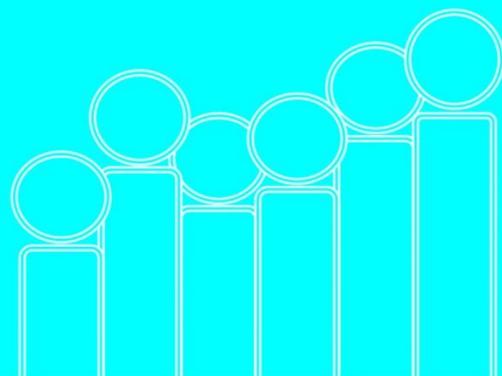




Health Checks for People with Learning Disabilities: An Audit Tool

Eric Emerson & Sue Turner



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IHAL 2011-10

Foreword

It remains a considerable concern that most mainstream health care professionals including General Practitioners (GPs) lack confidence in caring for people with a learning disability. Whilst this is partly due to negative attitudes, limited knowledge and understanding of the person's needs, GPs and primary care staff can actually identify and meet most of the health care needs of a person with a learning disability. Our generalist approach, combined with problem solving skills, family knowledge and community orientation is most likely to identify and meet the high level of health inequalities compared to the general population. At the same time we need to recognise that both people with learning disabilities and GPs need more time when they consult in primary care.

The annual health check offers an opportunity for protected time for a comprehensive "head to toe" health check with a person's GP and practice nurse. The RCGP Learning Disabilities group has produced a Step by Step guide to annual health checks for GPs www.rcgp.org.uk This health intervention helps practices to meet the requirements within the Equalities Act (2010) as a reasonable adjustment to reduce the inequalities and remove barriers to access for this particular population and their carers. Usually we as GPs will encounter the person when they are ill so the health check may allow us to gain a fuller understanding of the person's life.

The IHAL Health Checks for People with Learning Disabilities: A Systematic Review of Evidence (2010) report found that health checks for people with learning disabilities result in : (1) the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia); and (2) targeted actions to address health needs.

The skills we as GPs and our staff gain in these structured reviews are transferable to other groups of vulnerable people, such as the annual health checks for people with dementia and mental health needs as well as people with physical disabilities. Currently there is wide variation in the number and quality of health checks being offered across our GP practices in the UK. Review and reflection are essential components of quality assurance as well as showing evidence of continuing professional development for doctors' revalidation. This clinical audit tool is designed to help our practices review our processes and outcomes and will be rewarding for all of us including GPs, Practice Nurses and support staff as well as leading to better care for people with a learning disability and their carers. As the BBC Panorama programme on 31st May 2011 about Winterbourne View has shown we cannot be complacent about the safeguarding and care of people with learning disabilities.

"No person can change the world but together we change the world for one person"

Dr Matt Houghton RCGP CIRC Learning Disabilities Clinical Champion

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Acknowledgements

We would like to thank all those people who have commented on earlier drafts of this audit tool including: Rachel Bailey, Geoff Baines, Umesh Chauhan, David Congdon, Anna Cooper, Robert Davies, Beverley Dawkins, Jeanette Dean-Kimili, Alison Giraud-Saunders, Gyles Glover, Rob Greig, Crispin Hebron, Matthew Hoghton, Theresa Joyce, Henny Lantman, Nicholas Lennox, Peter Lindsay, Graham Martin, Helen Mycock, Patrick Olszowski, Jill Rasmussen, Hazel Roberts, Dominic Slowie, Sue Smith, Judi Thorley and Victoria Welch.

Introduction

The NHS Operating Framework for 2011/12 states that 'Annual health checks for people with learning disabilities remain an important means of ensuring improved access to health services' (p.41). Funding for the inclusion of health checks as a Directed Enhanced Service (DES) has been agreed for 2011/12.

