
Community Eye Care for Adults & Young People with Learning Disabilities Pathway

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Foreword

The Local Optical Committee Support Unit (LOCSU) has already successfully established a range of enhanced local eye care services pathways for areas of eye health such as glaucoma and cataracts. Delivered by local community based optometrists and dispensing opticians across England and Wales, LOCSU's pathways are backed by accredited training with the Wales Optometry Postgraduate Education Centre (WOPEC). This ensures successful outcomes in terms of clinical results and improved access for the local community to a local eye health service which is highly cost-effective.

This latest Pathway – for Adults and Young People with Learning Disabilities (PwLD), those aged 16 years and older – has been developed by LOCSU's Clinical Advisory Group from established successful Learning Disability services provided by community optometrists in a number of areas across the UK¹, supplemented by the expertise of a multi-disciplinary team, and with advice and support from other leading eye health organisations and visual impairment charities through SeeAbility² and Mencap³.

This Pathway is designed to enable people with learning disabilities to access NHS sight tests in the same way as the wider population.

Executive Summary

People with learning disabilities are ten times more likely^{4,5} to have eye problems, but are less likely to receive timely and appropriate care, than the rest of the population⁶.

The majority of people with mild learning disabilities should be able to have a sight test in any optical practice. In such cases patients and their relatives/carers are still recommended to use the bespoke SeeAbility support tools (especially Step 1 of the Pathway below), to ensure that they get most benefit from their sight test.

The aims of this Community Eye Care Pathway therefore are:

- to provide an additional enhanced service, information and support, where appropriate, to enable people with more complex learning disabilities to access NHS eye health services care (e.g. a sight test and any necessary visual correction) in a community setting like everyone else

¹ NHS Barking and Dagenham, NHS Bexley, NHS Sutton and Merton, NHS Tower Hamlets

² <http://www.seeability.org/>

³ www.mencap.org.uk

⁴ The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK
Eric Emerson & Janet Robertson – 2011

www.rnib.org.uk/aboutus/Research/reports/2011/Learn_dis_small_res.pdf

⁵ Estimates of the number of adults in the UK with learning disabilities and visual impairment – summary report SeeAbility & RNIB - 2011
www.seeability.org/includes/documents/cm_docs/2011/p/pwld_summary_report_june_2011.pdf

⁶ McCulloch, D. L., Sludden, P. A., McKeown, K., et al (1996) Vision care requirements among intellectually disabled adults. Journal of Intellectual Disability Research, 40, 140–150

- to improve access to front-line eye health services for all people with learning disabilities
- to minimise stress and distress for all people with learning disabilities when accessing eye care services
- to provide reporting of the results of the sight test in an agreed format to the patients and their carers where appropriate

The UK Vision Strategy⁷ seeks a major transformation in the UK's eye health, eye care and sight loss services. A determined and united cross-sector approach will make that change a reality.

Three strategic outcome areas are identified:

1. Improving the eye health of the people of the UK
2. Eliminating avoidable sight loss and delivering excellent support for people with sight loss
3. Inclusion, participation and independence for people with sight loss

This Pathway specifically addresses all three strategic outcome areas and particularly areas 2 and 3.

The Pathway is designed to be provided by accredited, or suitably experienced, optometrists or Ophthalmic Medical Practitioners (OMPs) in a community setting.

The Pathway involves:

- patient preparation using SeeAbility's "Telling the optometrist about me" form⁸, including a familiarisation visit to the practice where appropriate
- a sight test with provision for more time to be spent on familiarisation, explaining procedures and equipment to both the patient and supporting carers at the time of the sight test, and repeat visits to complete procedures where needed
- post-sight test feedback to patients, carers and GPs using SeeAbility's "Feedback From The Optometrist About My Eye Test" form⁹
- signposting/communication to other local services as appropriate.

The post-sight test feedback form contains important information and should be taken to any clinical appointments with other healthcare professionals.

People to whom this Pathway applies may still choose to have a GOS sight test (if eligible) at any optical practice of their choosing and this Pathway does not affect their right to do so.

