CHECKING UP ON DES

An investigation into implementation of Annual Health Checks for people with learning disabilities in Oxfordshire

Jan Walmsley Associates Ltd
with My Life My Choice

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RIDGEWAY Partnership

my life my choice

The Health Foundation Inspiring Improvement

NHS Oxfordshire

Executive Summary and Recommendations

Annual Health Checks (AHCS) were introduced in 2008 as a response to findings that people with learning disabilities have significantly worse health care than other groups, which contributes to lower life expectancy. GP practices are incentivized by a Directed Enhanced Service to offer extended annual health checks. Early results of national evaluations of the AHC indicate significant variation in access. This pilot project investigated implementation of AHCs in Oxfordshire where the percentage of AHCs completed in 2009/10 was only 26.1% (national average 41%).

Methodology

A sample of 5 GP practices in Oxon participating in the Directed Enhanced Service (DES) representing large / small and rural / urban practices were visited by a team comprising a researcher and a My Life My Choice Health Champion (advocate) plus supporter, to interview GP(s) and the practice team, and to report on the welcome given to the Health Champion as a person with a learning disability. One further practice completed a written survey.

The Project aims were to:

- Find out about GPs' experience of doing the annual health check
- Find out about outcomes from the health checks (how many health problems identified etc.)
- Better understand the challenges practices face in introducing the health check and improving access to primary care for people with learning disabilities
- Identify what support practices need to meet those challenges, both organizational and in improved written and oral communication
- Advise Community Learning Disability Teams (CLDTs) on how they can support general practice to implement the DES to best effect
- Gather evidence to persuade NHS Oxfordshire to convert the DES into a Locally Enhanced Service (LES)
- Devise innovative methods to capture patient experience of the AHC

Results

The findings are set out under headings related to the project aims listed above.

Find out about GPs' experience of doing the annual health check

GPs' experiences varied. All practices had struggled with knowing who to target and with aligning the different 'lists' of people who might be eligible.

Some GPs were positive about the potential to improve health care, some were sceptical, and one highlighted the importance of educating carers to support healthier lifestyles, and to actively manage long term health conditions.

Find out about outcomes from the health checks

The team gathered limited data on outcomes, as only 2 practices had collated detailed records. The limited information indicated that some serious health conditions were identified through the AHC, that numerous less serious conditions (podiatry, constipation, hearing loss) were identified and treated. In one practice 90 health conditions were identified from 65 AHCs

'Softer' outcomes include that:

- The AHC familiarises people with learning disabilities, and the services that support them, with GP practices, thus encouraging appropriate use of primary care
- The AHC enables GPs to spread health promotion messages
- The AHC enables GPs to offer support to carers with, for example, challenging behaviour
- The DES draws attention of GPs to people with learning disabilities and their needs.

Better understand the challenges practices face in introducing the health check and improving access to primary care for people with learning disabilities

The principal challenges were:

- Agreeing eligibility for the AHC both within the practice and with the PCT. All practices viewed this as time consuming and confusing, and GPs were of the view that their read codes for learning disability were frequently more accurate than PCT supplied lists
- Need for documentation (in particular the Cardiff Health Check) to be compatible with practice software systems
- Need for documentation which is compatible with Health Action Plans
- Need for advice on the most effective way of organising health checks within the practice
- Need for clear guidance as to where to access specialist support and advice on learning disability issues
- Need for information about making 'reasonable adjustments' under the Disability Discrimination Act to promote access
- Need for training on implementation of the Mental Capacity Act 2005
- Need for access to easy read information to use for invitation letters, preparation, and follow up advice / instructions
- Need to educate carers, in particular paid carers, on the exercise of best interest, and the importance of following up appointments
- How to reach people who are harder to reach by primary care

- How to reduce DNAs

Identify what support practices need to meet those challenges

GPs are not, on the whole, well informed about lds, and access to specialist advice was widely recognised to be desirable. Some GPs have ready access to LD consultants, however most felt they would not know where to go for advice.

The following needs were inferred but not directly mentioned by GPs:

- Information about 'reasonable adjustments' including easy read resources
- Awareness of the DDA requirement to make 'reasonable adjustments'
- Training in the application of the Mental Capacity Act
- Advice on what constitutes good practice in undertaking Annual Health Checks
- Advice on ways to manage Health Checks both for clinical effectiveness and cost effectiveness to the practice
- Proactive measures to increase the numbers of people accessing the Annual Health Check
- Given the proposed shift of responsibility for commissioning services to GPs, announced after the project fieldwork was completed, it is important to highlight the project's finding relating to GPs' needs for education around the particular needs of people with learning disabilities.

Advise Community Learning Disability Teams on how they can support GPs to implement

This small study gives clear indications as to the areas where GPs would benefit from expert advice and training opportunities. It indicates that there is a role for the 3 Oxfordshire CLDTs to be more proactive in supporting GPs to implement the DES effectively. GPs want a named contact in the CLDT, and this is under consideration within the Ridgeway Trust. The publication of the Royal College of General Practitioner's Step by Step Guide offers a platform for CLDTs to use in working with GPs to improve implementation. GPs need advice on what constitutes a 'reasonable adjustment', and the CLDT could be an important resource for this.

Gather evidence to persuade NHS Oxfordshire to convert the DES into a Locally Enhanced Service (LES)

The evidence from this study is that relatively limited progress has been made in implementing the DES in Oxfordshire, and it is early to be precise about its clinical or cost effectiveness. It indicates that the DES has drawn attention to learning disabilities within primary care, and that there is potential for its implementation to be more effective. If the DES ends this momentum will be lost, and an important lever to address the poor service people receive from primary care will also be lost. We understand that the DES is likely to be extended for a further year (2011-12) and would argue for steps to be taken to ensure that AHCs become routine, possibly through the Quality and Outcomes Framework.

Devise innovative methods to gather patient experience of Annual Health Checks

The project devised four methods to gather patient experience of AHCs, through working with My Life, My Choice, an Oxfordshire organisation, run by and for people with learning disabilities. .