Evidence suggests that health checks are effective in identifying unmet health need and result in actions to address health needs.¹ They may also result in GPs having a better awareness of health issues for people with learning disabilities. However, data on the uptake of health checks in 2010/11 indicates that while figures have improved, only 48-49% of people eligible to receive them did so.²

This brief audit tool has been developed to support practices, primary care liaison staff, health facilitators and others to improve the uptake and quality of health checks and thereby reduce the health inequalities experienced by people with learning disabilities. It builds on the work already undertaken by the Royal College of General Practitioners,³ the East Midlands Regional Health Facilitators Network and Judi Thorley, Regional Lead for Learning Disability and Safeguarding Adults.

The audit tool (based on seven simple questions) can be used by GP practices and those providing support to GP practices to:

- Identify good practice and encourage services to improve their practice further
- Establish whether health checks and primary care services are provided consistently across a geographical area
- Monitor progress
- Embed key 'reasonable adjustments' within primary care

There are three levels of success; bronze, silver and gold. Bronze is the basic level and includes the minimum requirements needed to meet DES specifications. There is also a column listing suggested evidence which auditors may find helpful.

The audit tool has been developed to support local self-assessment of practice, either by individual GP practices or by Primary Care Organisations. As such, it is consistent with the ethos behind both the Learning Disabilities Self-Assessment Framework:

http://www.improvinghealthandlives.org.uk/self_assessment/ and the NHS Equality Delivery System:

<http://www.dh.gov.uk/en/Managingyourorganisation/Workforce/Equalityanddiversity/index.htm>

The results of undertaking the audit do not imply endorsement by any external organisations or bodies.

An accessible version of this document is available at

<http://www.improvinghealthandlives.org.uk/publications.php5?rid=976&edit>.

1: How well are we doing at identifying patients with learning disabilities?

Rationale

Unless adults with learning disabilities are identified on GP registers, they will not be offered a health check. The QOF register should include all adults with learning disabilities known to the practice. Whilst these people are not necessarily eligible for an annual health check under the DES, Primary Care Organisations and GP practices should consider that they may be covered under the new Public Service Equality Duty.⁴ This means that reasonable adjustments should be made to services and because of the specific difficulties people with learning disabilities face, clinical commissioning groups should consider whether targeted health checks form an effective and important adjustment for all people with learning disabilities known to the practice.⁵

The DES register should include all “Learning disabled clients known to Councils with Adult Social Services Responsibilities (CASSR): 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 service. In addition include learning disabled clients who should be reviewed by the CASSR in a financial year but are not.” All people with learning disabilities on the DES register should be offered a health check.

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at identifying patients with a learning disability?	<p>GP practices have a health check learning disabilities register (DES register) which includes all adults with learning disabilities known to Adult Social Care.</p> <p>There is a process in place to update the register and ensure the QOF learning disabilities register includes all patients on the health check register.</p>	<p>In addition to level 1 -</p> <p>There is a process in place to ensure that young people with learning disabilities who turn 18 are added to the health check register if they are eligible.</p> <p>GPs have a process for referring people with learning disabilities not known to social services for a local authority needs assessment if necessary</p>	<p>In addition to level 2 -</p> <p>Health checks are offered to all people with learning disability known to the practice (people on the QOF register).</p>	<p>Number of individuals on the QOF and DES registers.</p> <p>Correspondence between QOF and DES registers.</p> <p>Date when the registers were last updated.</p> <p>Description of process to add young people becoming 18 to the register.</p> <p>Protocol for referral to the local authority.</p>

2: How well are we doing at arranging for people to attend for a health check?

Rationale

If people with learning disabilities do not understand the information they have been sent, and the reason for having a health check, they may not attend their appointment. Therefore practices need to offer appointments in a manner that the person can understand. This may include sending easy read/accessible appointment letters and/or telephoning the individual. Telephone reminders the day before the appointment can also increase uptake. There are examples of easy read appointment letters and pre-check information in A Step by Step Guide for GP Practices.³ Easy read health information can be found at www.easyhealth.org.uk and www.apictureofhealth.southwest.nhs.uk.