⁷ www.vision2020uk.org.uk/ukvisionstrategy – UK Vision Strategy – VISION 2020 UK & RNIB (2008)

⁸ www.lookupinfo.org/includes/documents/2010/t/telling_the_optometrist_about_me_draft_d.pdf

⁹ www.lookupinfo.org/includes/documents/2010/f/feedback_from_optom_about_my_eye_test_nov_2009.pdf

Background

It is important to define “learning disability” in order to differentiate it from mental health problems and ‘specific learning difficulties’ such as dyslexia and dyspraxia.

The definition currently used by the Department of Health in *Valuing People*¹⁰ is:
“A significantly reduced ability to understand new or complex information (reduced intelligence); a reduced ability to cope independently (reduced social functioning); which started before adulthood with a lasting effect on development.”

Mencap’s definition¹¹ is:

“A learning disability is a reduced intellectual ability and difficulty with everyday activities - for example household tasks, socialising or managing money - which affects someone for their whole life.

“People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

“The level of support someone needs depends on individual factors, including the severity of their learning disability.”

Learning disability should be perceived as a cognitive impairment making it harder to make sense of information. It is not mental illness (although due to a variety of factors mental illness is more prevalent in this group of patients). Most importantly for commissioners the very factors causing the learning disability may also affect normal visual development and people with a learning disability are more likely to need, but less likely to have, access to high quality eye care.

Prevalence and inequalities

It is estimated¹² that there are 1,447,300 people with learning disabilities in the UK. This number is expected to increase by about 12% over the next 20 years to 1,534,500 in 2021 and to 1,615,600 in 2031.

Recent studies have shown that the estimated prevalence of visual impairment or significant refractive error in people with learning disabilities is 52.43% in children, 62.3% in the 20-49 age group and 70.1% in the over 50s¹² - far higher than for the population as a whole.

¹⁰ Valuing people: A New Strategy for Learning Disability for the 21st Century. A white paper - DH
www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf

¹¹ www.mencap.org.uk/all-about-learning-disability/about-learning-disability

¹² The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK
Eric Emerson & Janet Robertson – 2011
www.nib.org.uk/aboutus/Research/reports/2011/Learn_dis_small_res.pdf

Most of this impairment is refractive¹² and can be corrected with spectacles; however people with learning disabilities are less likely to access sight tests and are also less likely to receive visual aids¹³.

“Health Checks for People with Learning Disabilities: A Systematic review of Evidence” by Robertson, Roberts and Emerson, sponsored by the Department of Health¹⁴, also highlights many of the other health inequalities experienced by people with learning disabilities.

This Pathway for adults and young people with learning disabilities is designed to enable access to local NHS eye health services for all patients aged 16 years and older with learning disabilities in the most cost-effective way.

Frequency of sight testing

We recommend that people with learning disabilities should have a sight test every two years or earlier if recommended by the optometrist. This is particularly important for people with learning disabilities because:

1. Under-reporting of eye and sight problems by people with learning disabilities either;
 - a. due to poor understanding of normal versus abnormal visual phenomena and
 - b. due to difficulties in communicating their concerns to carers or health professionals
2. The prevalence of cataract, keratoconus, tumours and even blepharitis is higher in people with learning disabilities and can manifest at an earlier age. This is especially true in people with Down's syndrome.

Access

Accessing sight tests and suitable spectacles is often a problem for patients with learning disabilities. The RNIB has reported that many adults with learning disabilities have never had a sight test¹⁵. This may be because they, or their carers, are not aware that they could have problems with their vision, and so do not seek a sight test or they may be reluctant to attend a practice through fear of the process, or their carers may feel that they would be unable to participate or read the letters on the letter chart. There may also be unnecessary fears over costs¹⁶.

On this latter point, the majority of people in receipt of benefits have access to free NHS sight tests and an NHS voucher towards the cost of spectacles or contact lenses. All optical practices will be able to advise on these issues in advance of booking a sight test.

