learning disabilities overall have some skills in symbolic communication using pictures, signs or symbols. Although people with learning disabilities do not have one recognized set of language tools' and may need an individually tailored communication plan.The interview schedule for people with learning disability was supported with pictorial prompt cards to help support those who were able to express their views on the care they receive. For those with profound learning disabilities no amount of visual or other supported process for accessing views make the interview method possible. With research participants who have profound learning disability, the interview process relied on other communication partners (family carers and support workers).

When interviewing a proxy person about the person with learning difficulties, we recognised that it is sometimes hard for the person being interviewed (family carer or support worker) to separate their own views than the possible interpretation of the views and experience of the person with learning disability.

Thus the interview schedule for carers included open ended questions which allowed the interviewee to respond in an unrestrained manner and express their own views (Appendix 3, Page 94).

3.2.12 Interview Schedule for Health Professionals

The topic guide, was informed by previous literature and developmental interviews [39]. Key questions included whether practitioners carried out health checks, reasons why they were or were not able to provide health checks, what factors motivated them to carry out health checks, and what barriers prevented practices from participating in (Appendix 3, Page 94) and a similar guide was used for the interviews with the Community Learning Disability Nurses (Appendix 3, Page 94).

All interviews were conducted by UC and SH.

3.2.13 Recruitment of participants with learning disability and family carers

Participants were from practices taking part in the DES but included those who had recently undergone a health check (within three months of the interview) or had been invited for a health check and did not attend in the last 12 months. Participants from practices who were taking part in the DES but had not been offered a specific health check in the previous 12 months were also invited to take part in the research. Participating practices were asked to provide information to participants as soon as possible after the health check and no later than three months after as participants are more likely to recall having had a health check when interviewed. Participants were sent a letter of invitation (and where appropriate, their personal consultee) by their practices on their practice's letter headed paper and signed by their GP either at the time of the health check or as soon as possible after the health check. They were also provided with a participant information sheet, expression of interest form and a prepaid envelope. Practices were also asked to identify participants who had been invited for a health check in the last 12 months but had not attended for a health check. Practices were asked to liaise with the Community Learning Disability Nurse attached to their practice to make contact with the potential participants in order to support them with the decision of whether they wanted to take part in the research. GP practices were also asked to identify and provide details about the research to family carers' of participants who were deemed unable to take part in the research because of the severity of their disability and in such cases family carers were invited to take part in the research. All the participants in this study were identified by either their GP practice or the Community Learning Disability Team as having moderate to severe learning disability and thus eligible for health checks through the DES.

3.2.14 Recruitment of participants for health professional views

A total of twenty practices were approached to take part in the interviews with health professionals in East Lancashire and Haringey. A purposive sampling approach (recruiting specific practices and people) was used to select practices in order to maximize representativeness and variability within practices in the two PCTs. The criteria used to select practices included practice patient list size, number of GP partners and practice population characteristics such as rurality, deprivation and ethnicity. This facilitated the capture of views of health professionals working in different settings. Views were also sought from practices known not to have undertaken health checks. Community Learning Disability nurses, attached to the practices, who had been involved in delivering training, ratifying registers and in some cases, helping to carry out health checks, were also approached to take part in the interviews.

3.2.15 Data Analysis

Interviews with people with learning disability and carers were analysed using 'Framework' approach which incorporates five stages of analysis and interpretation: familiarization, identification of themes, indexing, charting, mapping and interpretation [40]. To increase the trustworthiness of the interpretation and analysis, transcripts and notes were read and re-read independently by three of the research team (SH, PN and UC). The transcripts were read to identify units of meaning (first level nodes) which were then grouped together to form themes (second level nodes) from which were described broad domains (third level nodes). Findings from the analysis were shared with KF (person with learning disability) on a regular basis by holding face to face meetings. The broad topic areas in the interview schedule were used to guide the initial stages of the data analysis process. Deviant cases were actively sought throughout the analysis and emerging ideas and themes modified in response.

Normalisation Process Theory (NPT) is a sociological toolkit that can be used to understand the dynamics of implementing, embedding, and integrating a new technology or complex intervention into an existing service [33]. NPT proposes that to understand practice, we need to look at the actions of people who individually and collectively do the work. NPT provides a robust analytic framework for understanding the organization and operationalization of tasks (their implementation), of making routine elements of practice (their embedding), and of sustaining embedded practice in their social context (their integration). Implementation, embedding and integration depend on 4 mechanisms: sense making, engagement, action, and monitoring. Deficiencies in any of these areas may limit implementation and continuity. The work of implementation requires continuous investment by people: it is important to look not only at what people do now, but explore for evidence of change. NPT provides a conceptual construct which has been used to evaluate the implementation of an number of interventions such as telehealth [41, 42] but has also been used to characterise the 'work' that patients themselves have to do when managing chronic illnesses such as heart failure [43].

NPT was used as framework to explore whether and how a short term DES can change practice with regard to the care of people with learning disability. Two of the authors (UC and JR) drew on published work describing NPT [44]. A Framework based on the above 4 themes was used to interrogate the data set to identify presence or deficiencies in each of the four mechanisms needed for normalisation. Three of the researchers (SH, JR, UC) independently reviewed and coded individual transcripts using the following four core concepts of the NPT framework: coherence (making sense), cognitive participation (engagement), collective action (doing) and reflexive monitoring (Appendix 4, Page 103).

3.2.16 Verbatim quotes and presentation of findings

Verbatim quotes have been used to illustrate the main findings. Individual participants are identified by using the codes PwLD (person with learning disability), by participant number (i.e. 001 to 032) and gender (M (male); F (female)). If the quote is from a family carer or a support worker this is also indicated with the quote. Individual participants are identified by using the codes GP (General Practitioner), PN (practice nurse or nurse practitioner, PM (practice manager or non-clinical business partner), CN (Community Learning Disability Nurse); and by participant number.

In order to protect the anonymity of the individuals who have taken part in the research, all names have been changed including those of people who have supported the interviews.

3.5 Presentation of Findings

The findings are presented in the following section, using the following heading:

- Results from the quantitative study
- Results from the qualitative studies
    - Demographic data
    - Thematic analysis findings of interviews with people with learning disability and carers
    - Thematic analysis findings of interviews of health professionals using NPT

4. Results of the Quantitative analysis

4.1 Demographic Data

A total of 171 practices were recruited across the 6 PCTs to take part in the study (see Table 8, page 41). It was possible to extract data from 164 practices for the 2010 time period (April 2009 to March 2010 financial year for QOF and DES payment purposes) of which 120 practices delivered health checks based on coded extracted from practices and data were extracted from 166 practices for the 2011 time period (April 2010 to March 2011 financial year for QOF and DES payment purposes) (Table 9, Page 41).

Data were extracted for a total of 3,929 patients for the 2010 time period and 4,032 patients for the 2011 period (Table 10, Page 41 and Table 11, Page 42). It was possible to extract data for both time periods from 160 practices with matched patient data available for 3,661 patients in these practices (Table 13, Page 42).

There was no significant change in the proportion of men and women identified with learning disability across the two time frames (57.9% in 2010 compared to 57.8% in 2011 for men). The mean age for men was 41.1 compared to 42.1 for 2010 and 2011 respectively and 42.5 and 48.3 for women.

In patients with matched data across both time periods 30.5% (1115/3661) of patients had a health check in 2010 and 41.7% (1525/3661) had a health check in 2011 (Table 14, Page 43) compared to an overall figure of 30.9% (1215/3928) for 2010 across the PCTs and 41.5% (1674/4032) for 2011.

Table 7 Number Practices taking part in the DES in each PCT

	Number of practices taking part in the DES	
PCT	**2009/2010**	**2010/2011**
Blackburn with Darwen	29/29	29/31
Central Lancashire	53/86	68/86
Cumbria	83/91	84/90
East Lancashire	46/68	48/65
Haringey	30/62	41/62
Plymouth	29/42	31/42
Total	**270/378**	**301/376**

Table 8 Number of practices recruited to take part in study from each PCT

PCT	Number of practices recruited to take part in the study
Blackburn with Darwen	17
Central Lancashire	36
Cumbria	46
East Lancashire	54
Haringey	05
Plymouth	13
Total	**171**

Table 9 Number of Practices delivering health checks based on Coding information

	Number of practices delivering health checks based on data extract from practices	
	2010	2011
Blackburn with Darwen	9/15	12/14
Central Lancashire	26/36	34/36
Cumbria	38/46	43/46
East Lancashire	36/53	39/52
Haringey	3/3	3/4
Plymouth	8/13	11/13
Total	**120/166**	**142/166**

Table 10 Prevalence of learning disability based on total population of each practice in 2010

	Extracted data 2010			QOF Data 2010
	Number of patients with learning disability	Total practice population	Prevalence /1000	Number of People with learning disability on QOF register/(as % of total PCT population)[19]
Blackburn with Darwen	322	54474	5.9	615 (0.37%)
Central Lancashire	791	224718	3.5	1624 (0.37%)
Cumbria	1020	284957	3.6	1946 (0.38%)
East Lancashire	1269	330158	3.8	1377 (0.35%)
Haringey	88	16756	5.3	607 (0.22%)
Plymouth	438	95248	4.6	1299 (0.48%)
Total	**3,928**	**1,006,311**	**3.9**	**8735 (0.35%)**

Table 11 Prevalence of learning disability based on total population of each practice in 2011

	Extracted data 2011		
	Number of patients with learning disability	Total practice population	Prevalence
Blackburn with Darwen	318	78853	4.0
Central Lancashire	836	227851	3.7
Cumbria	1073	284957	3.8
East Lancashire	1204	318672	3.8
Haringey	141	24532	5.7
Plymouth	460	96099	4.8
Total	**4,032**	**1,030,964**	**3.9**

Table 12 Patients available for analysis for 2010 and 2011

	In either or both years	
	Matched Practices	Total Patients
Blackburn with Darwen	13	315
Central Lancashire	35	821
Cumbria	46	1,055
East Lancashire	50	1,219
Haringey	03	93
Plymouth	13	460
Total	**160**	**3,963**

Table 13 Matched patient data from practices in 2010 and 2011

	Number of matched patient data from practices for both 2010 & 2011
Blackburn with Darwen	290
Central Lancashire	761
Cumbria	1005
East Lancashire	1080
Haringey	87
Plymouth	438
Total	**3661**

Table 14 Number of health checks Delivered in Matched patient groups

		2010		
2011		Had Health Check	No health check	Total
	Had health check	723	802	1525
	No health check	392	1,744	2136
	Total	**1115**	**2546**	**3661**

4.2 QOF incentivised processes

Patients were more likely to have a medication review, their ethnicity recorded, carer detail recorded and receive influenza vaccination if they received a health check (P<0.001) in both 2010 and 2011 (Table 15, Page 43 and Table 16, Page 44). Overall the recording of carer detail increased from 28.5% (1118/39928) in 2010 to 41.5% (1672/4032) in 2011. Ethnicity recording has also increased from 43.8% (1719/3928) in 2010 to 53% (2136/4032) to 2011.

Table 15 QOF incentivised processes 2010

	Record by health check for 2010		
	No health check [2713] (%)	Health check [1215] (%)	P-value
Medication Review (<15 months)	615 (22.7)	424 (34.9)	P<0.001
Ethnicity (ever)	1040 (38.5)	679 (55.9)	P<0.001
Carer Detail (ever)	422 (15.6)	696 (57.3)	P<0.001
Influenza Vaccination (annual)	748 (27.6%)	482 (39.7)	P<0.001

Table 16 QOF incentivised processes 2011

	Record by health check for 2011		
	No Health Check [2358] (%)	Health Check [1674] (%)	P-value
Medication Review (<15 months)	552 (23.4)	677 (40.4)	P<0.001
Ethnicity (ever)	1108 (47)	1028 (61.4)	P<0.001
Carer Detail (ever)	569 (24.1)	1103 (65.9)	P<0.001
Influenza vaccination (annual)	649 (27.5)	681 (40.7)	P<0.001

4.3 QOF Health Promotion incentivised processes

Patients were more likely to have assessments recorded for smoking, alcohol, exercise and diet if they received a health check (P<0.001) for both time periods.