People with learning disabilities may need reasonable adjustments such as longer appointment times to successfully use services. Placing an auto-alert/flag on the patient record system which tells practice staff about an individual's needs is helpful for planning a successful appointment. An example of an auto-alert can be found in A Step by Step Guide.³

People with learning disabilities (particularly those with autistic spectrum disorders) can find it hard to wait, and may find busy waiting rooms difficult to cope with. A choice of appointment times should be offered taking these issues into account. Although accessing GP surgeries should always be the preferred option, practices should offer health checks in other settings such as the person's home or familiar day setting if people are unable to come to the surgery for whatever reason.

People with learning disabilities should be offered an extended appointment, enabling time to gather the right information, explain what is happening and put people at ease. The RCGP suggests 30 minutes with the practice nurse and 30 minutes with the GP³. A recent survey of the DES carried out in Yorkshire and Humber showed that responses to the question regarding how long health checks took ranged from between 10-20 minutes (18%) to more than 50 minutes (12%).⁶

If people do not attend, practices should review their appointments process to ensure that reasonable adjustments are in place, and liaise with the specialist learning disability team for extra support. Working with community learning disability teams, care providers, family carer and self-advocacy organisations can promote awareness of health checks and support increased attendance.

Providing a health check questionnaire which can be completed prior to the appointment saves time, and helps avoid the situation of someone with learning disabilities being supported by a support worker who does not know key information. For an example of a pre-health check questionnaire please go to: www.oxleas.nhs.uk/site-media/cms-downloads/Microsoft_Word_-_Oxleas_HAP_prehealth_check_for_DES.pdf or www.rcgp.org.uk

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at arranging for people to attend for a health check?	<p>All patients on the DES register are offered an annual health check.</p> <p>Any patient who declines a health check will have this recorded in their medical record.</p>	<p>In addition to level 1 -</p> <p>Where appropriate, patients on the health check register receive an accessible letter inviting them for the health check and accessible information about:</p> <p>(1) why the health check is important;</p> <p>(2) what it involves;</p> <p>and (3) the importance of bringing their Health Action Plan with them.</p> <p>All patients are offered a choice of appointment and the appointment is planned taking into account any reasonable adjustments that need to be made (for example avoiding busy times or doing the health check in another setting).</p> <p>All patients are offered an extended appointment (minimum 30 minutes).</p> <p>The practice works with the local learning disability team to promote awareness of health checks</p>	<p>In addition to level 2 -</p> <p>All patients receive a phone call or text a week before the appointment to check whether they may have any difficulties attending.</p> <p>All patients receive a phone call or text the day before the appointment reminding them to attend and to bring their Health Action Plan with them.</p> <p>The practice makes reasonable adjustments to their protocol for patients who do not attend.</p> <p>After two attempts, the practice will liaise with the local health facilitator/primary care liaison nurse, local CLDT or similar for advice and support.</p> <p>The practice works with care providers, self-advocacy and family carer organisations to promote awareness and uptake of health checks.</p>	<p>Number of people offered a health check.</p> <p>Number of people who have had a health check.</p> <p>Example of accessible invite letter.</p> <p>Example of accessible information regarding the health check.</p> <p>Example of accessible pre-health check questionnaire.</p> <p>Information about people who did not attend for their health check and what was done about this.</p> <p>Times of health check appointments.</p> <p>Details of any health checks carried out away from the surgery and if yes, details of how the decision was made.</p> <p>Average length of health check appointment.</p> <p>Description of how the practice works in partnership with other groups.</p>

3: How well are we doing at making people feel comfortable when they arrive?

Rationale

The way that people with learning disabilities and family carers are greeted at the surgery is very important. One barrier to increasing uptake of health checks is the reluctance of some people with learning disabilities to have them. Making people feel welcome and comfortable in the surgery is one way of overcoming this barrier.

Some people with learning disabilities can find it hard to wait, and may find busy waiting rooms difficult to cope with. The use of alternative waiting areas (and strategies for minimising waiting times) should be considered reasonable adjustments for particular patients for whom this is known to be an issue.

Seeing a familiar face can help. Therefore it is better if the person with learning disabilities is able to see their own GP.