¹³ McCulloch, D. L., Sludden, P. A., McKeown, K., et al (1996) Vision care requirements among intellectually disabled adults. *Journal of Intellectual Disability Research*, 40, 140–150

¹⁴ www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemicReview.pdf

¹⁵ www.rnib.org.uk/professionals/healthsocialcare/eyecareprofessionals/Pages/vild.aspx

¹⁶ NHS Sutton & Merton - Service Specification - Primary Care Optometry Service For adult patients in Sutton & Merton with learning disabilities

Problems with the current pathway

Experience has shown people with moderate to severe learning disabilities often require familiarisation visits to the optical practice to enable them to be comfortable in that environment. In this case an enhanced service is needed to allow time to be spent on familiarisation, explaining procedures and equipment to both the patient and supporting carers at or before the sight test is completed.

The enhanced service also includes reporting of the results of the examination in the agreed appropriate format. Only accredited practitioners (optometrists or OMPs) would provide this enhanced service.

For some patients a domiciliary or home visit may be required. This Pathway is designed to offer additional support to patients, carers and practitioners to enable people with severe learning disabilities or other challenging behaviours to access their right to a sight test in the same way as any other NHS patient.

Inability to carry out an NHS sight test on a particular patient

In the rare cases that an optometrist does not feel able to provide a full NHS sight test to a patient with learning disabilities, they should, as in any other case, refer the patient to a colleague who is able to perform a sight test in line with this Pathway. The referral and reason for it should be noted and reported annually to the commissioning authority. Analysis of such information will enable commissioners to ascertain whether population health needs are being addressed or whether there are any access inequalities in the system which need to be addressed as part of local commissioning plans.

SeeAbility resources

SeeAbility, the national charity which provides specific support and information on eye care and vision for people with learning disabilities, has assisted with and endorses this Pathway and related information. A range of information resources to support the pathway are available on SeeAbility's LookUp website¹⁷.

Where necessary, pre-visit support for patients should be provided as part of the pathway. This can be delivered by a range of people including family carers, support workers, Learning Disability Nurses, Rehabilitation Workers or Specialist Learning Disability Workers depending on the patient's requirements. For further information see SeeAbility's factsheet "Preparing for an eye examination"¹⁸.

¹⁷ www.lookupinfo.org

¹⁸ www.lookupinfo.org/eye_care/eye_care_factsheets/preparing_for_an_eye_examination.aspx

SeeAbility's West Sussex eye 2 eye project sampled a wide range of groups and asked about the difficulties that were faced by people with learning disabilities when accessing eye care¹⁹. The results clearly demonstrate that better preparation of the patients and practitioners significantly improves the outcome for people with learning disabilities, and this is reflected in the design of this Pathway.

This preparation may take the form of looking at booklets, pictures or videos explaining the procedure, or may entail visiting the examination room and meeting professionals and other staff in advance of the appointment date. This allows time for individuals with learning disabilities to understand what is involved in the procedure and often facilitates a better outcome for both patients and professionals.

This degree of preparation is rarely, if ever, needed for the general population who can more easily understand the examination processes, and discuss concerns with professionals. Two useful Look Up forms for this purpose are "Having an eye test"²⁰ and "Telling the optometrist about me"²¹.

A very small number of people may have difficulty in complying or co-operating with a sight test in normal optometric practice or with standard equipment, due to the severity of their disability, other physical disability or challenging behaviour. These patients will be referred to a multi-disciplinary team at the Hospital Eye Service (HES), regional centre of excellence or other appropriate team.

Description

Patients may enter the pathway via several routes. They may be referred by their GP via their Annual Health Check (AHC), or by learning disability services, a carer or advocate, optometrist or OMP. Alternatively, they may self-refer. GPs should have a learning disabilities pack which contains all the relevant SeeAbility forms along with a list of accredited practitioners and other relevant agencies.

Patients who need the additional support in this Pathway should be able to choose from a list of practices and practitioners accredited to provide this enhanced service, including domiciliary providers. Copies of the list should be distributed to GPs, optical practices, optometrists, dispensing opticians, relevant hospital services, social services and national and local charities.

The service should be available to anyone who is recognised by their GP as having a moderate to severe learning disability or who has been registered on a local learning disability register as a person with a moderate to severe learning disability.