1 MLMC Health Champions visit to 3 practices and to write report from perspective of a person with a learning disability

This approach highlighted the importance of punctuality, courtesy, basic communication and attitudes of reception and clinical staff. There is undoubtedly potential to use this method (akin to 'mystery shopper') to provide feedback to practices

2 Focus Group discussions using a semi structured illustrated questionaire with groups of people with learning disabilities in Oxford, Banbury and Wantage

These indicated a need for people with learning disabilities to be better informed about Annual Health Checks and what to expect from them.

3 Reflective account by a MLMC Health Champion on his own experience of receiving a Health Check

One account was collected in this way. The Health Champion's reported experience was that the AHC did not differ from a routine appointment, and that this was not value for money from the DES. The widespread use of this approach is unlikely to be possible given limited knowledge of what to expect from the AHC, and poor literacy among people with learning disabilities, it could, however, be of wider applicability if used by carers and / or advocates.

4 Recall of patients who had received an AHC in the preceding year to attend the surgery for an informal discussion

With the active support of one large practice which has completed over 70 AHCs, invitations were issued, however no one attended. Our conclusion is that careful preparation will be required to access patients' and carers' experiences.

Recommendations

If the AHC is to meet its aims the following need to be in place, particularly with regard to the advent of GP commissioning of learning disability services.

PCT /Ridgeway Trust

- Take steps to clarify eligibility for the Health Check and to set up a process by which GPs can recommend that people they regard as being in urgent need are added to the 'List'
- Clinical leadership within GP community in Oxfordshire needs to be more visible.

Ridgeway Trust

- CLDTs need to improve their visibility to general practice. Develop CLDT role so that DES participating practices have a named contact in the CLDT, and ensure that a personal relationship is established
- An ongoing dialogue between CLDT and GP surgery to promote longevity of work / primary service improvement.

- Annual, rolling training programme focused on how to support people with a learning disability needed for practice staff, facilitated by CLDT / MLMC
- Raise awareness of the RCGP Guidelines amongst GPs, use as lever to improve implementation
- Develop website resources for practices to use to improve communication – easy read appointment letters, health promotion advice etc.
- Create forum for GP champions to meet and share ideas about good practice with LD specialists and patient representatives
- Programme of education about AHCs and what to expect for people with learning disabilities, carers and service providers.

Regulators

- Extend 'Experts by Experience' to GP practices.

My Life My Choice

- Build on valuable work on methods for understanding AHCs from perspective of people with learning disabilities through future funded research on how to access patient experience.
- Market services to GPs to improve services for people with learning disabilities
- Information and education for people with learning disabilities to inform them about Annual Health Checks, what to expect, how to prepare, and what to do if they do not receive a good service.

GPs

- Implement best practice using the Royal College of General Practitioners *Step by Step Guide*
- Identify proactive champions amongst GP community, consider ways of creating and marketing learning disability centres of excellence in primary care, through the GPs with Special Interest route
- Use services available through My Life My Choice to review learning disability access, attitudes and resources.

Carers

- Important that paid carers prioritise attendance at Annual Health Checks
- Training for front line staff in supporting improved health and helping people manage long term conditions
- Commissioners of care services ensure that commissioned services support people to attend Annual Health Checks, and any follow up actions identified.

Contents

Introduction

Research Team

Project Lead: Jason Warner – Oxfordshire Ridgeway Trust Primary Health Care Facilitator

Researchers

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Gareth Price, Neil Kinsella and Bryan Michell - My Life My Choice Health Team

Sponsor

We are immensely grateful to The Health Foundation for funding this investigation.

Background – The 'DES'

The Directed Enhanced Service (DES) for People with Learning Disabilities incentivised GPs to offer an Annual Health Check in 2008 as a response to concerns relating to the quality of health care for people with learning disabilities. The DES gives participating GPs £100 per head to provide an extended health check annually to people with learning disabilities. A systematic review of research indicates that this intervention has the potential to detect hitherto undetected health conditions (Roberts et al 2010).

All people with learning disabilities 18+ 'known to local authorities who have been assessed as being potentially eligible for services' are eligible for an Annual Health Check

The Check covers physical and mental health, and a review of medication. It is intended to lead to early detection of serious health issues.

The DES was introduced because people with learning disabilities are amongst the most marginalised and disadvantaged groups in terms of health outcomes. They are 58 times more likely to die before the age of 50, and 4 times more likely to have a preventible cause of death. The Government commissioned Michaels Report *Healthcare for All* (2008) reported that:

- People with learning disabilities live shorter lives than average
- People with learning disabilities are more likely than others to have a health problem
- Often these health problems are not known about

The Report concluded that despite a strong legislative framework, including the Disability Discrimination Act's provision for 'reasonable adjustments', the NHS was providing poor, and sometimes appalling care. Lack of awareness of needs in primary care was 'striking' and particularly serious given its role as a gateway to other services, and to health promotion (p.8).

Recommendation 8 of the Report was that DH should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and this was implemented in 2008 / 10 and extended in 2010/11 as a Directly Enhanced Service (DES) which enables GPs to claim payment for providing Annual Health Checks for people who are known to social services primarily because of their learning disability.

Specific problems relating to primary care were highlighted by Alborz et al (2005) whose systematic review identified, inter alia, that many people with learning disabilities access GPs and dental surgeries less often than others. This was attributed to poor physical access, communication problems, and provision shortage.

Implementation of the DES – what is known currently

The National Primary Care Development Centre, University of Manchester has a Programme of work to monitor the implementation of the DES: http://www.npcrdc.ac.uk/ProjectDetail.cfm?ID=203.

The Royal College of GPs has issued a Step by Step Guide to Getting it Right to advise GPs on implementation, this had not been issued at the time the Project was conducted, and no GPs were aware of it. It may influence implementation in future.