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at making people feel comfortable when they arrive?	<p>The person with learning disabilities and their carer are greeted and given clear information about what is going to happen.</p>	<p>In addition to level 1 –</p> <p>There is an auto-alert or flag on the patient’s records detailing any specific communication needs and the contact details of the main carer if there is one.</p> <p>Arrangements are in place to ensure the person can see their own GP if they wish to.</p>	<p>In addition to level 2 –</p> <p>Reasonable adjustments to minimise waiting times are in place and, where possible, alternative waiting areas are provided.</p> <p>People with learning disabilities are enabled to attend the surgery prior to their health check so that they can get used to the building and equipment.</p>	<p>Feedback from people with learning disabilities and family carers.</p> <p>Example of auto-alert or flag.</p> <p>Examples of familiarisation techniques and strategies used.</p>

4: How well are we doing at performing the health check?

Rationale

People with learning disabilities should be asked if they want their carer with them during the health check. Some people with learning disabilities may not feel comfortable about discussing some aspects of their health with a carer present, and it may be helpful to have a part of the check without the carer in the room.³

If the person with learning disabilities is unable to consent (either to having the health check or to some specific tests undertaken as part of the health check), the principle of 'best interest' will need to be considered and documented in the notes. See:

http://www.gmcuk.org/guidance/ethical_guidance/consent_guidance_index.asp

The DES guidance specifies that practitioners should base their health check on the "Cardiff" health check protocol available through the Royal College of General Practitioners' website or a similar protocol agreed with the Primary Care Organisation.⁷ Any health check provided under the arrangement will, as a minimum, include—

- a review of physical and mental health with referral through the usual practice routes if health problems are identified
- health promotion
- a systems enquiry and review of chronic illness
- a physical examination
- a review of epilepsy
- a review of behaviour and mental health
- a syndrome specific check (if relevant)
- a check on the accuracy of prescribed medications
- a review of co-ordination arrangements with secondary care
- a review of transition arrangements where appropriate

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at doing the health check?	<p>The person with learning disabilities is asked if they would like to have a particular carer or advocate with them for the whole or part of the health check.</p> <p>If the person is unable to consent (either to having the health check or to some specific tests undertaken as part of the health check), the principle of 'best interest' has been used and is documented in the notes.</p> <p>The Cardiff health check or a similar protocol agreed with the Primary Care Organisation is used. The health check includes the minimum requirements set out in the DES specification (including a systematic review of efficacy and side effects of medications).</p>	<p>In addition to level 1-</p> <p>The health check includes an assessment of need (and if appropriate referral) for more detailed assessment of vision and hearing.</p> <p>The health check covers an assessment of eating, bowel and bladder function with particular attention to dysphagia, an assessment of need (and if appropriate referral) for more detailed assessment of oral health, a review of menstrual history where appropriate and consideration of dementia and depression where appropriate.</p> <p>Reviews of epilepsy should include a review of the seizure record and epilepsy protocol.</p> <p>The health check should include consideration of safeguarding issues such as neglect, physical, sexual or emotional abuse.</p>	<p>In addition to level 2-</p> <p>Health checks are provided to at least 90% of people on the DES register.</p>	<p>Copy of health check template.</p> <p>Feedback from people with learning disabilities and family carers.</p> <p>Documentation on 'best interest' decision making.</p> <p>Examples of use of accessible information on health conditions.</p>

5: How well are we doing at arranging for and supporting the uptake of follow-up actions?

Rationale

The primary purpose of health checks is to identify treatable health conditions or impairments *so that appropriate and timely action can be taken*. Ensuring that these actions are taken will be dependent on:

- having a clear record of what specific actions are to be taken following the health check that specifies **who, will do what, by when**;
- having a system in place to review whether follow-up actions have been undertaken, identify and record any resulting actions and/or any additional steps to ensure that follow-up actions are undertaken.