Table 17 Incentivised and partially incentivised process related to health promotion in 2010

	Record by health check for 2010		
	No health check [2713] (%)	Health check [1215] (%)	P-value
Alcohol data (annual)	605 (22.3)	904 (74.4)	P<0.001
Exercise assessment (annual)	384 (14.2)	712 (58.6)	P<0.001
Diet assessment (annual)	231 (8.5)	321 (26.4)	P<0.001
Smoking Status (<15 months)(excluding non smokers	503/1096 (45.9)	353/416 (84.9)	P<0.001

Table 18 Incentivised and partially incentivised process related to health promotion in 2011

	Record by health check for 2011		
	No health check [2358] (%)	Health check [1674] (%)	Chi-Square P-value
Alcohol data (annual)	455 (19.3)	1148 (68.6)	P<0.001
Exercise assessment (annual)	583 (24.7)	1096 (65.5)	P<0.001
Diet assessment (annual)	321 (13.6)	625 (37.3)	P<0.001
Smoking Status (<15 months) (excluding non smokers)	428/854 (50.1)	614/614 (92.6)	P<0.001

4.4 Screening Processes linked to the QOF

All screening processes linked to QOF related morbidity were more likely to occur in patients who underwent health checks (P<0.001). For example: in both years, measurement of blood pressure was recorded for over 85% of patients receiving a health check. In contrast, for patients not receiving a health check only 48% had their blood pressure measured in 2010, rising to 55% in 2011 (Table 19, Page 45 and Table 20, Page 46). Blood tests for glucose, renal function, thyroid and cholesterol were also more likely to occur in those who had a health check.

Table 19 Screening Processes linked to QOF incentives and outcomes 2010

	Record by health check for 2010		
	No health check [2713] (%)	Health check [1215] (%)	P-value
Blood Glucose Test	538 (19.8)	529 (43.5)	P<0.001
Renal Function	784 (28.9)	677 (55.7)	P<0.001
Thyroid Function Test (TFT)	669 (24.7)	577 (47.5)	P<0.001
Blood Pressure	1312 (48.4)	1051 (86.5)	P<0.001
Cholesterol	579 (21.3)	583 (48)	P<0.001
Urine analysis*	224 (8.3)	385 (31.7)	P<0.001

*Screening for protein, blood and glucose

Table 20 Screening Processes linked to QOF incentives and outcomes 2011

	Record by health check for 2011		
	No health check [2358] (%)	Health check [1674] (%)	P-value
Blood Glucose Test	495 (21)	600 (35.8)	P<0.001
Renal Function	772 (32.7)	865 (51.7)	P<0.001
TFT	623 (26.4)	759 (45.3)	P<0.001
Blood Pressure	1301 (55.2)	1493 (89.2)	P<0.001
Cholesterol	621 (26.3)	766 (45.8)	P<0.001
Urine analysis*	210 (8.9)	447 (26.7)	P<0.001

*Screening for protein, blood and glucose

4.5 learning disability specific processes

Health checks were associated with better recording of learning disability specific processes (P<0.001) with 50.4% of checked patients having a hearing assessment in 2010 and 42.2% having a visual assessment, compared to 3.1% and 4.8% respectively for patients who did not receive a health check. However, some processes were infrequently recorded even for patients receiving a health check, for example: in 2010 only 0.6% of checked patients had a feeding assessment, 2.6% had a behaviour assessment and 3.5% had a bowel function assessment (Table 21, Page 47 and

Table 22, Page 47). Recording of mobility assessment was also infrequent, but improved over time (13.8% in 2010, 23.9% in 2011 for all patients). Information about Health Action plans was only recorded for about a fifth of the patients. Overall, learning disability specific data were more likely to be recorded for patients who had a health check, although the levels were far lower than for QOF specific processes.

Table 21 learning disability specific health check Processes 2010

	Record by health check for 2010		
	No health check [2713] (%)	Health check [1215] (%)	P-value
Health Action Plan (annual)	24 (0.9)	279 (23)	P<0.001
Visual Assessment (annual)	129 (4.8)	513 (42.2)	P<0.001
Hearing Assessment (annual)	84 (3.1)	612 (50.4)	P<0.001
Bowel Assessment (annual)	15 (0.6)	42 (3.5)	P<0.001
Mobility Assessment (ever)	52 (1.9)	423 (34.8)	P<0.001
Behaviour Assessment (ever)	55 (2)	49 (2.6)	P<0.001
Self-neglect Assessment (annual)	0 (0)	4 (0.3)	P=0.009
Housing Dependency (ever)	251 (9.3)	330 (27.2)	P<0.001
Feeding Assessment (annual)	4 (0.1)	8 (0.6)	P=0.01

Table 22 learning disability specific health check Processes 2011

	Record by Health Check for 2011		
	No health check [2358] (%)	Health check [1674] (%)	P-value
Health Action Plan (annual)	9 (0.4)	342 (20.4)	P<0.001
Visual Assessment (annual)	74 (3.1)	743 (44.4)	P<0.001
Hearing Assessment (annual)	45 (1.9)	883 (52.7)	P<0.001
Bowel Assessment (annual)	5 (0.2)	94 (5.6)	P<0.001
Mobility Assessment (ever)	169 (7.2)	693 (41.4)	P<0.001
Behaviour Assessment (ever)	38 (1.6)	142 (8.5)	P<0.001
Self-neglect Assessment (annual)	7 (0.3)	19 (1.1)	P<0.001
Housing Dependency (ever)	300 (12.7)	504 (30.1)	P<0.001
Feeding Assessment (annual)	1 (0.04)	5 (0.2)	P=0.09

4.6 Prevalence of QOF register comorbidities and disease case finding

Just under nine percent (347/3928) of patients in 2010 did not have a code recognised for the purposes of QOF as being on Learning Disability QOF but had other codes (such as code for Down’s Syndrome), suggesting they had learning disability. This was reduced to just over 6% (254/4032) in 2011 (Table 23, Page 48).

94.6% of learning disability patients had a QOF-related comorbidity recorded in 2010 – this increased to 96.5% in 2011. Diabetes prevalence increased from 4.71 to 6.27 and epilepsy prevalence from 18.1% to almost 21% (Table 23, Page 48).

Table 23 QOF comorbidity prevalence in 2010 and 2011

	Year			
	2010		2011	
	Total	Percent (%)	Total	Percent (%)
learning disability QOF Register	3581	91.17	3778	93.7
Diabetes	185	4.71	253	6.27
Epilepsy	711	18.1	845	20.96
Heart Failure	33	0.84	37	0.92
Mental Health	277	7.05	292	7.24
Palliative Care	9	0.23	9	0.22
Thyroid Disease	312	7.94	354	8.78
Asthma	434	11.05	475	11.78
AF	25	0.6	29	0.7
Cancer	67	1.71	78	1.93
CHD	33	0.84	37	0.92
CKD	48	1.22	71	1.76
COPD	40	1.02	53	1.31
Dementia	29	0.74	37	0.92
Depression	468	11.91	483	11.98
Stroke	68	1.7	76	1.9
Hypertension	86	2.19	109	2.7
Obesity (based on BMI)	671/1873	35.8	869/2274	38.2

The analysis for newly identified QOF comorbidities was limited to data available for matched patients present in both 2010 and 2011 (3661 patients in 160 practices). For each condition, we only used patients that were not associated with the condition in 2010 and went on to examine whether the health check was a predictor of identifying the specific condition in 2011. More patients were diagnosed as having diabetes in those who had a health check (42 compared to 19, P<0.001) (Table 24, Page 49). The numbers identified as having, epilepsy, thyroid problem as a new condition also increased (P=0.07 and p=0.03).

Table 24 QOF Diseases coded in 2011

	Case Finding of QOF conditions by health check in 2011 (condition not present in 2010)		
	No health check [2136]	Health check [1525]	Chi-Square P-value
Diabetes [3489]	19/2043	42/1445	42.33 P<0.001
Epilepsy [3011]	58/1760	89/1250	22.21 P=0.07
Heart Failure [3630]	0/2119	3/1511	2800 P<0.001
Mental Health [3412]	11/1992	8/1420	6.24 P=1
Palliative care [3652]	0/2130	0/1522	-
Thyroid [3364]	20/1968	26/1376	19.92 P=0.03
Asthma [3254]	10/1893	11/1340	7.7 P=0.38
AF[3661]	0/2136	0/1252	-
Cancer [3598]	5/2095	7/1503	6815.77 P<0.001
CHD [3632]	0/2118	4/1510	2.49 P=0.9
CKD [3618]	14/2114	8/1504	14.85 P=0.02
COPD [3625]	2/2112	9/1513	6306 P=0.01
Dementia [3634]	3/2119	4/1515	12.64 P=0.05
Depression [3230]	16/1880	11/1350	2.96 P=0.8
Stroke [3661]	0/2136	0/1525	-
Mental Health [3412]	11/1992	8/1420	6.2 P=0.4
Hypertension [3579]	35/2098	22/1481	35.7 P<0.001

4.7 QOF Comorbidity and exception reporting

Overall rates of exception reporting (irrespective of whether a health check occurred or not) were highest for COPD (17/53, 32%), diabetes (31/253, 12.3%), asthma (35/475, 7.4%) and epilepsy (61/845, 7.2%), in 2011 (Table 25, Page 50).

Table 25 Exception reporting rates in 2011

	Exception coding by health check in 2011		
	No health check [2358]	Health check [1674]	P-value
Diabetes [253]	18	13	P=1
Epilepsy [845]	37	24	P=0.79
Heart Failure [37]	-	-	-
Palliative care [9]	-	-	-
Asthma [475]	21	14	NS
Atrial Fibrillation (AF) [29]	-	-	-
Cancer	-	-	-
CHD [37]	4	3	NS
CKD [71]	0	3	p=0.07
COPD [53]	10	7	NS
Dementia [37]	0	2	NS
Depression [483]	8	4	NS
Stroke [76]	10	5	NS
Mental Health [292]	17	6	NS
Cervical Cytology	76	94	P=0.004
Sexual Health	12	9	NS

4.8 Intermediate outcomes and referrals related to health checks

Analyses for intermediate outcomes for patients with an underlying QOF comorbidity (CHD, diabetes and/or hypertension) were not significantly different between the health check and no health check groups (Table 26, Page 51, Table 27, Page 51). However, the likelihood of being referred to the learning disability community team is greater for those who have a health check (P<0.001), for both 2010 and 2011. Overall, those who had a health check, were more likely to have a referral code for one of the conditions identified in Table 27 (Page 51) and Table 28 (Page 51) in either year.

Table 26 Intermediate Outcomes for patients known to have CHD, hypertension and or diabetes

	Intermediate Outcomes		
	No health check	health check	P-Value
BP Controlled	255/311	207/244	NS
Cholesterol	182/226	140/175	NS
HbA1c	97/191	94/162	NS
BMI <30	1083/1774	1359/2141	NS

Table 27 Referrals related to health check 2010

	Referrals by health check 2010		
	No health check [2753]	Health check [1215]	P-value
Choose and Book	165 (6.1)	88 (7.2)	P=0.18
Audiology	5	17	P<0.001
OT referral	8	6	P=0.3
Physiotherapy	1	2	P=0.23
Orthotics	5	4	P=0.47
Chiropodist	8	6	P=0.39
Speech therapist	7	9	P=0.05
learning disability team	18	38	P<0.001

Table 28 Referrals related to health check for 2011

	Referrals by health check 2011		
	No health check [2753]	Health check [1215]	P-value
Choose and Book	132	110	P=0.2
Audiology	7	7	P=0.59
OT referral	8	15	P=0.03
Physiotherapy	1	2	P=0.57
Orthotics	0	1	P=0.42
Chiropodist	4	1	P=0.41
Speech therapist	1	7	P=0.01
learning disability team	19	59	P<0.001

4.9 Regression Analysis

Logistic multilevel regressions were used to investigate a) the effect of patient and practice characteristics on health assessment performance and b) the effect of health assessment and patient and practice characteristics on case findings – odds ratios are reported (Table 29, Page 51 and Table 33, Page 54). Linear multilevel regressions were employed to assess the effect of health assessment and patient/practice characteristics on the QOF, learning disability and referrals information domains – coefficients are reported (Table 30, Page 53, Table 31, Page 54 and Table 32, Page 54).