IHaL, the Learning Disabilities Health Observatory has collected data on 2 salient aspects of AHCs.

The numbers of people known to GPs to have learning disabilities

Analysis of Quality and Outcomes Framework data shows that numbers of people with learning disabilities known to GPs in England has increased from 3.7 in 2008/9 to 4.2 in 2009/10. The number varies from 5.6 per 1000 in North East SHA to 3.1 per 1000 in London and 3.4 per 1000 in South Central (Oxfordshire – 3.4 per 1000):
http://www.improvinghealthandlives.org.uk/numbers/doctors/maps2010/

The numbers of health checks undertaken in each Primary Care Trust in 2009/10.

This shows that more Health Checks are being undertaken nationally, increased from 23% of those eligible in 2008/9 to 41% in 2009/10.

It also shows considerable variation across PCTs. The top 10% of PCTs completed checks for 67% of people eligible, the bottom 10% completed checks for fewer than 14%. **Oxfordshire – 26.1%.**

http://www.improvinghealthandlives.org.uk/numbers/checks/maps/

There is undoubtedly considerable research required to understand these variations, and this small study makes a contribution in a geographical area which appears to be underperforming.

Background – why Oxfordshire, why now?

The investigation into the implementation of the DES followed county wide education for GPs and their staff conducted by The Ridgeway Trust in partnership with My Life My Choice in Feb. / March 2009. All GPs wishing to sign up for the DES were required to attend this training, and 58 of the 84 practices in the county sent representatives. (Currrently 79 of the 84 GP practices in the county have opted into the DES.) Initially the project was to evaluate the training, and funding was secured from The Health Foundation to do this, however the Oxfordshire Learning Disability Partnership Board's incumbent Primary Care Facilitator was aware that implementation of the DES was slow in the county, and, following consultation with the Project Steering Group representing major local stakeholders, it was decided to extend the investigation to consider how the DES was being implemented by a sample of GPs who had signed up for the DES, and to experiment with ways of finding out how people with learning disabilities experience the AHC.

Aims

The investigation set out to:

- Find out about GPs' experience of doing the annual health check
- Find out about outcomes from the health checks (how many health problems identified etc.)
- Better understand the challenges practices face in introducing the health check and improving access to primary care for people with learning disabilities
- Identify what support practices need to meet those challenges, both organizational and in improved written and oral communication
- Advise the CLDT on how it can support general practice to implement the DES to best effect
- Gather evidence to persuade PCTs to convert the DES into a LES
- Experiment with methods to gather patient experience of Annual Health Checks.

GP Sample

Given the limited funding available, it was decided to limit the sample to 5 GP practices.

Sampling considerations were:

- GPs who had signed up to the DES, attended the training and indicated willingness to participate in follow up study
- GPs who had undertaken some health checks
- Inclusive of large and small practices
- Inclusive of urban and rural practices.

An opportunity arose through interest from a GP in a neighbouring county to survey an additional practice by post and the results have been incorporated into this Report.

Methodology

The investigation used mixed methods, drawing on the complementary expertise of the researcher, Jan Walmsley and MLMC Health Champions.

GP Perspectives

- Semi structured questionnaire sent in advance (see Appendix 1)
- Interview with GP(s) in the 5 Oxfordshire practices
- Postal questionaire to 3 GP practices in neighbouring counties (Bucks and Berks).

Methods to gain people with learning disabilities' perspectives

This had four elements:

- MLMC Health Champions attend the visit to interview the GPs, and undertake an evaluation of the practice's response to the Health Champion.
- Accessible questionnaire administered to MLMC groups across the county by their group facilitator (see Appendix for questionnaire)
- Reflective account of his own Annual Health Check by Gareth Price, a MLMC Health Champion
- Consultation with patients who have had a Health Check in one Oxfordshire practice.

Findings 1 GP perspectives

The Participating Practices

The Practices were:

- Practice 1: Urban, 18,000 patients, 89 eligible patients
- Practice 2: Urban, 19,000 patients, 25 eligible
- Practice 3: Urban, 12,500 patients (Berks), 6 eligible[1]
- Practice 4: Rural, 10,000 patients, 15 eligible
- Practice 5: Rural, 8,400 patients, number eligible unknown at practice, estimated to be 100
- Practice 6: Urban, 7,912 patients, 52 eligible

GP Perspectives

Numbers of Health Checks completed

	Practice List Size	Number of ld patients expected (@ 0.3%)[2]	Number formally eligible for AHC/ practice estimate	Health checks completed/ offered	Percentage Health Checks completed year
1	18000	54	104 / 140	65 /89	60%
2	19000	57	25	16	63%
3	12,500	37	6	6	100%
4	10,000	30	15	6	45%
5	8,400	25	/100	10/20	10%
6	7,912	24	52/84	29	45%

Notes: Expected patients figure taken from projections advised by NHS Information Centre 2009

Except Practice 6, year refers to 2009/10

Eligibility – 'The list'

Formally eligibility for the Check is the responsibility of Primary Care Trusts which were instructed to determine the number of people with learning disabilities on GP lists who are known to social services primarily because of their learning disability. The clinical Guidance for the DES specifies that it is the number of "Learning disabled clients known to Councils with Adult Social Services Responsibilities: those clients who are assessed or reviewed in the financial year and who have received a service, as well as those who are assessed and/or reviewed but who have not received a

[1] This practice was surveyed by postal questionnaire
[2] Figure taken from NHS Information Centre 2009

service. In addition, include learning disabled clients who should be reviewed by the CASSR in a financial year but are not." (quoted in Emerson and Glover 2010 p. 2).

The findings from this investigation indicated considerable confusion and controversy around eligibility.

- Agreeing who is eligible exercised all participating practices.
- All practices reported that it was time consuming to review lists, particularly when their lists did not correspond with the lists supplied by the Ridgeway Trust.
- The practice 'ld' read codes do not coincide with lists held by Ridgeway, PCT and Social Services
- Confusion as to whether GPs can ask for people to be added to the list – the PCT follows DH guidance and refuses to add people without a formal assessment
- One practice reported that it did not know who was formally eligible, but was working from their own list
- Steps are being taken by the Oxfordshire Partnership Board's Primary Health Facilitator to coordinate lists, these were in progress as the project was conducted.