¹⁹ www.lookupinfo.org/includes/documents/2010/e/eye_care_and_vision_evaluation_and_feedback_form.pdf

²⁰ www.lookupinfo.org/includes/documents/2010/h/having_an_eye_test_011210.pdf

²¹ www.lookupinfo.org/includes/documents/2010/t/telling_the_optometrist_about_me_draft_d.pdf

The practitioner will ensure that the patient, and carer (if appropriate), is aware of the full range of local support services available and how to access them. A list of information to be provided is at Appendix 1.

The service should follow the Pathway described in this document.

Domiciliary Service provision

The same principles apply to the provision of this service in a person's home or normal place of residence.

The domiciliary service should be made available where the patient is unable to attend a high-street practice unaided because of physical or mental illness or disabilities.

It is likely that individuals who require the domiciliary service will have more complex needs and challenging behaviour than those that are able to attend a high street practice, and consequently preparation with the patient is crucial. The carer should be advised by the practitioner about the requirement for a suitable room for the sight test and ways in which the patient can be prepared for the visit.

For domiciliary visits, it is essential that carers complete the 'Telling the Optometrist about me' form in advance so that the practitioner can ensure they have the most appropriate equipment with them.

During the sight test, the patient's normal carer should be present in the room to minimise the stress and to help with any communication issues. Their presence also provides reassurance for the practitioner if the patient has challenging behaviour.

In some cases, not all tests may be possible because of the nature of the patient's disabilities. The patient and/or carer will be consulted about this and the detail noted in the patient's follow-up report and record together with the reason for the test not being able to be performed on that particular patient.

Accreditation and quality assurance

All optometrists have undergone basic training in the care of people with learning disabilities or limited communications. Most practitioners would not, however, consider themselves to be experts in this area and would need further advice and training to deliver this Pathway.

A training and accreditation package is being developed by LOCSU in conjunction with SeeAbility and other appropriate bodies.

This Pathway should be delivered only by accredited practitioners, or those who are recognised by the commissioners as suitably experienced.

A standardised clinical audit must be carried out regularly.

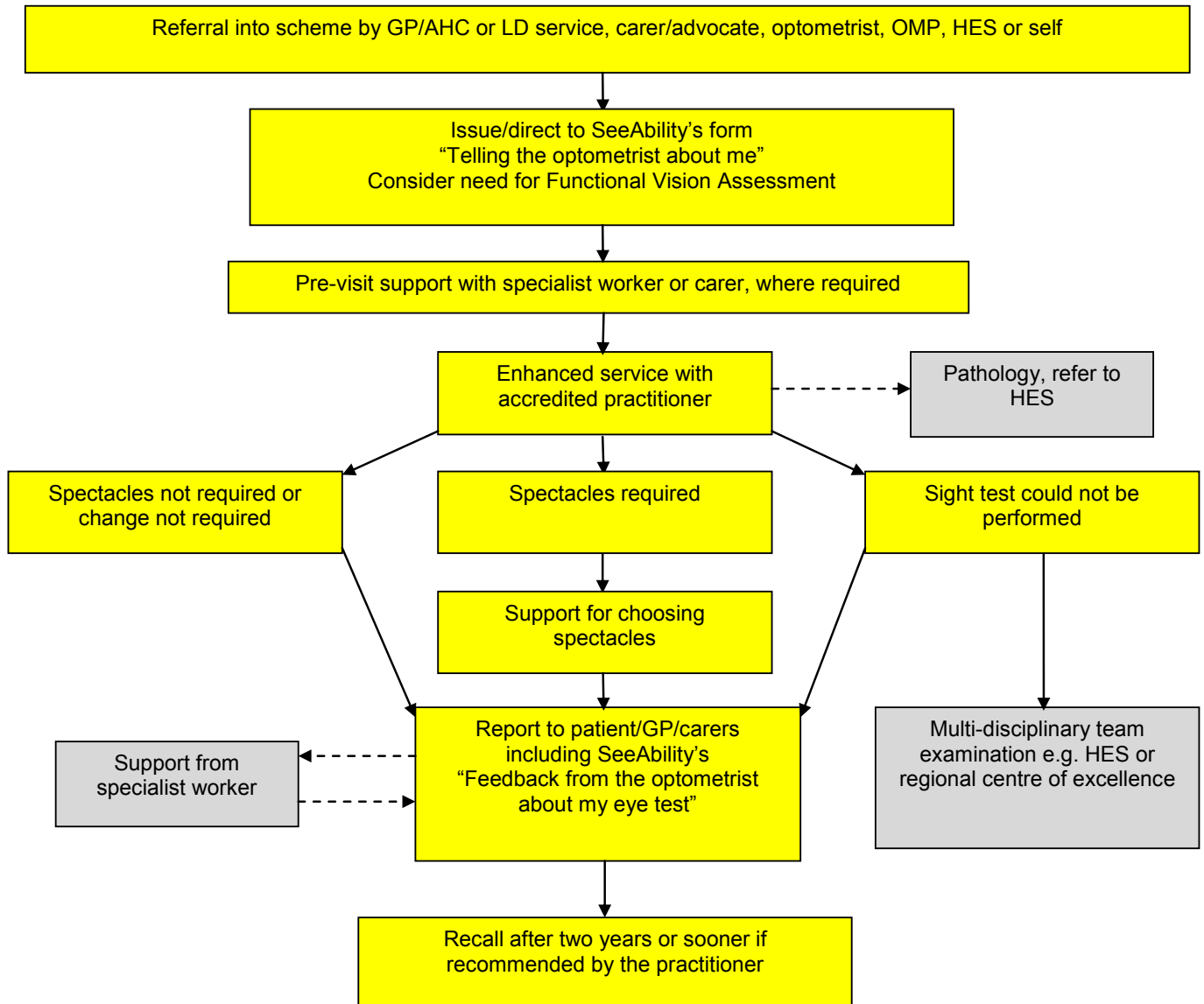
A patient satisfaction audit must be carried out annually.