Increasing age, female gender and the presence of comorbidity were associated with a higher probability of receiving a health check, particularly in the second year (2011).

On average, recorded information for patients who underwent a health check was 18.9% higher in the 'LD specific' domain (95% CI: 18.3, 19.5, p<0.001) and 20.7% higher in the 'QOF specific' domain (95% CI: 19.9, 21.9, p<0.001), compared to information recorded for those who did not have a health check (Table 30, Page 53 and Table 31, Page 54).

Due to the complexity of the models, we could only examine a few patient and practice level characteristics as potential predictors of recorded information (across both domains). Older patients and females were associated with a higher percentage of recorded information. Having one or more QOF comorbidity was strongly associated with QOF specific data being recorded, on average 16.4% higher compared to patients with no QOF conditions (95% CI: 13.4, 19.5, P<0.001) but not for the LD specific domain (p=0.37). QOF specific data were also more likely to be recorded in 2011 compared to 2010, with an average increase of 3.7% (95% CI: 2.82, 4.5, P<0.001). However, size of the learning disability register and IMD at the Super Output Area (SOA) level were not found to be significant predictors for recording QOF specific data. SOAs are presumed socially homogenous units of geography used in the UK for statistical analysis each covering between 1,000-3,000 people (Office for National Statistics, 2009).

Health checks were also associated with increased coding for referrals with an average increase of 2.2% (95% CI: 1.7, 2.4, P<0.001) (Table 32, Page 54) and case finding for new QOF condition by almost 8% (95% CI: 2.4, 26.2, P<0.001) (Table 33, Page 55). However, no significant associations were found for intermediate outcomes (control of blood pressure, HbA1c, cholesterol and BMI) being achieved for the following underlying QOF comorbidities (CHD, diabetes and hypertension) with health checks.

Table 29 Association between health checks patient and practice characteristics

	Odds Ratio(95% Confidence Interval)	P value
Age	1.01 (1.02,1.02)	p<0.001
Male	0.87 (0.76,0.98)	P=0.03
Practice learning disability Register Size over 18 years	1.0 (1.0-1.0)	p=0.32
learning disability Practice Register size	1.0 (0.98,1.02)	p=0.81
Super Output Area Index of Multiple Deprivation	0.99 (0.97, 1.00)	p=0.17
QOF comorbidity (one or more)	2.9 (1.99, 4.21)	p<0.001
Year 2011 compared to 2010	2.0 (1.72, 2.31)	p<0.001

Table 30 Association between health check and learning disability specific information for both years

	Coefficient % (95% Confidence Interval)	P value
Research questions		
Difference in 'LD specific' informational domain between those who had a health check and those who did not	18.9 (18.3, 19.5)	p<0.001
Covariates		
Age	0.4 (0.02, 0.06)	p<0.001
Male	-.13 (-0.67, 0.41)	p<0.001
Practice list size over 18yrs	0.00	p=0.7
learning disability Practice Register size	-0.09 (-.16,-0.01	p=0.03
Super Output Area Index of Multiple Deprivation	-0.03 (-0.09, 0.02)	p=0.02
QOF comorbidity (one or more)	-.89 (-2.3,0.52)	p=0.22
Year 2011 compared to 2010	0.37 (-0.16,0.88)	p=0.17

Table 31 Association between health check and QOF specific information for both years

	Coefficient % (95% Confidence Interval)	P value
Research questions		
Difference in 'QOF specific' informational domain between those who had a health check and those who did not	20.72 (19.85,21.85)	p<0.001
Covariates		
Age	0.38 (0.34,0.42)	p<0.001
Male	-4.48 (-5.79,-3.17)	p<0.001
Practice list size over 18yrs	-0.00	p=.15
learning disability Practice Register size	0.07 (-.0.04,0.18)	p=0.23
Super Output Area Index of Multiple Deprivation	0.00 (-0.08,0.08)	p=0.97
QOF comorbidity (one or more)	16.31 (13.2,19.4)	p<0.001
Year 2011 compared to 2010	3.68 (2.84,4.53)	p<0.001

Table 32 Association between health check and referral information for both years

	Coefficient % (95% Confidence Interval)	P value
Research questions		
Difference in 'Referral' informational domain between those who had a health check and those who did not	2.2 (1.7, 2.7)	p<0.001
Covariates		
Age	1.0 (0.9, 1.00)	P=0.56
Male	0.83 (0.69, 1.0)	p<0.07
Practice List size over 18 years	1.00 (0.99-1.01	P=0.5
learning disability Practice Register size	1.01 (0.99,1.02)	P=0.24
Super Output Area Index of Multiple Deprivation	1.00 (-0.99, 1.01)	p=0.75
QOF comorbidity (one or more)	0.91 (0.55,1.5)	p=0.7
Year 2011 compared to 2010	0.81 (0.69,0.96)	p=0.01

Table 33 Results of regression analysis for QOF related case finding and health checks

	Odds Ratio (95% Confidence Interval)	P value
Research questions		
Difference in 'new QOF disease' coding between those who had a health check and those who did not	7.97 (2.42, 26.27)	p<0.001
Covariates		
Age	1.02 (0.99, 1.05)	P=0.27
Male	1.29 (0.51, 3.26)	p<0.59
Practice List size over 18 years	1.00 (1.00-1.00)	P=0.78
learning disability Practice Register size	1.01 (0.95,1.08)	P=0.62
Super Output Area Index of Multiple Deprivation	0.99 (0.95, 1.09)	p=0.53

5. Results from the qualitative studies

5.1 Demographic details of people with learning disability and carers interviewed

We were able to explore the lives of 32 people with learning disability (20 in East Lancashire and 12 in Haringey PCT). All were considered to eligible for health checks by their practice or the Community Learning Disability nurses. Nineteen of the participants were men (aged between 25 to 69 years) and 13 women (aged between 24 to 70 years) (Table 34, Page 56). Twenty one participants (10 men and 11 women) had received a health check and 11 had not (9 men and 2 women). The family carers and support workers were carers of the participants with learning disabilities.

Table 34 Overview of interviews undertaken for people with learning disability

	Participants		
	with learning disability	Family Carer	Support workers
Female	13	13	12
Male	19	7	0
Total	32	20	12

Table 35 Demographic details of participants with learning disability

		Gender	
		Male	Female
Ethnicity	White British	11	10
	Asian/ Asian British	4	2
	Black/ Black British	4	1
Age Range (years)		25 to 69	24 to 70

5.2 Demographic details of the health professionals interviews

A total of forty participants were interviewed (Table 36, Page 57). This included sixteen doctors (partners, salaried and trainee doctors, see Table 37, Page 57), seven practice/business managers, eight practice nurses/nurse practitioners and two health care assistants from twenty different practices. Four out of twenty practices were not delivering health checks at the time of the interviews. Seven Community Learning Disability nurses who had a working relationship with the practices in the two PCTS were also interviewed.

Table 36 Overview of interviews undertaken with health professionals

	GPs	Practice Managers/non-clinical partners	Practice Nurse/Nurse Practitioner	Health Care Assistant	Community Learning Disability Nurses
Female	6	6	7	2	5
Male	10	1	1	0	2
Total	16	7	8	2	7

Table 37 Overview of General Practitioners interviewed

	GP Partner	GP salaried	Trainee GP
Male	4	0	1
Female	9	1	1

5.3 Barriers and facilitators to access to care (getting an appointment with the doctor)

Irrespective of whether the participants had a health check or not there were a number of underlying factors which affect the care received. These are related to access to care which is often influenced by how communication is facilitated or hindered. A number of problems were highlighted with getting an appointment. For example, some commented on difficulties with using the telephone system by surgeries whilst others experienced problems with how appointments are allocated such as having to ring on the same day before a certain time.

'*I phoned up the surgery.. It's a bit hard to get through… you press 1 for booking appointments… yeah they (the receptionists) give you appointments when you need it.'* PwLD 032F (Had a health check)

'*whenever you're in the doctors it's like, ring us on the day, ring us before 9, well sometimes I'm not here before 9. I do my best but sometimes I'm dropping my kids off at school but sometimes I'm here 12 in the morning to 12 at night and that gets a bit difficult for me. Sometimes I say, 'can my brother have a home visit 'cos he's not feeling too good' - it'll be, well the doctor's on his home visits now and it's a bit too late - they give you a good telling off!'* Family carer 003M (No health check).

' *We find them (the practice staff) really good if you ring up for an appointment you can always get one, you know, perhaps not with a doctor you want but at least you get to see one and they'll always put you in as an extra*' Family carer 001M (No health check)

Community Learning Disability Nurses are able to facilitate access for some people with learning disability but same day appointment systems can also be problematic when people with learning disability need support as this may not be possible.

'*most of the surgeries we work with will allow the nursing team to make appointments in the future because we've got to fit them into our diaries you see. Nearly all the doctors surgeries, you've got to phone up on the day to get them (an appointment) - that doesn't work with our folk …*' Support worker 010M (Had a health check)

There was evidence of reasonable adjustments being made by some practices who routinely phone people with learning disability to make appointments for them for routine care and also to remind them of their appointment but there was also examples of this not happening with other health professionals who may work within the practice (dieticians for example) which suggests information is not being passed consistently across health professionals and may rely on individuals who know the people with learning disability well.

5.4 Barriers and facilitators to communication (talking to a doctor or nurse)

Effective communication is essential to the delivery of high quality services. Friendly and approachable communication is also essential for a patient to feel relaxed and able to say what they need to say, and ask questions. Both of these points are particularly important for people with a learning disability. There were examples of good and poor communication as well some evidence of reasonable adjustments being made. Problems with communication can occur at the practice level, at the individual level and across services (primary care and secondary care). Often communication is facilitated by family carers, community and hospital learning disability nurses, support workers and there is some evidence that Health Action Plans can also help.

5.4.1 At the practice level

How practices make contact with a person with learning disability is an important part of communication. When practices made contact to make appointments, some practices wrote to the individuals but no one interviewed said that their practices provided letters in an Easy Read format but some were advised in the letter that they could bring family or a carer with them. Appointment letters do not always make sense to people with learning disability which can lead to appointments being missed and people with learning disability often seem to rely on friends, family and carers to explain what a letter says. The method of contact and the information provided does not necessarily allow people with learning disability and carers to understand the difference between an appointment for a health check and other appointments which may be sent by a practice. Making contact and appointment by telephone appears to one way practices are making reasonable adjustments to how appointments are offered.

‵ *…she (receptionist) said we'd missed the referral, our yearly referral, you know. We call it a yearly- you know. So I said, "When did she miss that?" So she said, "Last year." I said, "Well, we didn't get any letters." I said, "If I'd have got a letter, it would have gone on the calendar.*‵ Family carer 019F (Had a health check)

5.4.2 At the individual level

Feeling that you know your GP is something that is valued by people with learning disability and family carers and there are many examples from the interviews of this making a difference to the care provided.