Two GPs believed that the lists excluded significant numbers of people who in their opinion should be eligible, and included some who should not be eligible. One practice has 104 patients on the official list but the practice believes that 30/40 more should be added.

The extent of confusion both over eligibility and responsibility for deciding who is eligible is indicated by this quotation from a GP who implied that the practice itself decided on eligibility

> Since the introduction of the DES we have reviewed the list of LD patients and have actually taken a few off. There was some debate about how we classify LD patients- ie based on IQ etc. We decided to base it on general functioning- ie whether they have a job etc.

Documentation

The recommended documentation is the Cardiff Health Check (see Hoghton and RCGP 2010 for details).

- All but two practices used the Cardiff Health Check
- One amended the Cardiff Health Check to add a space for follow up action
- One developed a practice IT compatible version combining elements with their standard practice template, to include family history
- One practice sent the Cardiff Health Check to patients in advance so they could prepare – and reported that it was too complex for this purpose

GPs were broadly approving of the Cardiff Health Check. One noted that it gave permission to probe in areas which would not be explored in a routine appointment, another that he prefers to use this as a validated tool. The following suggestions for improvement were made:

- No space for follow up action plan. We added our own link to Health Action Plans

- Not enough prompts on mental health or health promotion
- No space for family history, but this is important.

Practice Organisation of AHCs

There was, at the time we undertook the investigation, no advice for GPs running AHCs as to the optimum way to organize them, though the Guidelines issued in autumn 2010 by RCGP (after this data was collected) advise

'The health check is ideally split into two half an hour appointments which are sequentially arranged with the practice nurse and the patient's usual GP.' (Hoghton and RCGP 2010 p.4)

The participating practices organized the AHCs in different ways:

- Special LD clinic run by GP and hca at a quiet time of year (1)
- One GP specialising in health checks for the practice (3)
- Patients see their own GP (4)
- Option of home visits (2)
- Practice Nurses do some Annual Health Checks (1).

This wide variation is not surprising in the absence of guidance, however the findings indicate that giving one GP responsibility for completing AHCs, sharing the task with other practice staff (hca / practice nurse) and organising in a dedicated clinic rather than as part of routine surgery may enhance attendance, and enables the practice to make ready use of the clinical lead for ld, and to build expertise in this area.

Adjustments made under the Disability Discrimination Act

The Disability Discrimination Act (1995) requires reasonable adjustments to be made to facilitate access. Although 4 of the GPs interviewed did not appear to be aware of this requirement, the project uncovered the following which could be represented as 'reasonable adjustments':

- Easy access letter (4 practices)
- Home visits option (2 practices)
- Send out health check questions in advance (1 practice)
- 30 minute appointments (all)
- Choice of appointment times (5).
- Telephone prompt to respond to AHC invitation (1)

None of the GPs was aware of easy read resources available elsewhere eg those produced by Easy Health http://www.easyhealth.org.uk/ and Easy Read online http://www.easy-read-online.co.uk/

nor had any made adjustments to facilitate physical access, though two were aware that this was desirable).

Two practice representatives stated that they 'treat everyone the same', when asked what reasonable adjustments they make, indicating that they do not understand their obligations under the DDA.

There would appear to be scope for raising awareness of GPs and practice managers of their legal obligations under the DDA, and for issuing some advice as to what constitutes an effective 'reasonable adjustment' to facilitate improved access for people with learning disabilities.[3]

Benefits of AHCs identified by GPs

GPs were able to identify a number of benefits of the Annual Health Checks, however data on the clinical outcomes of AHCs was not readily available in 5 of the 6 practices. The following represent GP views

- Asking GPs to think about people with learning disabilities is beneficial even for those not eligible for the AHC
- Identifies some serious hitherto undetected clinical conditions (90% new diagnosis rates at one practice, close to 100% at another)
- Cardiff Health Check gives permission to range beyond strictly medical concerns which cannot be raised during a normal appointment.
- Helps with improving QOF scores for ld
- Minor health needs were identified and steps taken to address them including podiatry, dentistry, hearing, constipation
- Opportunity to offer lifestyle advice eg healthy eating, smoking, exercise, alcohol
- Encourages younger people (especially those who live independently) to contact Dr if they have met her, she is able to explain when and how to contact surgery eg for constipation.
- Opportunity to support carers, advice on managing behaviour.

Limitations of the Annual Health Checks

GPs noted the following as limitations of the Annual Health Checks. Foremost among these were concerns about the quality of (paid) carers who accompany patients. The following were noted:

- Carers who don't know patients they accompany, so are unable to provide background or family history information
- People who do not attend because no carer is available to accompany
- Carers who fail to book follow up appointments
- Carers who believe that they should not seek to influence health behaviours such as diet, long term conditions self management because of an exaggerated respect for client autonomy.

[3] IHaL is running a National Survey into Reasonable Adjustments currently, see http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments

- The need for carers to be educated about acting in 'best interest' Other limitations noted were:GPs can do little in face of lifestyle issues: eg poor diet, Vitamin D deficiency
- GPs do this anyway, so little new is detected through Health Check
- GPs know who should be on the list better than the PCT or Ridgeway, and should be able to influence who is on the list of those eligible.

Costs

The research team sought to find out whether GPs found it cost effective to participate in the DES and offer AHCs. Data on this was available from only 2 practices.