The collection of data on patient and carer experience including patient/carers reported outcomes should be integrated into the pathway.

Note: At the time of publication, the UK Vision Strategy is consulting on a set of core standards “Seeing it My Way”²² developed by and with people with visual impairment. Once this national framework is finalised, LOCSU will review how the final standards can be integrated into this Pathway.

²² <http://www.nib.org.uk/aboutus/organisation/ukvisionstrategy/pages/seeingitmyway.aspx>

PwLD Pathway



LD: Learning Disability
AHC: Annual Health Check

The dotted lines in the flowchart above indicate alternative pathway depending on need

Pathway

1. Many carers will be able to download and complete SeeAbility's pre-sight test "Telling the optometrist about me"²³ form with the patient. For those that do not have this facility additional options should be available including collecting the form from the optometrist practice or having it sent to them. A list of accredited practices / practitioners can also be downloaded or made available. An appointment is made and the pre-sight test form is sent to the chosen accredited practitioner prior to the sight test. The practitioner will review the pre-sight test form and ensure adequate measures are in place for the appointment to take place
2. Consideration should be given to the need for a Functional Vision Assessment (FVA), especially where there are likely to be communications difficulties. This should be carried out by carers, specialist workers, learning disability nurses etc and the information provided prior to the sight test. A FVA designed specifically for carers and support staff (non eye care and vision professionals) is available²⁴. In addition some local primary healthcare services, now employ primary care liaison nurses/facilitators for people with a learning disability, in addition to community learning disability nurses (who often have a more specialist role)
3. Information should be available for the carer to help the patient prepare for the appointment in advance. For example the "Having an Eye Test" form from LookUp's Easy Read section²⁵. Additionally this may involve the patient visiting the practice on one or more occasions before the appointment day to familiarise them with the surroundings, the personnel and having a cover placed in front of each eye
4. Suitable equipment will be available e.g. Kay Pictures, Cardiff Cards, Sheridan Gardiner, attention grabbers (toys). The additional physical equipment required is not major; it is the willingness of the practitioner to offer a flexible and patient-centred approach that is the key to success
5. Once the sight test has been carried out, any required spectacles will be dispensed as appropriate, with support as necessary. A GOS3 voucher will be issued where a patient is eligible. Where spectacles are prescribed, issue "Getting used to glasses"²⁶ and "Looking after your glasses"²⁷
6. Where necessary the patient will be referred to the HES or other support services as appropriate e.g. where new pathology is found
7. SeeAbility's post-test "Feedback from the optometrist about my eye test" form must be completed and copies given to the patient, their GP and carer as well as being retained in the patient's records