‵ *It was a bank holiday Sunday and he suddenly couldn't walk. He couldn't get up, he couldn't walk, he couldn't do anything so we rang the services, the out of hours services, and as luck has it, our own GP was on the, erm, emergency service that day.*

Anyway, we got him in, we had to actually take him in a wheelchair because he couldn't walk, and luckily our doctor knew all about his case because he's looked after him for a number of years, and he said, 'it's gout. I was very worried when you rang' and he told me because he thought it might be a DVT (a blood clot in the leg).` Family carer 007M (No health check)

There were also examples of poor communication during a consultation such as the doctor looking at the computer screen and not making eye contact with the patient when talking. Some people with learning disability would like longer appointment times with health professionals as they often feel rushed and do not have enough time to explain their problems.

`*I think it would help me if, like I say, I am bad at speaking, they would let me take my time and instead of saying ` Come on, spit it out`you know what I mean? That would be an ideal thing if they would let me do that.`* PwLD 008M (Had a health check)

`*Every practice should give people with a disability a bit more time to see them. Instead of 10 minutes they should get 15. Because then you can really get to tell him (the doctor) my problem. Because with 10 minutes, you tell him half of it then you've run out of time.`* PwLD 025M (No health check)

Families from minority ethnic groups face additional difficulties when trying to communicate with doctors about the person with learning disability and need the support of an interpreter who are not always available.

`*I sometimes manage to explain what the problem is but if I struggle, I ask one of the Asian staff members to interpret for me, or sometimes I get it written down but mostly the doctor understands what I am trying to say. If need be I take someone with me.`* Family carer 011F (Had a health check)

There were many examples of support workers and the Community Learning Disability team helping people with learning disability to make sense of what doctors are saying either during a consultation or later. Community Learning Disability Nurses also liaise with health professionals in different settings (hospital and community) and are often involved in helping to make best interest decisions.

Mike (PwLD): `*Like some of them like these doctors, sometimes they say these big words but I don't understand what they - they don't explain what they mean you know.'*

Support Worker: *'When Mike was diagnosed with diabetes, the doctor told you didn't he, and he phoned me up to tell me and I came round to see Mike and said to him, do you know what diabetes is, did the doctor explain….'*

Mike: *'Yeah he didn't actually explain what it were you know?'* 008M (Had a health check)

5.4.3 Across services

There are problems with communication across different health professionals working within the same practice and as well as across services. Services such as the NHS Breast Screening programme may send appointments directly to people with learning disability without making contact with the GP practice and thus may not be aware of the needs of the person with learning disability.

'It's one of these huge mobile vans. I could hear what was going on, I could hear them saying over and over again, when she (the technician) came out she said 'Who are you?' I said 'I'm her sister'. She said, 'Does Trudy have a problem?' I wasn't quite sure what she was asking and then she said, 'Does she have Learning Difficulties' and I said 'she does have Learning Difficulties.' Family carer 028F (Had a health check)

The presence of a hospital based Learning Disability Liaison Nurse has helped to improve communication across departments within the hospital and also within the community settings.

Health Action Plans appear to be used routinely for people who live in supported living environment or living independently and are in contact with the Community Learning Disability Team but families carers were either not aware of them or did not use them. They detail a personal plan about what a person with learning disabilities can do to be healthy and a record of what appointments and treatment people have had. They also contain information for health professionals on how the person likes to communicate and some people have a special Health Action Plan for hospital admissions and can be particularly useful in the case of emergency admissions. People with learning also find them helpful.

'They come in handy and you know where you're up to' PwLD 010M (Had a health check)

'The health action plan is his routine appointments, when he's attended the GP and what for, what was done just general things like that, there's a thing in it that simplifies it for Trevor when we do need to take him. What's going to be done and that's it. It just covers his medication, all appointments that Trevor has to attend, at

the GP, and just to make sure that we keep up to date with it and we make a record every time he goes.' Support worker 015M (Had a health check)

Choose and Book is a national service that combines electronic booking and a choice of place, date and time for first hospital or clinic appointments. In some cases patients need to telephone their chosen hospital directly to make their appointment. There appears to be possible problems in the way appointments are arranged through the Choose and Book system as some people with learning disability are unable to use the system. Some practices are however coordinating this process with the Community Learning Disability Team or Support Workers by informing them when someone has been referred.

'they just don't know how to use it so we have to make all the appointments for our clients. Choose and Book, the doctors will tell you, is an absolute nightmare because we can do it but our clients can't. They can't use the system they just don't know how to. And that's partly why surgeries has started phoning (the learning disability nurses)… because if they're making appointments I've got to be able to cover them but they just aren't able to use the Book and Choose system. So everyone who gets a letter phones me up and then we make appointments.' Support worker 010M (Had a health check)

5.5 Continuity of care

Some people with learning disability preferred to see the same doctor and family carers also valued being able to see the same doctor. However, there appears to be reluctance to change doctors even when there has been reason for complaint about the care delivered or people with learning disability may not be in a position to change their practice because of access issues.

There was evidence of practices understanding the needs of individuals and making reasonable adjustments.

'They are really good, erm, the receptionist like I said, if we ring up and we say who it is, they try and make sure that he gets his named doctor, because he knows him. And he (the doctor) has a good relationship with Trevor. Erm, whenever I've taken him anyway, personally, they've been really patient with him. And you know, allowed him time, and if he doesn't understand, they will try and reword it themselves, or they will allow us to explain it to him.' Support worker 015M (Had a health check)

Both family carers and support workers appreciated having access to practices and doctors who have an interest in learning disabilities and have been carrying out health checks for a number of years.

'I don't know who, which doctor he had then but it wasn't working whatever it was, and then when he went to (name of a local practice) they've (people living in the residential care home) all got the same doctor's practice. So really, really excellent, she's (the doctor) got time for him. She will literally see them at the drop of a hat, and listens to what you say and she's very interested in learning disabilities.' Family carer 027M (Had a Health Check)

There is also a suggestion that DES has helped to change the way some practices now respond to the needs of people with learning disability.

'It's taken, you know, a while to get on board with what were going on and then all of a sudden it just came to and now everybody knows what's expected and they (GP practice) send us a letter now to say your yearly review is due. We'd like to invite you for a yearly health check to see your doctor in surgery; you can bring a friend or carer with you. That were last year, you know. But before that yeah it were a bit, you know, well why are you coming just for a check up, you know, what's the point of it? But yeah we get one sent now to each one of them so they all get them.' Support worker 020F (Had a health check)

5.6 Views on the value of health checks

health checks, in the first instance, are not necessarily recognised as being different from routine care by both people with learning disability and family carers. This may in part be related to how information about health checks is communicated by practices. People generally felt that the health checks were useful and would be happy to have it again, although there were certain aspects of the health check which led to negative comments (such as having cervical smear done for example). The family carers of those participants who had not been offered a general Health Check felt it would be useful because some people with a learning disability cannot always say when they feel unwell.

'Cos I don't think he always tells you if there's anything wrong, he'll not, you know you've to guess sometimes, like you'll make certain foods and you can tell 'cos you'll think it's taking him ages to eat that and you'll say Luke do you not like that – well no not really – and so – why didn't you say?' Family carer 001M (No health check)

There seems to be a lack of information for family carers and perhaps expectation about the level of care that should be provided for people with learning disability.

'every year for a very long number of years, the practice that we all go to, the doctor's practice, they hold both a well man and a well woman clinic. Both Rose and

myself attend these, where all the things that you've asked John (blood pressure, blood tests, weight for example) , they do check mine and Rose's, but there's never been any indication that they wanted to see John, or that he could come with us, but to be perfectly honest I never thought about it.' Family carer 007M (No health check)

A health check would also be reassuring for family carers and it was also seen as an opportunity for health professionals to see people with learning disability when they are well so they can 'see their real personality' and can be a positive experience for family carers.

'he doesn't ever go to the doctor, you know they're always calling – 'come and have a health check' or whatever they call it. So I'm just glad I made the effort to take him because he wasn't unwell and it was nice for the doctor to see him.' Family carer 021M (Had a health check)

Some family carers would have preferred to have the health check done at home as the person with learning disability has mobility problems and there are difficulties with transport. In one particular case, the person with learning disability was invited for a health check but his family did not take up the offer because they could not get him to the surgery. The surgery had organized some care (flu vaccination) to take place in the home but not the health check.

'He's having a bit of a problem with his legs especially, so he's finding it very, very hard to walk and even making an appointment with the surgery, to take him for the flu jab or anything like that, he can't walk, he can't even put on a pair of slippers, so the doctors come home and give it to him.' Family carer 030M (No health check)

Most of the people recalled the experience of having health as being 'alright' or 'OK' but some people with learning disability find the idea of going for a health check confusing and can become anxious.

'He associates going to the doctor with being ill. So he doesn't understand the concept of going to the doctor for a health check, you know just to be checked over just to make sure there's nothing wrong. He thinks if he goes to the doctor, he's poorly.' Support worker*015M* (Had a health check)

However, some carers may not value the benefits of a general health check and this may be a reason why some people with learning disability may not be taken for a health check particularly those who live in residential homes as the carers feel they are likely to be seen quite often anyway.

> '*don't know it's hard to say really – we go because we know it's sort of an expectation to go but we don't always – in these people – in Tracy's case, in people who live in supported environments, I'm not entirely sure they're necessary because I'm quite confident they need to go to the doctors as often as they need to go if that makes any sense.*' Carer 004F (Had a health check)

For some living in residential homes, sometimes it is not easy to make a decision about what is best to do as the person with learning disability may get very upset when talking about anything medical or seeing anybody from the health care profession.

> '*It's just because we can't do any health checks on Stephen, you know, you can't even ask him. He suffered a few months ago, he suffered with little abscesses or ulcers underneath his armpits, which went away when he got some antibiotics but, the thing is you can't take him to the doctor's and at some point he's going to have to have a full* health check*, which he wouldn't agree to at all.*' Support worker 014M (No health check)

In this case a best interest decision was made with the support of a Mental Capacity Advocate, his carers, the Community Learning Disability Team and several health care professionals to carry out parts of the health check (such as blood test) whilst he is undergoing some treatment he needs under a general anaesthetic.

5.7 Drivers and Barriers to Normalisation: considering 4 key mechanisms

5.7.1 Coherence (making sense)

NPT predicts that for a new intervention to become normalised within practice, it must 'make sense' to the professionals delivering it. People must individually and collectively understand the purpose and value of the intervention, and understand why and how it is a necessary addition to existing care. Analysis revealed both drivers and barriers to normalisation in this area.

It was clear that practices and practitioners considered the 'sense' of the new intervention within the context of the wider service they were delivering. Sense making involved a complex consideration of a range of factors including the perceived value for participants, the impact on the wider practice, and the 'fairness' in the context of the wider population.

'We were looking at the, um, the actualities of the enhanced service: is this doable, is it achievable and, and so on…the evaluation was based on A, is it financially viable, B, is it doable..Is it achievable, have we got the resource, have we got the time, um, is it, is it worthwhile in terms of, um, patient care? So I guess we have to look at things and say well what value is there to the patient, um, you know, rather than just oh yes, well we'll do it because somebody else says we've got to do it. PM00610 Participated in the DES

'Because the demands…well you know what capacity's like in general practice. I mean the demands are such that you're going to address the things for which you're being paid because you probably don't have the capacity to do the things for which you're not being paid. So if they're going to move the money into something else that's the something else you'll do…' GP0430 Participated in the DES

'Because what we're doing, in essence, is we're using up time that would otherwise be used for a minor surgery list. And if we weren't getting the learning disability resourcing then we would be doing minor ops again in that time which is resourced.. to find an hour of clinical time at some other time of the week is just not practical, it's not possible because it's going to impact on other clinical services, there's isn't a time to create that unresourced in primary care.' GP0460 participated in the DES

The 'financial incentive' was insufficient motive for change in existing practice. Practices (including those which did and did not take part in DES) spoke of weighing up opportunity costs included interpretation of the 'value' of the new service (and whether it is seen as sufficiently distinct from usual care). Issues such as workload, lack of resources and the health check itself being considered as clinically of little value outweighed any financial reward.