Practice 1 'cost effective'

Practice 1 reported that the Annual Health Check brought in income to the practice:

- 30 minute Annual Health Check organised in half day special clinic at quiet time of year (May/June). HCA does basic checks, GP clinical lead for ld does rest
- Income to practice from undertaking 65 checks: £6,500
- Additional cost of locum cover for half day clinics: £975
- 'Profit' to practice: £5525

Practice 5 'not cost effective'

This practice offers an Annual Health Check of up to 40 minutes by patient's usual GP, with the option of a home visit. The practice estimated that income was lost to the practice for the following reasons:

- Opportunity costs - 40 minutes with GP is charged privately at £130
- Home visits add costs
- Extra administrative time – organise list, special letter, print health check and send.

This indicates that practices might benefit from undertaking a business planning exercise to identify the most effective way to organise AHCs, taking account both of clinical and cost considerations.

Expertise

All practices had identified a clinical lead for lds as this was a requirement for participating in the DES. This in itself did not enhance the practice expertise, though the research team was encouraged that 3 GPs interviewed showed enthusiasm to learn more. Overall GPs regard themselves as having little expertise in learning disabilities, and very little training:

- Two GPs emerged as having a particular interest
- Most GPs claim they lack expertise
- Low awareness of DDA requirement to make 'reasonable adjustments'

- Low awareness of challenge of requirements of the Mental Capacity Act (2005) to assess capacity to consent
- Improved access to specialist advice regarded as desirable by most.

There would appear to be scope for clarifying with GPs how and when to access specialist advice, and for identifying named CLDT members to support individual practices.

Support needs identified by GPs

GPs were asked about ways they could be better supported to offer AHCs. Access to specialist advice appeared to be ad hoc. Some GPs felt they could call (medical) consultants and get good advice, but most were unaware of sources of advice locally.

The following ideas were put forward:

- Easy read resources including appointment letter, pre appointment questionaire, health promotion, advice to carers available online
- Advice on confidentiality – when to ask carer to leave the consultation[4]
- Named contact in CLDT – 'it would be good to meet on a monthly basis with someone from the Community Learning Disability Team for a chat and know there was a friendly person I could ask for advice'.
- Healthy living groups to refer people to
- Short and accessible questionnaire to send out with the invitation to the Annual Health Check to enable people to prepare for the appointment
- Education for carers on acting in best interest.
- How to help carers with behaviour management
- Incorporate into EMIS, VISION etc.
- Opportunities to learn from good practice elsewhere
- Sort the LISTS, end confusion over eligibility

[4] Awareness of the requirements of the Mental Capacity Act was low in the sample

Findings 2 Experiment with methods to gather patient experience of Annual Health Checks

Background

Research and government reports (Alborz et al 2005, Michaels 2008) indicate that access to healthcare is problematic, and the DES was introduced in part to address this. There has, however, been little research to date on how people with learning disabilities understand and experience the AHC[5].

This project sought to address this gap, in the following ways:

- MLMC Health Champions attend the visit to interview the GPs, and undertake an evaluation of the practice's response to the Health Champion.
- Accessible questionnaire administered to MLMC groups across the county by their group facilitator (see Appendix for questionnaire)
- Reflective account by MLMC Health Champion on his own AHC
- consultation with patients who have had a Health Check in one Oxfordshire practice.

MLMC Health Champions report on Practice Visits

A MLMC Health Champion (see Box below) attended three of the GP practice visits (Practices 2, 4 and 5) and wrote reports on the visit. The Health Champions commented on the information they were given, and reported on the reception they had from practice staff. These Reports are reproduced in full in Appendix 2.

My Life My Choice Health Champions

The My Life My Choice Champions project assists one of the most socially disadvantaged groups in society to speak up for themselves. The Champions, all people with learning disabilities, work on a local, regional, and national level in order to influence decision makers. The Champions have a chance to meet important people, express their point of view and to shape the decisions that impact upon their, and the lives of their peers. They lobby, campaign, inform and ultimately work towards improving the rights and quality of life for people with learning disabilities.

[5] One exception is a service evaluation undertaken in Devon which surveyed 62 people who had had AHCs (Walsh et al nd)

Key issues

The welcome was important. Being seen on time, being taken seriously, and being offered courtesies such as a drink, in short shown respect. This method, akin to mystery shopper, could provide valuable feedback for GPs and their practice staff if adopted more widely.

Focus Group Results

Three My Life My Choice groups in Oxfordshire (Oxford, Banbury and Wantage) were asked to complete a Health Questionnaire which asked about Health Checks. The questionnaires were completed by the Group Supporter. Results from two Focus Groups are available at the time of writing.

These indicate that of 28 people, 23 had had a Health Check, of these 15 said they knew what a Health Check is. One person indicated they would not want a Health Check. Several comments were made on likes and dislikes

This method appears to have potential both for raising awareness of AHCs amongst the target population, and for gathering information on how people experienced it.

For maximum benefit, there would be value in an experienced researcher attending future Focus Groups to explore responses in more depth.

Health Champion's Reflective Account of his own Annual Health Check

Gareth Price, a MLMC Health Champion, wrote an account of his own health check (see Appendix 3). It indicates that although Gareth as a Health Champion knew what to expect, and took steps to prepare, the Check did not stand out from a routine surgery appointment.

As a method for collecting patient experience it has limited potential because few people with learning disabilities are aware of what to expect from the AHC, and few have the expertise to write such an account. However, it indicates the importance of raising awareness amongst people with learning disabilities and carers about what to expect, and there may be potential to use this approach to ask carers or advocates to collect and feed back information.

Consultation with patients who have had a Health Check in one Oxfordshire practice

The research team responded to a request from Practice 1 to find out how patients and carers had experienced the AHC. The practice sent invitations to meet the research team at the surgery. However, no one turned up on the day. This indicates that gaining information on how people experience AHCs will require a more proactive approach.

Conclusion

Overall, implementation of Annual Health Checks is in its infancy in Oxfordshire. The project undoubtedly accessed GPs who had some interest in the area, despite this practice was variable and some GPs were dismissive of the value of the AHC, indeed dismissive of the view that additional steps need to be taken to ensure equitable access. 'We treat all patients the same' was a surprisingly common refrain, given the passage of time since the DDA became law. Our conclusion is that if the AHC is to meet its aims of addressing some of the barriers to good primary care identified by Michaels and others, more effort will be required on the part of major stakeholders to share good practice (now facilitated by RCGP Guidance), to educate, encourage and incentivize.