Some of the follow-up actions are likely to involve supporting the patient with learning disabilities and, where appropriate their carer(s), to better manage their own health through Health Action Plans. See:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4098111

This could involve them taking greater responsibility for specific health actions (e.g., medication) or broader changes to lifestyle to reduce health risks (e.g., improving diet, increasing participation in exercise). Careful thought will need to be given to how best to support the patient with learning disabilities and, where appropriate their carer(s), to achieve these goals. Easy read health promotion information can be found at www.easyhealth.org.uk and www.apictureofhealth.southwest.nhs.uk.

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at arranging for and supporting the uptake of follow-up actions?	<p>Follow-up actions are agreed with the patient with learning disabilities (and if appropriate their carer).</p> <p>Follow-up actions include a reminder to attend other relevant health checks (for example asthma, diabetes and bowel screening).</p> <p>Follow-up actions for women with learning disabilities include a discussion regarding cervical smears and mammograms.</p> <p>Agreed follow-up actions are recorded in the patient's record and Health Action Plan.</p> <p>If a Health Action Plan isn't in place one is offered.</p>	<p>In addition to level 1-</p> <p>Review dates for follow-up actions are recorded in the patient's record and (where available) Health Action Plan.</p> <p>Delivery/attainment of the agreed follow-up actions is systematically reviewed and recorded.</p> <p>Reasonable adjustments necessary for the delivery/attainment of the agreed follow-up actions are recorded and communicated to relevant personnel and agencies (e.g., in referral letters).</p> <p>Accessible information is provided to the patient with learning disabilities for at least 75% of all agreed follow-up actions.</p>	<p>In addition to level 2-</p> <p>The practice is liaising with learning disabilities services regarding ways of improving support to patients to deliver/attain agreed follow-up actions.</p> <p>The practice has established referral criteria for providing ongoing support with learning disabilities services.</p> <p>The practice has an agreed way of updating health action plans.</p>	<p>Review of patient records.</p> <p>Referral letters.</p> <p>Examples of accessible information.</p> <p>Feedback from people with learning disabilities and family carers.</p> <p>Number of Health Action Plans offered.</p> <p>Use of Health Action Plans as 'working documents'.</p> <p>Review of patient satisfaction data.</p>

6: How well are we doing at collating information about the health needs of people with learning disabilities to inform the commissioning process?

Rationale

Collating the outcomes of annual health checks across GP practices can provide key information on the health needs or health status of adults with learning disabilities in a given area (e.g., an area covered by a Clinical Commissioning Group) and how that may be changing over time. This information is vitally important for the effective commissioning of health services for adults with learning disabilities. In the future it may be possible to collate and extract this information using the General Practice Extraction Service (<http://www.ic.nhs.uk/gpes>). At present, it will require individual practices to collaborate with locally organised data extraction protocols.

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at collating information about the health needs of people with learning disability to inform the commissioning process?	<p>The practice has discussed with the commissioners the possibility of collating and anonymously sharing practice-based information on the health status and needs of patients with learning disabilities.</p>	<p>In addition to level 1-</p> <p>The practice has collated and anonymously shared with the commissioners practice-based information on the health status and needs of patients with learning disabilities.</p> <p>Information is used in the JSNA and SAF</p>	<p>In addition to level 2-</p> <p>The practice has an agreement in place with the commissioners to annually collate and anonymously share practice-based information on the health status and needs of patients with learning disabilities (including information on conditions newly identified as a result of health checks).</p>	<p>Agreements with commissioners</p> <p>Copy of the JSNA</p> <p>Copy of the SAF</p>

7: How well are we doing at improving our practices?