'I seem to remember there was quite a lot of work involved, it seemed like the…the patients were actually getting more input than non-learning disability patients. They were getting a lot of annual checks on things; it didn't seem to make much sense to me.' GP0520 Did not participate in the DES

'I don't think it was financially worth it. I think as well as that the format in which it was seemed to me to be a luxury really that we couldn't afford… 'I think it's got to be taken in conjunction with everything else that's going on in the practice and all the other projects that we're working on. And there are many areas in which we'd like to improve, but we can't do it all is the conclusion that we've come to basically.'
PM0550 Did not participate in the DES

The mandatory training event provided a useful opportunity to reflect and make sense of the possible benefits of delivering health checks as well as provide necessary levers to engage members of the wider team through a process of dissemination and changes within the practices. For others the training highlighted the level of work necessary in order to deliver health checks in a manner that is comparable to that already delivered by specialist services and may in part explain why some practices have struggled to engage with the DES fully.

'Yeah, it did...I think it has given us quite a bit of opportunity to rethink access to services and what barriers might be there that we didn't realise were there, and I suppose the thing that came across to me was more thinking of the alternative methods of communication that would be useful.' GP0460 Participated in the DES

'I didn't do the training, but the training, the practice nurse and one of our receptionists, who's since left, went on it, and they both came back very enthusiastic from it, and actually the receptionist and the practice nurse actually did a practice meeting to cascade the training, and both of them were really excited by it. But it was a huge amount of work to sort of take it to the level that the training would have suggested they needed to have done.' PM0510 Participated in the DES

'There was nothing aimed at the GPs in the audience about practically how they need to go about what was involved in the physical assessment of the patient or what they're going to need to have to do, what were the options.' GP0550 Did not participate in the DES

Thus there was evidence that the DES acted to prompt team reflection on current care and the need or the opportunity to do 'something different' to the standard chronic disease management/QOF structures which are already in place. However, we identified evidence of discrepancy between management and clinical perception of the 'sense' of the intervention with a lack of coherence about patient benefit. The DES makes sense in theory but in practical terms it not clear to clinicians that it will address the challenges of daily practice and it was considered a 'luxury we couldn't afford' (PM0550) in the context of improving care for the wider practice. Although the DES makes it legitimate from a managerial and specialist perspective to prioritise certain aspects of care over others, this view is not shared by generalist clinicians. There is a lack of coherence about patient benefit from health checks and the DES fails to offer a coherent account of why clinicians should change practice – to focus 'only' on people with learning disability rather than others; and to introduce a specialist-focused population screening rather than individualised care approach.

5.7.2 Cognitive Participation (engagement)

NPT predicts that for a new intervention to become normalised into practice, there must be a key leader driving engagement with the work, who in turn engages all necessary members of the team to both start, and continue with, the health checks. This is important not only in agreeing to take part in the DES but also in starting health checks.

In all practices which took part, there was evidence of a clinical lead with interest or experience in this area willing to take on the additional workload of getting the health checks up and running. Often responsibility for the health checks stayed with this person, rather than being integrated into changes across the team.

The financial incentive appeared to be a facilitator for practices in signing up to, and getting started with, the learning disability DES. However analysis revealed that alone, it is insufficient to explain engagement.

Rather, a significant barrier to starting health checks in practice related to the practical process of identifying those patients who are eligible for a health check under the terms of the DES. This process of ratification of registers of eligible patients was seen mostly as an organisational process in which clinicians are less likely to be involved; but also identified as a key barrier to engagement despite the involvement of Community Learning Disability nurses in supporting practices. The social services registers which practices were expected to ratify their own registers against were generally not trusted by practices, and were considered to be inaccurate and inconsistent. Further inconsistency was related to how the DES defines learning disability, with health checks only being incentivised for those with moderate or severe learning disability and thus leading to a difference in patients identified on the QOF register (which includes patients with mild learning disability). This difference based on social needs versus clinical assessment resulted in some confusion and reluctance in engaging with the DES.

'The way I understand it is they have to be registered with the borough, and we're on the borders of the three boroughs, mostly we're in Haringey, but some of our patients are in Enfield and Barnet. And there's still this discussion, because the practices in Haringey, if I go and see patients for instances in Enfield, who's paying? Is it Haringey who'll pay or is it…whose responsibility is it and whose list is it? So we've had to try and get lists from the different boroughs to identify the patients, and then look at those patients, identify them with the lists that we have identified.' GP041 Participated in the DES

`The practice manager has been in touch with Social Services about checking that the patients that we have on our register are people who are known to the Social Service register. But how well valid that is I don't know because I don't...I haven't been involved with the discussion with the practice as to what Social Services have found, we've not had any clinical discussion, as clinicians we don't discuss things with Social Services.' GP046 Participated in the DES

'and especially with the mild learning disabilities that are just don't do…from our experience they don't really want to do anything with anybody who isn't moderate or severe but, to us, if you're moderate or severe, you're already in the system so you're getting some care, you're going to a day centre, you know, so you're already getting care, what we need is support with those that aren't already going to day centres and, you know, in our experience, we're getting nothing.' PN0580 Participated in the DES

'What I found in some practices they'd already had a go really and started to build a register of people with learning disabilities and when we went through that some of the people who they'd included I felt shouldn't have been included and when we looked, you know, sort of, into the notes and the history some of those people were perhaps people with behavioural problems or with mental health problems so mainly they were happy to remove those people, one or two practices were a bit more forceful in wanting to keep them on, but I usually won.' CN0571, Community Learning Disability Nurse

In summary, the presence of a 'clinical lead', someone who has an interest in learning disability appears to be a key element for practices signing up to and taking part in the DES but does not necessarily lead to wider engagement across a practice. A significant barrier to engagement lies in uncertainty over who to target, including distrust in the administrative process of forming and maintaining registers of patients. Staff already involved in providing health checks work to continue to provide care. However it appears that contractual motivation becomes important in maintaining care, with a suggestion that removal of the DES may lead to discontinuation of the health check in its current format.

5.7.3 Collective action (doing – delivering the health checks)

Here, NPT predicts that interventions will only become embedded if delivered by professionals with the necessary skills, who are in turn adequately supported/resourced for doing the job. Work should also be shared appropriately across the team; and the new intervention should ideally support (and certainly not undermine) the integration and collective working of the team.

Data here again shows evidence of supports and barriers to the normalisation of the intervention.

(i) Necessary skills

Health checks are being delivered by staff with varied levels of expertise and experience (Health Care Assistants, trainee doctors, practice nurses and salaried GPs) with some evidence that this may account for some of the variation in delivery of the health checks in terms of patient experience and data recorded. There is a recognition that certain aspects of the health checks (auscultation of the heart and abdominal examination for example) cannot be performed by nurses and health care assistants and systems of checks are not in place to review the level of care being delivered by trainee doctors. In some cases, this was identified as a barrier for taking part in the DES. One Practice explained it was unable to take part in the DES because it required medically trained staff to deliver health checks, not nursing input; a resource which was not available.

(ii) Resources

Further variation in practice related to the recommended use of the 'Cardiff' health check protocol which is considered by some to be rather too long and cumbersome and clinically unnecessary. This seems to be corroborated by health checks observed by Community Learning Disability nurses supporting their clients through the health check. Although templates provide structure for practice nurses and health care assistants, GPs on the whole were resistant to using such templates and consider their clinical/diagnostic judgement a more appropriate use of their time.

'We looked at the Cardiff questionnaire, and then the suggestions for the examination and the follow-up and everything. And in the end I think we made modifications to that questionnaire and we may be added some things and took away

others, so it's not exactly as the Cardiff one is published, so it's slightly different. But I think that's still permissible as far as I understand, as long as you're doing certain things, and that works quite well.' GP041 Participated in the DES

'Well we found the (Cardiff) template was rubbish actually, the examination side of it, we felt it was very restrictive, old fashioned medical student model type. So we don't do that. We started off going through the template and we've very quickly adapted it so we tend to, you know, go with what the patients' problems are, make sure we do basic examination.' GP0650 Participated in the DES

'I've got misgivings about the widespread appropriateness of doing blood tests on everyone and, personally, feel that should be over forties unless they're significantly over weight and thyroid function tests for Down's Syndrome people….and the other people where there's a real difficulty with is with severe learning disabilities who are just too agitated to be able to take any blood off and that could be a real difficulty, you know, I can do a finger prick but with some there's just no way, unless they were under a general anaesthetic that you can take blood.' GP0590 Participated in the DES

*'Out of the fifteen clients on the caseload, I think I've supported three and all the checks have been slightly different as well. The first one I did was quite a, just a quick, not as in depth a check as I thought it was going to be, and I didn't think the practice filled in, didn't ask as many questions as they should have done, what was on the Cardiff health check. The other end of the scale was that another practice was absolutely fantastic and the GP led the check, not the practice nurse, and it was really thorough and really, you know, it was completed really well.'*CN0573 Community Learning Disability Nurse

(iii) Capacity for flexibility

Allowing flexibility in how practices structure health checks based on the resources available to them makes it more likely that a practice will deliver health checks. However this also contributes to variation in the process of delivery of health checks. Although there was recognition that this may lead to variation in the quality of the health check itself (dependent on the person delivering the health check) the ability to design locally appropriate approaches to delivering health seem to outweigh the benefit of using a structured template such as the Cardiff Template

For example, in some practices health checks are being delivered by one member of the team (GP partner, salaried GP, practice nurse/nurse practitioner or trainee doctor) whilst others involve a combination of team members working together (usually a general practitioner and either a practice nurse or health care assistant).

'so what I eventually did was when we got the FY2 doctors (trainee doctors) in, as part of experience to them going out into the community and seeing what the community is rather than just purely hospital doctor, see what the community is like we decided we'd say during your formal visit here I'd like you to go and see these people in nursing homes and give them a check over ... health check.' PN0420 Participated in the DES

(iv) Shared working

Practices who rely on a single member of the team to deliver health checks (either a practice nurse or GP) feel there are a number of advantages to this including a greater level of continuity of care (knowing the patient) and confidence in delivering health checks. However, such structured care is less likely to lead to changes across the team in terms of how patients can access care or how care is delivered for other aspects of their care. For example, changes made to systems for communicating (inviting patients for appointments, providing appropriate health information) and delivering health checks (longer appointment times) are unlikely to be shared within a practice and unlikely to lead to change in how routine care is provided beyond the health check. This also has implications for ongoing participation with the DES should there be any change in personnel at these practices. In summary, the presence of a 'clinical lead', someone who has an interest in learning disability appears to be a key element for practices taking part in the DES and implementing health checks but does not necessarily lead to change across a practice. The delivery of health checks can be delegated to one or two people within a practice who either have interest in learning disability or are considered to be the most appropriate persons but this does not necessarily lead to change across the practice. Thus changes made to systems for communicating (inviting patients for appointments, providing appropriate health information) and delivering health checks (longer appointment times) are unlikely to be shared within a practice and unlikely to lead to change in how routine care is provided.

There appears to be a need for greater flexibility in letting practices design locally appropriate approaches to delivering health checks and this is being done to some degree by some practices seeking to adapt/modify what they consider as useful aspects of the Cardiff Template to fit their own model of care.

5.7.4 Reflexive Monitoring

Finally, NPT predicts that for a new intervention to be integrated into practice, practitioners must get feedback about their work. Which in turn supports an individual and collective appraisal that health checks are worth the effort, and also adaptation of the intervention to suit local needs.

Although a process of feedback exists between PCTs and practices (practices undergoing training, ratification of registers and number of health checks delivered annually) as a process for achieving payment, there is little evidence for other forms of formal external feedback. For those practices who consider generating income as a facilitator for taking part in the DES, this alone is unlikely to lead to normalisation of health checks into routine practice once any incentive is removed. There were examples of practices using significant event audits for reviewing care and making changes to delivery of care but such mechanisms do not appear to be routine and more likely to be a mechanism of other processes (QPA or part of trainee doctor audit).