The DES is probably the single most important investment in the health care of people with learning disabilities of the twenty first century. Our conclusion is that financial incentives alone will not be enough to change practice, and that concerted action on the part of the major stakeholders to provide leadership is essential if this major investment is to yield results for more than the minority of people with learning disabilities in the county. It will be important to invest effort into transforming attitudes in some GP practices. Even if this takes place we have doubts whether the aspiration that all primary care providers develop the necessary expertise and facilities to support all people with learning disabilities is realistic. There may be a case for identifying Primary Care practices which specialize in learning disabilities, building on the GP with Special Interest concept.

An additional impetus for more effort to go into making Annual Health Checks work for people with learning disabilities is that GPs will become commissioners of services, including, as far as is known, services for people with learning disabilities. It is vital to inform and influence GPs in every way possible to ensure that they are in a position to commission intelligently and in ways that are sensitive to the needs of this very poorly served group of people. Effective GPs with Special Interest are a place to start.

Finally, the project indicates that it is important to educate people with learning disabilities and carers about the Annual Health Check so that they can prepare, know what to expect, and make representations if they are not invited to a Check, or if it is cursory.

Recommendations

If the AHC is to meet its aims the following need to be in place, particularly with regard to the advent of GP commissioning of learning disability services.

PCT /Ridgeway Trust

- Take steps to clarify eligibility for the Health Check and to set up a process by which GPs can recommend that people they regard as being in urgent need are added to the 'List'
- Clinical leadership within GP community in Oxfordshire needs to be more visible.

Ridgeway Trust

- CLDTs need to improve their visibility to general practice. Develop CLDT role so that DES participating practices have a named contact in the CLDT, and ensure that a personal relationship is established
- An ongoing dialogue between CLDT and GP surgery to promote longevity of work / primary service improvement.
- Annual, rolling training programme focused on how to support people with a learning disability needed for practice staff, facilitated by CLDT / MLMC
- Raise awareness of the RCGP Guidelines amongst GPs, use as lever to improve implementation
- Develop website resources for practices to use to improve communication – easy read appointment letters, health promotion advice etc.
- Create forum for GP champions to meet and share ideas about good practice with LD specialists and patient representatives
- Programme of education about AHCs and what to expect for people with learning disabilities, carers and service providers.

Regulators

- Extend 'Experts by Experience' to GP practices.

My Life My Choice

- Build on valuable work on methods for understanding AHCs from perspective of people with learning disabilities through future funded research on how to access patient experience.
- Market services to GPs to improve services for people with learning disabilities
- Information and education for people with learning disabilities to inform them about Annual Health Checks, what to expect, how to prepare, and what to do if they do not receive a good service.

GPs

- Implement best practice using the Royal College of General Practitioners *Step by Step Guide*
- Identify proactive champions amongst GP community, consider ways of creating and marketing learning disability centres of excellence in primary care, through the GPs with Special Interest route
- Use services available through My Life My Choice to review learning disability access, attitudes and resources.

Carers

- Important that paid carers prioritise attendance at Annual Health Checks
- Training for front line staff in supporting improved health and helping people manage long term conditions
- Commissioners of care services ensure that commissioned services support people to attend Annual Health Checks, and any follow up actions identified.

References

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Emerson E and Glover G (2010) Health Checks for People with Learning Disabilities Durham: Improving Health and Lives, The Public Health Learning Disabilities Observatory.

Hoghton M and RCGP Learning Disabilities Group (2010) *Annual Health Checks for People with a Learning Disability A Step by Step Guide* London: Royal College of General Practitioners

Michael J (2008) *The Independent Inquiry into Access to Healthcare for People with Learning Disabilities.* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255

Robertson J, Roberts H, Emerson E. (2010) *Health Checks for People with Learning Disabilities: Systematic Review of Impact 2008/9 & 2009/10* Durham: Improving Health & Lives: Learning Disability Observatory

Walsh K et al (nd) Annual Health Check Experience for People with Learning Disabilities: A service evaluation report written for the South West Strategic Health Authority University of Plymouth

Websites

The Public Health Learning Disabilities Observatory.

www.improvinghealthandlives.org.uk

This website has downloadable easy read information leaflets and books about health issues for people with a learning disability.
www.easyhealth.org.uk

This website has easy read resources
www.easy-read-online.co.uk/

Appendix 1 GP Questionnaire

Questions for GPs and Practice Staff

We would like to discuss all the questions with people who actually conduct the Health Checks, we assume GPs and Practice Nurses

In addition, we would welcome the opportunity to discuss those highlighted in yellow with Practice Manager and administrative staff

How many patients have you got with a learning disability?

Have you recently treated someone with a learning disability?

Do you think that since the training, that you are more understanding of people with learning disabilities?

Has your surgery identified, since the introduction of the DES, more patients with learning disabilities?

Have you developed any special techniques to improve communication with or access for people with learning disabilities?

How has the introduction of the annual health check gone in your practice?

How many checks have you done? And with what outcomes? Eg have you identified any previously undetected health conditions

What documentation do you use (eg Cardiff Health Check)? Do you have any views on whether and how it could be improved?

What reasonable adjustments has the practice made to ensure people with learning disabilities can access your services? (requirement of Disability Discrimination Act)

Can you show us any letters or other documents which you use to invite people with learning disabilities to health check appointments?

What special arrangements do you make for health check appointments? Eg end of day, longer time slots

Do any of your staff have a special interest in or responsibility for patients with learning disabilities?

Do you have any residential care homes for people with learning disabilities in your patient list? If so, do you make special arrangements to offer health checks to their residents? And with what success?

Do you have any contact with the Community Learning Disability Team? If so, what for and who with?