²³ www.lookupinfo.org/includes/documents/2010/t/telling_the_optometrist_about_me_draft_d.pdf

²⁴ www.lookupinfo.org/forms_booklets/functional_vision_assesement_pack/default.aspx

²⁵ www.lookupinfo.org/includes/documents/2010/h/having_an_eye_test_011210.pdf

²⁶ www.lookupinfo.org/includes/documents/2010/g/getting_used_to_glasses_011210.pdf

²⁷ www.lookupinfo.org/includes/documents/2010/l/looking_after_your_glasses_011210.pdf

Notes

Funding should be per patient enhanced service and the fee for the service should be subject to periodic review.

In addition a supplementary domiciliary fee should be agreed to cover the additional costs of providing the service at patients' homes, where appropriate, bearing in mind that the practitioner might need to visit on more than one occasion to achieve the best results for the patient.

Appendix 1

Information to be provided as part of the enhanced service

Before the sight test

- SeeAbility's Look Up information service - Phone 01372 755 066 for information or advice, or view www.lookupinfo.org which contains the following easy read information:

- Having an eye test
- Telling the Optometrist about me form

The website also contains information for carers and supporters, including a Functional Vision Assessment tool and other guidance on preparing for a sight test and supporting people to wear glasses.

After the sight test

General – for those with correctable refractive error

- “Feedback From The Optometrist About My Eye Test” form
- SeeAbility's Look Up information service: phone 01372 755 066 for information or advice, or view www.lookupinfo.org which contains the following easy read factsheets:
 - Choosing the right glasses
 - Looking after your glasses
 - Getting used to your new glasses
 - Wearing glasses

The website also contains information for carers and supporters on supporting people to wear glasses.

- How to get other support services

Low vision - for those with sight loss/low vision

- SeeAbility's Look Up information service: phone 01372 755 066 for information or advice, or view www.lookupinfo.org which contains easy read factsheets and information for carers and supporters on eye conditions and treatment
- RNIB information service – contact details required
- Eye Clinic Liaison Officer (ECLO) - contact details required
- Learning disability liaison nurse (some hospitals have this resource) – contact details required
- Independent Living Coordinator (ILCO) - contact details required
- Local Sensory Impairment Team - Rehabilitation Officer for Visual Impairment - contact details required
- Other local social services, what they can offer and contact details required
- Local sight loss charities – you can search for contact details on www.visionary.org.uk
- Nearest Action for Blind People team – contact details required
- Local Citizen's Advice Bureau – contact details required

Appendix 2

Background Documents

- Improving outcomes and supporting transparency – A public health outcomes framework for England, 2013 – 2016 (DH 2012)
- The Operating Framework for the NHS in England 2012/13 (DH 2011)
- Health action planning and health facilitation for people with learning disabilities: good practice guidance (DH 2008)
- Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (DH 2008)
- Valuing People Now: a new three-year strategy for people with learning disabilities (DH 2009)
- Right Care: Increasing Value – Improving Quality (2010)
- Creating a Patient-led NHS: Delivering the NHS Improvement Plan (DH 2005)
- Implement Care Closer to Home: Convenient Quality Care for Patients (2007)
- Commissioning Framework for Health and Well-being (DH 2007)
- Trust, Assurance and Safety – The Regulation of Health Professionals (DH 2007)
- Safeguarding Patients (DH 2007)
- Health Reform in England: Update and Commissioning Framework (DH 2006)
- Transforming Community Services - Quality Framework: Guidance for Community Services – (DH 2009)
- Standards for Better Health (DH 2006)
- White Paper: Our Health, Our Care, Our Say (DH 2006)
- White Paper: Valuing People (DH 2001)
- NHS Plan: A plan for Reform, a Plan for Investment (2000)
- Falls Prevention – Older People’s NSF Standards (DH)
- Reducing Falls in Older People (Improvement Foundation)

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This Pathway is subject to review in April 2013