All Practices were actively engaged in reflexive monitoring of the processes of care. Generally, this reflexive monitoring added to a questioning of the value of the DES.

In two of the practices, who had recently achieved the Royal College of General Practitioners Quality Practice Award (QPA), health checks were considered to be part of routine care as these practices felt they were already providing good clinical and technical care and the DES itself added very little to clinical care.

'I think that the approach that we try to take is to integrate the learning disability checks into normal practice, it's how we would try and deal with anyone whether they've got a coded diagnosis of a learning disability or not, that we would aim to meet their needs as best we can with a variety of resources.' GP0461 Participated in the DES

For some, the DES has simply legitimised the level of care they were already providing to their practice population however this had not necessarily led to integration with work of the wider practice team (including the Community Learning Disability team).

Any informal feedback (patients and carers for example) has been mixed and tends to work at the individual level and mechanisms in place at the practice level (patient satisfaction questionnaire or practice patient group) were not identified as methods for reviewing the impact of the service being delivered to people with learning disability.

6. Discussion

6.1 Quantitative Data Analysis

6.1.1 Prevalence and uptake of health checks

The overall prevalence of learning disability for 2010 in the study PCTs is slightly higher comparable to the PCT prevalence rates available from QOF data available for 2010 (0.39 vs 0.35 (Table 10, Page 41). However, prevalence in Haringey is much higher for the study population (5%) compared to the PCT level. As it was only possible to extract data from 4 practices in Haringey, this is likely to be due to selection bias, as individually, data for these practices are consistent with the QOF data available for these practices. The number of health checks delivered increased from 30.9% in 2010 in these 6 PCTs to 41.5% in 2011 (see Table 14, Page 43). Although this is lower than the submitted figures by the PCT, this may in part be related to how the DES data submitted differentiates between severities of learning disability and excludes those with mild learning disability. The coding for severity of learning disability is poor with only 24.7% (949/3928) of patient records noting the level of severity in 2010, increasing to 27.9 (1125/4032) in 2011.

6.1.2 Case finding, screening and health promotion

From the 160 practices for which we have data for both years, the number of patients identified as having learning disability increased between 2010 and 2011 with an additional 249 learning disability patients (5.3%) identified. These figures are consistent with findings of the Public Health Observatory for learning disability, suggesting that the learning disability DES is leading to improved coding of people with learning disability [45].

The increase in prevalence of epilepsy (17.8% to 21.3%) would suggest that this may be related to an improved coding behaviour in practices rather than case finding (Table 23, Page 48). However, the increasing levels of screening activity undertaken may also have led to increased identification of underlying medical conditions (Table 19, Page 45 and Table 20, Page 46). Overall, screening activity was more frequent in those who have had a health check compared to those who did not.

An increase in the importance of health promotion and disease prevention is highlighted by its inclusion in the General Medical Council's guidance, *Good Medical Practice*, which states that professionals should "encourage patients to take an interest in their health and to take action to improve and maintain it. This includes advising patients on the effects of their life choices on their health and wellbeing" [46]. Before health professionals can promote health promotion activity, they need to be aware of what those needs might be. These include assessment of alcohol use, exercise, diet and smoking status, all which were more likely to be associated with a health check (Table 17, Page 44 and Table 18, Page 45).

Overall, health checks were associated with a greater level of screening activity, assessment for health promotion and recording of QOF-related diseases. These findings are consistent with pooled analysis of data from a number of small trial studies which confirm the increased clinical activity associated with health checks [47].

6.1.3 QOF comorbidity

In our 2011 data, the most common QOF-related diseases recorded were epilepsy (21%), depression (12%), asthma (11.9%), thyroid disease (8.8%) and mental health problems (7.2%). The level of obesity also increased from 35.8% to 38.2% over the two years but this is largely explained by the increased number of patients with a coded value for BMI in 2011 (2298/4032, 57%) compared to 2010 (1897/3928, 48%). The prevalence of epilepsy was much higher than the general population – a finding consistent with previous studies [4, 48]. The prevalence of obesity was greater than that identified in a recent study using General Practices Research Database (22%) but this study used data prior to the introduction of the QOF indicator for practices to keep a register of people with learning disability and used Read codes suggestive of learning disability to identify patients with learning disability [49]. The higher level of obesity amongst persons with learning disabilities is likely to be associated with an increased risk of diabetes (increased to 6.3% in 2011, Table 23, Page 48).

Regression analyses reviewing the impact of the health check on intermediate outcomes (control of blood pressure control, cholesterol and HbA1c levels) showed no association with health checks. Rates of exception reporting were high for people with learning disability compared to national rates (12.3% vs 6% overall). Higher rates of exception reporting for learning disability patients were apparent for a number of QOF-related conditions compared to national figures, for example: epilepsy (8.12% vs 7.2%), asthma (7.4% vs 5.36%) and COPD (32% vs 8.94%).

6.1.4 Learning difficulties specific processes

The use of templates within clinical systems is likely to lead to data around visual assessment, hearing assessment, and mobility assessment being recorded as templates standardise the diagnostic codes. The overall low level of recording information of learning disability specific process makes any comparison between those who had a health check compared to those who did not difficult. However the health professional interviews would suggest that part of the reason for the low level of recording of may be related to health professional only coding information which they consider to be clinically relevant. Comparison with non incentivised processes, such as testing for anaemia, suggests that clinical judgement is being used to decide which assessments to carry out on an annual basis (54% of those who had a health check had their haemoglobin check in 2010 compared to only 15% in 2011).

6.2 Findings of interviews with people with learning disability and family carers

This study has explored the lives of 32 people with learning disability, where possible, through their own words and sometimes with the help of those who care for them, particularly family carers.

The findings identified a number of obstacles affecting delivery of health care to patients with learning disabilities particularly in relation to access and communication irrespective of whether they had a health check or not.

Most people who have learning disabilities have difficulty in communication and understanding. This can make an appointment difficult for the doctor or nurse and result in the patient not understanding the consultation, treatment or advice given but getting an appointment in the first place can be challenge in itself because of complicated phone systems and rules for when and how an appointment can be made on the day or in advance. Even family carers and support workers struggle to use the system effectively. Co-ordination across services is problematic with important information about the needs of the person with learning disability known by one service but not being passed onto another provider.

The Disability Discrimination Act (2006) introduced the expectation that services will make ‘reasonable adjustments’ to enable fair and equal treatment and access for people who have disabilities and the 2010 Equalities Act provided greater clarity on the duties of public sector bodies [50]. Health services should ask themselves 'What extra things do we need to do, so people with learning disabilities can get health services as good as other people?’

This might be

- Making sure that information on health services is accessible to people with learning disabilities
- Nurses with special skills helping to care
- Giving people more time with doctors and nurses
- Making sure that annual health checks happen for everyone and that health problems are treated

The interviews identified several ways that health professionals are making reasonable adjustments to the service in order to improve the quality of service offered to people with learning disability.

These included adjustments in the way services could be accessed:

- Some practices routinely phone people with learning disability to make appointments for them for their health check and to remind them nearer the time for those who cannot read or are confused by the appointment letters.
- Offering appointment times at the beginning or at the end of the surgery and reducing the waiting time in the waiting area for those who find it difficult to wait for any length of time.
- Offering home visits for those who would struggle to get to the surgery.
- Coordinating care with Community Learning Disability Nurses who help to make appointments and support during a consultation to make sense of what doctors are saying.
- Learning Disability Nurses working in the hospital and secondary care setting help to improve access to services across different settings including adjustments to how appointments are made through the Choose and Book system.
- Health Action Plans are being used by some people living in supported living or living independently to help health professionals understand how the person likes to communicate and can be particularly useful in the case of emergency admissions.

Continuity of care bears an important relationship with the quality of care over time. There are several perspectives on this. Traditionally, continuity of care is idealized in the patient's experience of a 'continuous caring relationship' with an identified health care professional [51]. Being able to see a doctor 'who knows you' is valued both people with learning disability, family carers and support workers. Family carers had a positive view on the care provided and the relationship with their general practice which as in keeping with previous studies [28] and were reluctant to give negative feedback. A positive view was held even in those who had not had a health check which would suggest that carers may not seek extra care or question current practices as they feel they have a good relationship with the practice. This satisfaction with care, despite obvious room for improvement in some instances seem to stem from family carers comparing care being received now to care received in the past.

It would seem from these interviews that practices who have been carrying out health checks for a number of years and those practices who were in the process of carrying out health checks for the second year through the DES have changed the way they respond to the needs of people with learning disability leading to improved perceptions of the care being provided, however, this appears to be patchy and dependant on a small number of health professionals.

6.3 Health Professionals' Views

This study has explored the views of general practitioners, nurses, practice managers and Community Learning Disability nurses on delivering health checks to people with learning disabilities through a DES. Current health policy through the DES has aimed to overcome previously identified barriers to the delivering health checks by general practitioners and nurses including lack of training and experience, a low priority for managing this group of patients and poor co-ordination between primary care and specialist services such as learning disability teams. The DES for learning disability was designed to address these barriers through providing training, raising the profile and priority of learning disabilities by providing an additional financial incentive to practices, and providing a mechanism for Community Learning Disability teams to engage with general practices.

Our findings suggest that these were insufficient to address the changes needed to provide sustainable change in practice to normalise health checks for people with learning disability into usual practice. Training was not adequately targeted to the needs of the Practices; financial incentives do not 'raise the profile' of this patient group when compared with the wider context of the GP role, and engagement with CLD teams was limited by problems with shared understanding of who needs care and what care was needed.

In summary, our findings show that key drivers and barriers to the introduction of health checks include:

Table 38   Facilitators and barriers to the introduction of health checks

	Facilitator	Barrier
Making sense	Perceiving a value to health checks, over and above usual care	Lack of coherence : gap between clinical and management perspectives; and between specialist and generalist perspectives
Engaging	Financial resource to support implementation and/or as the justification for prioritising care for this group (and hence removing resource from elsewhere/not doing something else)	Lack of clarity on who to target /who needs care
Doing	Resources – existing presence of skills (and interest) within practice, possibly enhanced by training	Lack of skills a barrier Inappropriate resources a barrier – eg wrongly targeted training, or inappropriate implementation of an unsuitable tool eg the Cardiff tool. Failure to adapt resources to primary care environment Lack of sharing across team/systems changes, rather than just delivery by 1 or more persons
Monitoring	Contract acts as feedback that work is externally valued	Limited feedback Reflexive evaluation often contributed to uncertainty/lack of engagement with value of process

6.3.1 Generalist versus specialist perspectives

Coherence issues reveal a failure to consider learning disability within the broader context of a generalist primary care service. Though many practices could see value and purpose in health check in principle, in practice their interpretation is from a generalist perspective and how this fits into the wider goals and priorities of the practices' efforts to deliver a person centred model of care. The value of the intervention is then questioned as it is less clear how the work differs from other aspects of care; it becomes harder to justify the focus on this group of patients over others; and the opportunity cost of implementing the approach becomes harder to justify.

The findings from the concurrent quantitative study would suggest that health checks have helped practices to either identify pre-existing comorbidity (such as epilepsy and diabetes) or improve coding of these conditions in patients with learning disability. These patients are then more likely to be part of routine call and recall system through QOF [52]. QOF data supports practice perceptions that these patients, once recognised are given a comparable level of care to patients without learning disability for existing comorbidity.

6.3.2 Reviewing the process of delivery of care

Health care professionals recognise a need for something different to care for patients with learning disability, but do not necessarily agree the current structure of the health check through the DES meets the need. Processes for defining need, including the distinction and separation of people with mild learning disability as not being eligible for a 'health' check, appears to be a significant barrier to practices in engaging with the DES.