Is there any training, support or advice you would like from the CLDT / elsewhere?

Finally, what would help you most to offer a better service to people with learning disabilities?

February 2010

This questionnaire was amended for the postal survey

Appendix 2 Health Champions' Evaluation of 3 GP Practices

An evaluation of a surgery (Practice 2 Medical Centre) – Neal's story…

I am a member of My Life My Choice. I represent people with learning disabilities in Oxfordshire

I was a member of the team who trained GP surgeries in the DES and Health Checks. I am also a My Life My Choice Health Champion.

I am very interested in finding out if the training that we did made any difference.

I know from my work as a Health Champion that the Health Checks are a very important part of improving the health of people with learning disabilities. I expected surgeries to be trying hard to make the Health Checks work.

Before the evaluation visit I was very hopeful that Practice 2 would be able to tell me of all the great things that they've been doing.

This is what I thought about Practice 2…

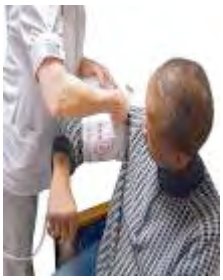
We went to the receptionist's desk and I was shocked to discover that nobody knew why we were there. After a few minutes we were told that a Doctor would meet with us but he was busy at the moment.

We waited for 45 minutes before the Doctor was ready. Nobody kept us up to date; nobody made us feel welcome or important; nobody offered us a drink while we waited. They probably think that we had nothing better to do than wait around for them. I suppose that they think that they are more important than us.

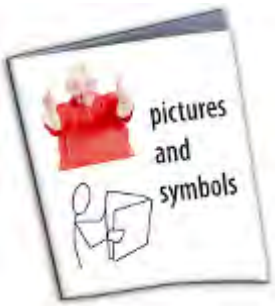
The Doctor apologised for keeping us waiting. He said that he was very busy and so only had 20 minutes to spend with us. I didn't know that that was a good excuse for being unprofessional; I suppose he didn't think that we might be busy as well.

I then asked the Practice Manager some questions about the Health Checks.

I was surprised that they said they only had 25 people with learning disabilities registered at their surgery. I thought that there must be more than that in the area. He explained that this was all he had on his 'patient list'.



16 of the 25 had already received Health Checks. I wondered why the other 9 had not received Health Checks.



They said that they sent letters to people inviting them for Health Checks but the letters were not in Easy Read – I thought that the letter they sent was rubbish. I do wonder sometimes why people think Doctors are clever.

The Doctor said that he wasn't particularly interested in learning disability issues and neither was anyone else in the surgery.

This did not surprise me.

He also thought that the Health Checks were a waste of time (I think he said "not effective" but I know what this really means!).

I thought that they're not going to be effective if none of you care about them or put any effort into it.

The GP also didn't like the Cardiff Health Check form – "it was too long".

I was waiting for him to say something positive; something positive about anything!

It seems like we've all got a long way to travel if all health workers are like this one.

We said goodbye and I was pleased to get out of there.

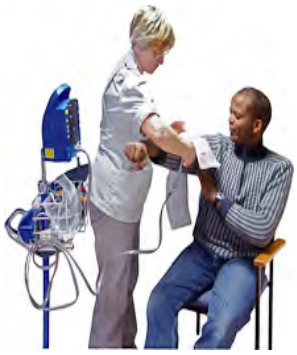
My conclusion; Practice 2 – Muppets! And they take extra money from the taxpayer for 'doing' the Health Checks – shameful.

An evaluation of a surgery (Practice 4) – Kevin's story…

I am a member of My Life My Choice. I represent people with learning disabilities in Oxfordshire

I am very proud to serve on the National Forum for people with learning disabilities. I am very interested in improving health for people and I am a Health Champion.

I was very happy to be asked to take part in evaluating Practice 4 on how well they were doing with the Health Checks.



I know from my work as a Health Champion that the Health Checks are a very important part of improving the health of people with learning disabilities. I expected surgeries to be trying hard to make the Health Checks work.

Before the evaluation visit I was very hopeful that Practice 4 would be able to tell me of all the great things that they've been doing.

This is what I thought about Practice 4…

I had a friendly welcome from the surgery manager but she seemed in a big hurry and quickly rushed us into the meeting room. She didn't even offer us a cup of tea!

We were left in a room with a Doctor. He didn't know who we were or why we were there. When we told him he didn't seem very interested in us or the health checks.

Even though we had travelled a long way for a meeting that had been arranged and confirmed the Doctor said that they were too busy to talk to us for the full 30 minutes. I was disgusted with this.

By this time I didn't feel very comfortable or welcome!

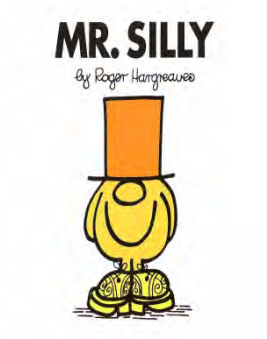
We were then joined by some other Doctors who were much friendlier. I hoped that things would get better.

I then asked the Doctors some questions about the Health Checks. The Doctors listened to me and gave some answers. One of the Doctors smiled as lot and looked interested in what I had to say – she made me feel better

I was surprised that they said they only had 15 people with learning disabilities registered at their surgery. This didn't seem right.

I was not happy that only 6 of these had been given a Health Check.

They said that they sent letters to people inviting them for Health Checks but the letters were not in Easy Read – they were the same sort of letters as they sent for people without learning disabilities…



This seemed a bit silly. They said that they didn't "look at improving access for specific groups… they looked at improving access for all". It sounds like they have never heard of 'reasonable adjustment' for people with disabilities.

One Doctor said that he thought the Health Checks were 'going through the motions a bit'. I think he thought that the Health Check was a waste of time. I hope that he didn't think that people with learning disabilities were a waste of time as well.

The meeting ended and we left.