Rationale

Considerable gains have been made in recent years in more effectively supporting people with learning disabilities to access and use primary health care services. There is, however, always more that can be done (e.g., in increasing the effectiveness and scope of reasonable adjustments to the provision of health care for people with disabilities). Continuous quality improvement is a core objective of an efficient and responsive health service. The Health Quality Improvement Partnership has produced detailed guidance on a four stage process of clinical audit

<http://www.hqip.org.uk/assets/Downloads/Criteria-and-indicators-of-best-practice-in-clinical-audit.pdf>

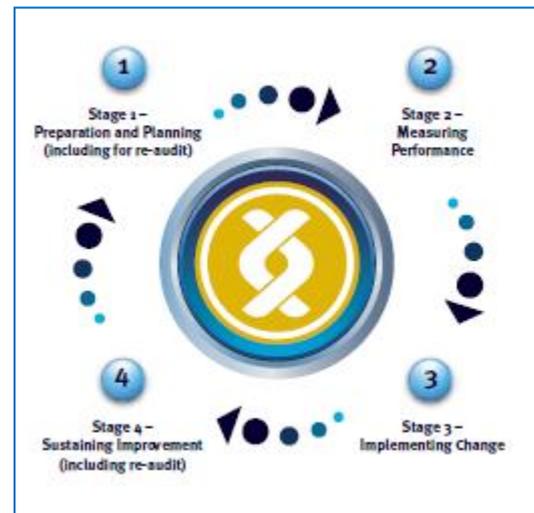


Figure 1: HQIP Clinical Audit Cycle

Indicators of success

	Level 1 	Level 2 	Level 3 	Evidence
How well are we doing at improving our practices?	<p>The practice formally reviews (on at least an annual basis) the quality of healthcare it provides to patients with learning disabilities.</p> <p>The practice has an identified learning disabilities 'champion' with responsibility for ongoing monitoring of the quality of healthcare the practice provides to patients with learning disabilities.</p> <p>The practice has a complaints process that is accessible to people with learning disabilities.</p>	<p>In addition to level 1-</p> <p>All complaints from or on behalf of people with learning disabilities are carefully reviewed and appropriate action taken at individual and collective levels.</p>	<p>In addition to level 2-</p> <p>Patients with learning disabilities and carers of patients with learning disabilities are involved in monitoring of the quality of healthcare the practice provides to patients with learning disabilities.</p> <p>A formal system is in place for collecting information on current practice and setting and reviewing the attainment of clear measurable and attainable targets for improving practice.</p>	<p>Monitoring/review arrangements.</p> <p>Recording of reasonable adjustments made in light of the specific needs of people with learning disabilities.</p> <p>Data on health gain across patients with learning disabilities (e.g., reduced prevalence of obesity).</p> <p>Feedback from people with learning disabilities and family carers.</p>

Use of Audit Results

Once the self-assessment of practice is complete, it is helpful to share the results with the Partnership Board, self-advocacy and family carer groups, the practice patient participation group and local learning disability teams. They can provide important information to inform local action planning and service improvement. Audit results can also be fed into the local health self-assessment process which should inform the JSNA and lead to better local planning. Ensuring information about services is transparent supports patient choice and inclusion and can lead to 'better care, better outcomes and reduced cost'.⁸

You can also share the results with other areas at www.ihal.org.uk/talk/ and go to 'Health Checks'.

References

1. Robertson J, Roberts H, Emerson E. Health Checks for People with Learning Disabilities: Systematic Review of Impact. Durham: Improving Health & Lives: Learning Disability Observatory, 2010.
2. Emerson E, Glover G. Health Checks for People with Learning Disabilities: 2008/9 & 2009/10. Durham: Improving Health & Lives: Learning Disabilities Observatory, 2010.
3. Hoghton M, the RCGP Learning Disabilities Group. A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability. London: Royal College of General Practitioners, 2010.
4. Equality and Human Rights Commission. The essential guide to the public sector equality duty. London: Equality and Human Rights Commission, 2011.
5. Turner S, Robinson C. Health Checks for People with Learning Disabilities: Implications and actions for commissioners. Durham: Improving Health & Lives: Learning Disability Observatory, 2010.
6. Ferguson S, Aylott J, Kilner K. An Evaluation of the Clinical Directed Enhanced Service for People with Learning Disabilities in the Yorkshire and the Humber Region, 2010.
7. Department of Health. The Primary Medical Services (Directed Enhanced Services) (England) (Amendment) Directions 2011. London: Department of Health, 2011.
8. Department of Health. Equity and Excellence: Liberating the NHS, 2010