Health professionals touched on the issue of access to care and examples of reasonable adjustments were provided by some, however, improving access through the DES was largely not considered as an important reason for taking part in the DES or as a reason for health checks not becoming embedded within practice. Health checks were seen as of value for improving continuity of care but communication problems across services (ratification of registers for example) was seen as a barrier to delivering health checks.

6.4 Strengths and Limitations

This study adds to the limited literature on the views of people with learning disability and family carers on the acceptability of health checks for patients with learning disabilities. The qualitative nature of the study has enabled a thorough analysis of the views of people with learning disability and family carers due to the study design. It was possible to recruit participants from varying socioeconomic backgrounds and ethnicity. This study also explored views of participants who had undergone a health checks as well as those who had not including those who had refused to have a health check.

Limitations include the fact that it was only possible to recruit one participant who was being looked after by their family and had actively refused to have a health check but informed dissent does not appear to be common problem. We were unable to identify anyone younger than 24 years of age and it would have been useful to gather views of participants who were closer to the age of 18 years to gain insight into their experience of being offered a health check.

This study also adds to the limited literature on the views of health care professionals on implementing annual health checks for patients with learning disabilities. The relationships built over the last four years with these practices, allowed access to views of health professionals. Based on the findings from study with people with learning disability and family carers, it was possible to interview practices and explore areas of variation in experience of care provided.

The study is limited to views from two areas which may not necessarily reflect the views of practices across England as there are PCTs were the uptake of health checks is much higher and some which are considerably lower.

The qualitative nature of the study has enabled a thorough analysis of the views of general practitioners and nurses and other health professionals involved in the care of people with learning disability.

The study’s strengths lie in the use of theory to support the analysis – supporting generalizability and findings from this study has implications for other services structured in a similar way to the learning disability DES.

A greater number of practices were recruited then planned for the quantitative study.

There may be selection bias in terms practices wishing to take part in this research, particularly for Haringey PCT. All practices taking part in the DES in East Lancashire were recruited to the study, although due to technical reasons, it was not possible to extract data from 3 practices for either 2010 or 2011 data.

The data extraction process is not a true reflection of the level of care provided by practices. Not all data could be extracted on the frequency of consultations, or the person delivering the care (nurse, GP or healthcare assistant). We also could not determine the place where consultations took place (home visit or surgery for example).

The data also does not directly capture a number of conditions which are not incentivised by QOF but which are likely to affect people with learning disability. These include dermatological problems such as eczema, and musculoskeletal problems such as osteoarthritis and back pain. Reactive care related to managing infections (chest and urine infections for example) was also not analysed.

Most practices used electronic templates, but some used a paper record for collecting information, thus the true extent of the assessment being carried out during the health check may not have been electronically coded.

7. Recommendations

- Funding for annual health checks should continue as this is leading to increased case finding both in terms of number of people with learning disability and level of comorbidity. Our findings would also suggest that practices are unlikely to continue health checks as they are structured if the funding is stopped.
- The DES should providing funding for health checks for all people with learning disability on the QOF register (including those with mild learning disability).
- The health checks appear to be associated with significant coding activity for QOF incentivised health screening, promotion and disease finding. However, there is considerable variation in coding of the other aspects of the health check, such as hearing assessment and visual assessment, which would suggest there may be resistance in undertaking certain aspects of the health check. We need to know more about the reasons for this. Whether it reflects lack of shared understanding of the value or problems with resources/facilities to conduct the tests.
- PCTs and the newly forming Clinical Commissioning Groups should also be asked to report on the number of practices taking part in the DES and the number of health checks being delivered at the practice level.
- A significant outcome missing is the level of input from other parts of the NHS which may be providing care to people with learning disability. Linking data with secondary care information (for example Hospital Episode Statistics and mortality data) should be a focus of further research.
- Further research is needed to review quality of health checks and variation in outcomes and how this may depend on the health professionals involved in the health check.
- The problems with the current process of checks including the variable uptake of the health checks across the country would suggest a need to revisit the model of learning disability health checks and develop a new approach to learning disability health checks in collaboration with people with learning disability, carers and health professionals.

8. Conclusion

The recording of health checks increased over the two years of this study with greater numbers of patients identified with learning disability. Health checks were associated with increased identification of disease conditions incentivised through the QOF. Health checks were also associated with increased screening and health promotion activity, with process incentivised through the QQF more likely to be recorded. Although processes which are specific for learning disability were also more likely to be recorded through a health check, there was considerable variability in the level of recording.

However, our results suggest that additional barriers exist to the introduction of health checks for people with learning disability which were not considered within previous research and therefore within the DES. These include understanding the generalist nature of primary care and the wider context in which changes are being made. Our evaluation of the implementation of the DES, supported by Normalisation Process Theory (NPT) has revealed a number of important insights into practice which may support development of future policy. The authors suggest using NPT within a multi stakeholder consultation to review and revise the care for people with learning disability and thus develop approaches to supporting the delivery of person-centred care for people with learning disability.

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Appendices

Appendix 1 Project Management

1.1 Research Team

Dr Umesh Chauhan is a GP and a Clinical Research Fellow at the University of Manchester. His clinical, academic and policy work have focused on developing expertise in addressing the systems and context issues needed to tackle inequalities.

Dr Evangelos Kontopantelis is a NIHR Research Fellow in medical statistics at the University of Manchester. His expertise includes the Quality and Outcomes Framework, complex interventions, large primary care databases and meta-analysis.

Dr Tim Doran is a NIHR Senior Clinical Research fellow in Public Health at the University of Manchester. He has expertise in health policy, health inequalities and physician incentives.

Dr Pauline Nelson is a Research Fellow at the University of Manchester.

Dr Susan Hinder is is a freelance qualitative researcher working for academic institutions, primary care and acute NHS Trusts.

Dr Joanne Reeve is a GP and an NIHR Clinical Scientist with clinical interests in developing generalist solutions for complex health needs. She is developing a body of work on enhancing Generalism through Scholarship at the University of Liverpool.

1.2 Research Advisory Group

The project advisory group met on three occasions during the course of this research and along with the researchers includes the following members:

1. Professor Eric Emerson, Professor of Disability & Health Research Centre for Disability Research, Lancaster University
2. Mr Stephan Brusch, Service Development Manager, Primary Care and Learning Disabilities, National Health Service (NHS) Westminster
3. Mrs Gwen Moulster, Nurse Consultant Learning Disabilities, Haringey PCT
4. Mrs Helen Gorton, Assistant Integrated Service Delivery Manager, Learning Disability Service, East Lancashire PCT.
5. Mr Tony McGrath, Community Learning Disability Nurse, East Lancashire PCT
6. Professor Helen Lester, Professor of Primary Care, University of Manchester
7. Mrs Karen Flood, Person with Learning Disability
8. Family Carers-Mrs Jill Darnborough and Mrs Susan Miller

1.3 Funding

These studies were funded by the Department of Health and supported by the National Institute for Health Research, through the Primary Care Research Network:

1. The views of people with learning disability and carer’s:
http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=9376

2. The views of health professionals on delivering health checks:
http://england.ukcrn.org.uk/StudyDetail.aspx?StudyID=9502 and

3. Practice data to evaluate uptake and quality of health checks:
http://public.ukcrn.org.uk/search/StudyDetail.aspx?StudyID=9186

Appendix 2 Ethical Issues related to interviews with people with learning disability

Research involving people with learning disability raises complex ethical issues. There is a need to balance the ethical and practical complexities of conducting research with people with learning disability including a) access and gatekeeping issues and b) gaining informed consent in a population who by definition may lack capacity (at some level); versus the right for all to take part in research which shapes the future of their health care, and the right to potentially benefit from being in a research study (linked to previous experience and evidence that people enjoy, and even find useful, the opportunity to sit and reflect on past health experiences).

The following steps were taken to support decision making related to research involvement for people with learning disability which is in accordance with the best interests of the individual with learning disability.

2.1 Recruitment

1. Recruitment: Since health professionals involved in their care played a key role in recruiting of participants, and therefore acted as important gatekeepers, their views were actively sought in relation to the benefits and rights of asking people with learning disability to participate in research as well as the potential for harm (at the stage of signing practices up for the study). Interestingly enough, one of the practices initially approached to take part in the research, declined to take part in the research as they were 'not happy about their patients or carers being interviewed.'

2.Recruitment: Obtaining consent for research team to contact person with learning disability living alone in a supported environment : Any individuals identified by the general practitioner as potentially lacking capacity to understand the invitation letter/patient information sheet were flagged up to the learning disability support nurse who arranged to visit the patient to assess whether consent needed to be obtained through a personal consultee (family or friend who has a role in caring for the person who lacks capacity) who would be able to provide informed consent (for the research team to make contact with potential participants via the personal consultee).

3. When a completed prior expression of interest to be interviewed form was received by the research team did the research team make contact with the individual or the personal consultee.

4. There was small group of participants who were assessed as not having capacity to consent to research by their GP or by the community learning disability nurse but it was not possible to identify a personal consultee; in such cases consent to interview the participant was sought from a nominated consultee.

As the study involves a vulnerable group, professionals who have experience in the area of learning disability have been involved in all aspects of recruitment, data collection, data analysis, reporting and will be involved with dissemination. Although it was not possible to use the expertise of a person with learning disability in collecting data in the field, it has been possible to do so in the analysis of the data and will be part of the process of disseminating the findings.

2.2 Informed consent

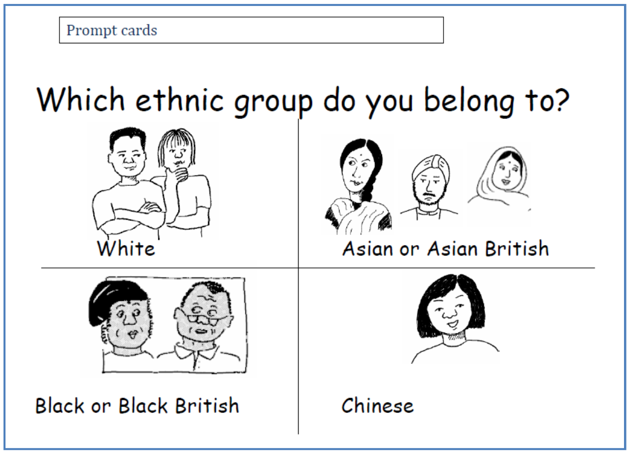
Where possible any individuals identified by the general practitioner as potentially lacking capacity to understand the invitation letter/participant information sheet were flagged up to the learning disability support nurse who arranged to visit the participant to assess whether consent needed to be obtained through a personal consultee (family or friend who has a role in caring for the person who lacks capacity) who would then be able to provide informed consent for the research team. Participants who agreed to take part in the research either by completing the expression of interest form or those who contacted the research team through the health professionals involved in their care were then approached directly or through their personal consultee to take part. Interviews took place in a place convenient to the participant.

The researcher obtained consent at the time of the interview either from the person with learning disability, personal consultee or nominated consultee.

During the consent interview, potential participants were given a written information sheet and consent form, or had this form read to them using participant centred pictorial prompt cards, and given opportunity to ask questions prior to giving consent or not. For those adults lacking mental capacity, we still used the consent procedure to ensure participants had an opportunity to say 'no' to taking part and written consent from their personal consultee (family carer for example) or nominated consultee (GP or Community Learning Disability Nurse) was taken before any interview.