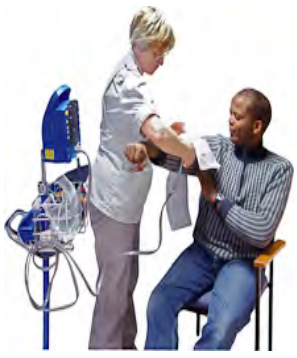
At first I was angry and disappointed with Practice 4, but now after thinking about it I just want to get back to fighting hard for the rights of people with learning disabilities to receive a fair service at their surgeries.

An evaluation of a surgery (Practice 5) – Neal's story…

I am a member of My Life My Choice. I represent people with learning disabilities in Oxfordshire

I was a member of the team who trained GP surgeries in the DES and Health Checks. I am also a My Life My Choice Health Champion.

I am very interested in finding out if the training that we did made any difference.



I know from my work as a Health Champion that the Health Checks are a very important part of improving the health of people with learning disabilities. I expected surgeries to be trying hard to make the Health Checks work.

Before the evaluation visit I was very hopeful that the Practice 5 would be able to tell me of all the great things that they've been doing.

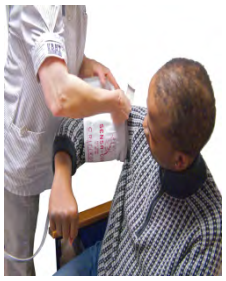
This is what I thought about Practice 5…

I had a very friendly welcome from the Practice Manager, a receptionist and from one of the GPs. I immediately felt welcome. The offered me a drink – I liked that! They seemed pleased to meet me.

The meeting started on time – I liked that a lot. It showed that I was treated seriously and with respect.

I then asked the Practice Manager some questions about the Health Checks.

I was surprised that they said they only had 20 people with learning disabilities registered at their surgery. I thought that there must be more than that in the area. She explained that this was all she had on her ‘patient list’ but she agreed that there were probably more people with a learning disability who hadn’t yet been identified.



10 of the 20 had already received Health Checks. She said that she would be trying hard to get the other 10 sorted out as well.

They said that they sent letters to people inviting them for Health Checks but the letters were not in Easy Read – I thought that this letter could have been improved.

However, when I read the letter I was delighted! People were offered a 40 minute appointment (although they would always get more time if it was needed), and a home visit if they felt that would be more comfortable.

Her attitude was great. She even said that the Cardiff Health Check template was a good thing! They also sent this out to patients to have a look at before the Health Check was conducted. Nice…

She said that the GPs were happy to do the Health Check and it was good because it allowed them to get to know their patients better.

It would be good, she said, if all practices could share their good ideas in order to improve. She especially wanted to hear the success stories.

With a few improvements I'd like to make Practice 5 the Champions!

Thank you.

Appendix 3 Banbury Focus Group Results

Banbury Group Health Questionnaire

Does everyone here have a doctor?

YES	

Would you all say that you are healthy?

YES 3	NO 5

Does everyone here know what a yearly health check is?

YES 4	NO 4

Has anyone here had a health check?

YES 7	NO 1

If yes, what happened at the health check?

Blood pressure checked
Blood Test
Weight/Height
Hearing test
Urine Test
Chest listened to
Eyes
Diabetes finger prick blood test
Feet checked

If no, would you like to have a health check?

1 person said no and would not want a check

What do you like about your doctor / doctor's surgery?

Sense of humour
Very sympathetic
Good Listener
Nurses helpful
Friendly – talks to me
Good communicator
My Doctor is hot!

What don't you like about your doctor / doctor's surgery?

Problems seeing same/regular Doctor for antidepressants
Problems getting appointments
Prescriptions being lost

Is there anything that could be better at your surgery?

Problems seeing same/regular Doctor for antidepressants
Problems getting appointments
Prescriptions being lost

Appendix 4 Gareth Price – Health Check

I received a letter from my surgery asking me to go for a Health Check. I didn't fully understand the letter because it was not in Easy Read.

I rang the receptionist at the surgery and she was very good at explaining to me what it was all about.

I asked my support worker to come along with me.

I've known my GP for years so I wasn't too worried about seeing him.

He was very kind to me when I lost my Mother

On the day of the Health Check we were seen on time.

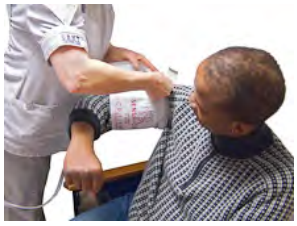
I entered my GP's room. He was polite and friendly.

I introduced my support worker to him.

He asked me what he could do for me and I told him that I'd come for the Health Check.

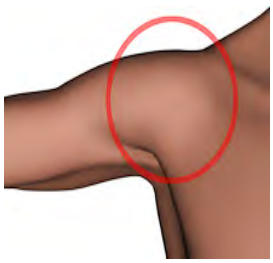
I was surprised he needed to ask me this because this was a Health Check appointment and not a normal visit to see my GP.

I asked him if I could have the Cardiff Health Check but he didn't reply to this.



The Health Check started and he took my blood pressure

He weighed me. He didn't say anything so I can only guess that he thought I was a lean, mean, fighting machine!



He also checked my shoulder. I've been seeing him a lot over the last year about this.
He gave me some treatment for this. We spent most of the time talking about my shoulder.

The whole appointment lasted between 10 and 15 minutes

Before I left I asked him one more question.

“What was your reaction when you found out that you were going to have people with learning disabilities as patients?”

He laughed and said, “We have a lot of patients with learning disabilities and we treat them the same as everyone else”.

I thought that this was a strange thing to say.

People with learning disabilities need to be treated differently and fairly. Being treated the same as everyone else often means that we are excluded.

I like my GP and he has been good to me in the past but I don’t think he knows what a proper DES Health Check is.

CHECKING UP ON DES

Thanks to:
The Health Foundation – funder
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Oxfordshire Learning Disability Partnership Board
www.EasyWords.co.uk

RIDGEWAY Partnership

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