Appendix 3 Interview Schedules

3.1 People with Learning Disability Interview Prompt cards (not actual size)



Prompt cards

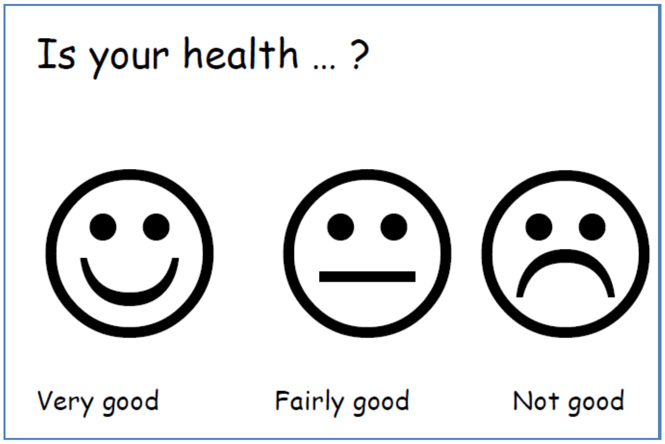
Which ethnic group do you belong to?

White

Asian or Asian British

Black or Black British

Chinese

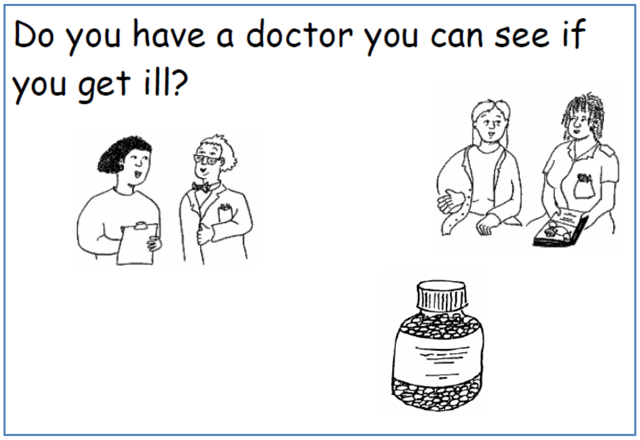


Is your health … ?

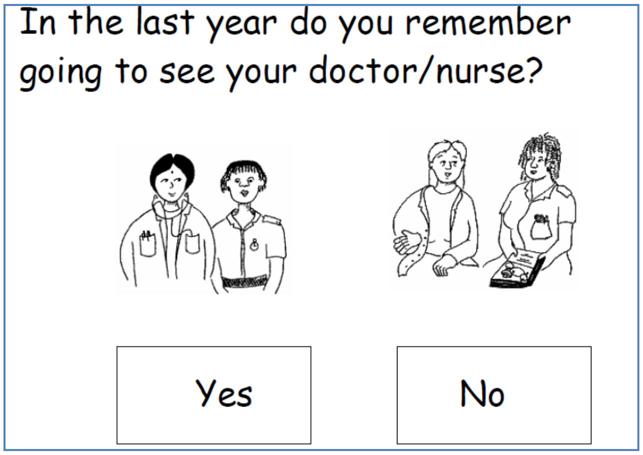
Very good

Fairly good

Not good



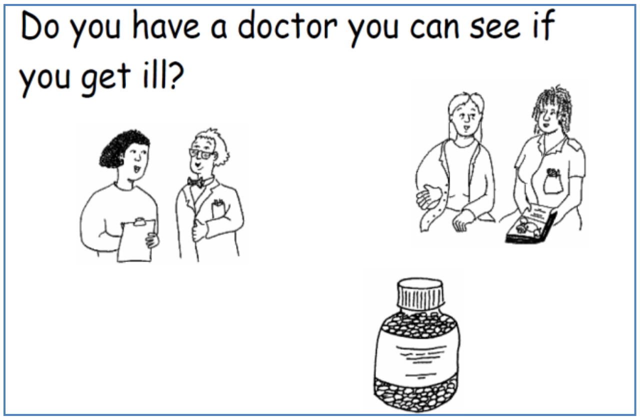
Do you have a doctor you can see if you get ill?



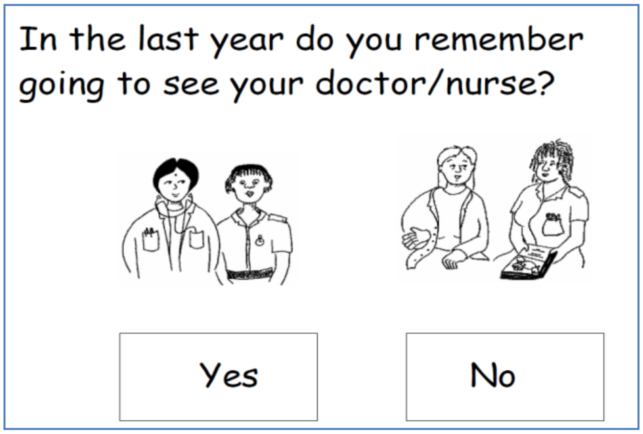
In the last year do you remember going to see your doctor/nurse?

Yes

No



Do you have a doctor you can see if you get ill?



In the last year do you remember going to see your doctor/nurse?

Yes

No

When my doctor wants to see me…

Letter

Telephone

Home

Was your visit to the doctor…?

☺	😐	☹
very good	fairly good	not good

Were the staff at the practice….?

☺	😐	☹
Very Helpful	Fairly Helpful	Not helpful

Were you given **time** to say what you need?

In the last year, have you been …?

To the dentist?

For an eye Test?

For a hearing Test?

Have you ever been …?

For a cervical smear test?

To have your breasts Checked?

In the last year, have you….?

had your Blood Pressure taken

been Weighed

had Blood taken/injection

3.2 Carers Interview Schedule

Demographic Detail

Age

Gender

Ethnicity

Background and general health

- Can you tell me about your relationship with X, what do you do for him/her (probe: domestic, personal care tasks, other kinds of support including any involvement in health care)
- How would you describe X's health?
- How often has X seen the doctor or nurse over the past twelve months? (Probe reasons for this).
- Has X attended a) the dentist b) for an eye test c) hearing test during past twelve months?
- Is X under the care of any specialist at the hospital?
- How would you describe your relationship with the health care practitioners at your practice?

Health check

- Was X invited to have a health check recently?
- How was X invited? (letter/phone call/other?)
- Did X accept or not?

IF NOT: why not? (probe past experiences with GP, frequency of attendance at practice, other issues)

IF YES:

- Where did the health check place (home/at the practice)?
- Did you accompany him/her? If not, did someone else go along?

- How easy was it for you to get to the appointment/practice?
- How long did you have to wait before you saw the nurse/doctor? What was it like waiting? How did you find the practice staff/receptionists whilst you were waiting?
- Is there anything that could have been done better?
- What happened during the health check? (probe: blood pressure taken, weight checked, smear, breast examination, general questions about X's health etc)
- How helpful did you find it? How helpful do you think X found it?
- What was good and bad about it? (probe: were you able to raise any concerns you might have had, did you/X feel comfortable talking to the doctor etc)
- Would X be happy to go again do you think?
- Any other points you would like to raise?

3.3 GP Practice Health Professionals Interview Schedule

Practice ID

Practice Status: GMS/ PMS/training practice

Number of partners/salaried GPs

List size (approx)

Number of participants with LD

Gender

Age

Years in General practice

Are you taking part in the LD DES?

If NO, can you take me through how your practice came to that decision?

(see questions below)

If YES

TRAINING ISSUES

Was your practice offered training on how …?

Who from your practice went for that training?

What was your overall impression about this training?

HEALTH CHECK PROCESS

Do you use a template to structure the health check and record information?

Is this one you have created yourself or one that was added to your system?

Who does the health checks in the practice?

How did you invite participants?

(letter, phone, visits etc)

Do you invite everyone on your register?

Did you have to change the way you invited people for a health check?

e.g. some people use a letter with pictures.

On average how long did it take you to conduct the health checks?

Did you have to make special arrangements for carrying out the health checks?

Time when appointments offered?

Length of appointment?

Rooms used?

CREATING A REGISTER

How accurate do you think your register is?

Did your practice have the register ratified by the community team with the social services register?

What were thoughts about this process?

Did this increase or reduce the numbers of people on your register?

CURRENT PRACTISE

Were you carrying out health checks before the DES?

FUNDING ISSUES

Would you carry on with the health checks if there is no funding for them in the future?

Do you think the funding is adequate for the workload it creates for the practice?

POLICY ISSUES

How else do you think appropriate care could be delivered to people with LD?

What is role of community LD teams?

What is the role of secondary care/specialists?

What should be the role of primary care in commissioning services for LD in the future?

How do you think the proposed changes to primary care will affect the care delivered to people with LD?

Who else in your opinion should be involved in structuring/designing care for people with learning disability in the future?

Are there other areas of clinical care where you think ideas or best practice could be applied or used to help improve the quality of care for people with learning disability?

CARERS ISSUES

Increasingly, carers are now are elderly and are at a stage where they need caring for, how do you think this group should be supported in primary care?

QOF AND LD

Many people with LD have other conditions such as obesity, mental health problems, epilepsy? How well do you think you are able to deliver care and meet say for example QOF targets?

There are some QOF targets that are quite difficult to implement, for example, newly diagnosed depression and assessment of severity using PHQ 9, what has been your experience? Are there other QOF indicators that you have found to be difficult for people with learning disabilities?

Routine screening, for example cervical screening, is a difficult area, how have you managed that in your practice?

IF NO

- Barriers to engaging with the DES
    - Confidence in carrying out health checks
    - Identifying people with LD
    - Uncertainty about definition of learning disability (moderate/severe)
    - Resources
- Barriers to carrying out health checks
    - Time
    - Environment
    - Communication difficulties
    - Training

3.4 Community Learning Disability Nurses Interview Schedule

PCT:

Gender

Age

Number of years working in community learning disability team.

Current role within learning disability team.

Background about current workload (number practices/cases, etc)

TRAINING ISSUES

Where you involved in training practices as part of the DES?

What was your overall impression about delivering the training?

Have you had any feedback about how useful practices felt the training was?

Would you change anything in the way the training was delivered?

Would you change the content of what is delivered in the training?

CREATING A REGISTER

Where you involved in helping practices ratify their registers?

What were thoughts about this process?

Did this increase or reduce the numbers of people on your register in the practices you were involved with?

HEALTH CHECKS

What has been experience of so far of practices delivering health checks?

Have practices contacted you for your help or support?

Have you supported any practices in carrying out health checks?

POLICY ISSUES

What external support or assistance would be most effective in increasing the coverage and impact of health checks for people with learning disabilities?

What are the main difficulties you encounter in offering and providing health checks?

How else do you think appropriate care could be delivered to people with LD?

What do you think should be the role of secondary care/specialists?

What should be the role of primary care in commissioning services for LD in the future?

How do you think the proposed changes to primary care will affect the care delivered to people with LD?

Who else in your opinion should be involved in structuring/designing care for people with learning disability in the future?

Are there other areas of clinical care where you think ideas or best practice could be applied or used to help improve the quality of care for people with learning disability?

CARERS ISSUES

Increasingly, carers are now are elderly and are at a stage where they need caring for, how do you think this group should be supported in primary care?

Appendix 4 Framework for analysis using NPT

Coherence (making sense)

Differentiation: Do health professionals agree health checks differ from usual care?

Communal specification: Do health professionals agree purpose of health checks?

Individual specification: Do health professionals individually understand what to do?

Internalisation: Do health professionals understand value of health checks?

Cognitive Participation (engagement)

Enrolment: Is there a key leader involved with the work?

Activation: Do all health professional agree health checks are part of work in principle?

Initiation: Do health professionals start health checks in practice?

Legitimating: Will health professionals continue to do health checks?

Collective action (doing)

Skill set workability: Who are the health professionals doing health checks?

Contextual integration: Do health checks help the team value each other’s work?

Interaction workability: Is work shared appropriately across the team?

Relational integration: Does the practice support health professionals in doing the work?

Reflexive Monitoring

Reconfiguration: Do health professionals get feedback about the work (including processes)?

Communal appraisal: Does the practice agree health checks are worth the effort?

Individual appraisal: Do individual health professionals agree health checks are the worth effort?

Systematisation: Is there change in response to feedback?

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