

GP health checks for people with learning disabilities report

Tuesday, 15th July 2014

Report summary

The following two pages summarise the main points from the report

Annual Health Checks for people with learning disabilities

- Since 2008, anyone who has been diagnosed with a learning disability is entitled to a free annual health check from the NHS. The service was initially only provided to those aged over 18. In April 2014 it was expanded to include 14-17 year olds.
- Carrying out these health checks is not part of the core GP contract. However it is thought that all GP practices in Southend are now signed-up to provide this service.
- All annual health checks should produce a health action plan that summarises a patient's condition and gives direction for any further treatment. This information should be shared with other healthcare providers that are involved in the care of the patient.

National Background

- The *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* CIPOLD (published in March 2013) reviewed the deaths of 247 people with learning disabilities in south-west England in the period between 2010 and 2012.
- The inquiry revealed that “men with learning disabilities in the CIPOLD study died on average 13 years earlier than in the general population, while the women with learning disabilities died 20 years earlier.”
- 71% of the people included in the CIPOLD study had received their annual GP health check in the year prior to their death. However the inquiry recognised that these health checks were variable in quality, were often poorly documented and that very little effort was made to share the information contained in the health action plans with other agencies involved in the care of patients.

Local background

- According to figures available at the time of the event, in Southend there are currently 621 people diagnosed with learning disabilities yet only 172 (27%) received an annual health check in 2013/2014. The national target is 70%.

Points discussed during the Healthwatch Southend event

- The low uptake of the annual health checks in Southend was flagged both as a cause for concern and as a target for imminent action by NHS England.
- The accuracy of the 27% figure for annual health checks in Southend (see above) was called into question. There were reports of one GP surgery that was carrying out the health checks but had experienced difficulty in reporting the outcomes.
- Very little seemed to be known about how the health checks are managed by GP practices in Southend; how the checks are being carried out and whether they meet the required standards.
- Some people had experienced difficulties booking appointments for annual health checks. Others reported variations in the amount time being set aside by GPs for these checks, with appointments lasting anywhere from five minutes to 45 minutes.

Further work

- NHS England has recently contacted local GPs requesting statistical information on annual health checks. They are also carrying out work to ensure that these checks are fit for purpose. Healthwatch Southend will study this data as it appears and take action or carry out follow-up work as is necessary.
- In a bid to find out more about how the health checks are being carried out locally, Healthwatch Southend will submit a list of questions to GP practices in Southend. We will publish a summary of any responses we receive.
- Healthwatch Southend will contact the South Essex Partnership University NHS Foundation Trust (SEPT) and Southend Hospital. We will ask whether the data from Health Action Plans is accessible to them and if so whether the information is useful and of good quality.

Contents

(Click on any of the underlined headings below to be taken to that section of the report)

(1) Introduction

- [About Healthwatch Southend](#)
- [About our public events](#)
- [Why we held this event](#)
- [About this report](#)
- [What happened on the day](#)

(2) Presentations

- **What health checks are and the role of SEPT**
Paula Pearl, health facilitation nurse, SEPT
- **My experience of the annual health check**
Jenny Gilliat, manager, SHIELDS Parliament
- **How it works and what your doctor should do**
Ian Ross, learning disabilities lead, commissioning directorate, NHS England

(3) A summary of the questions and answers session

(4) Evaluation of the event

(5) Comments on the event

(6) Follow-up work

(7) Thank you

Introduction

About Healthwatch Southend

We are an independent organisation that helps people of all ages who:

- need information about health or social care services
- want to see services improve
- need help to make a complaint or raise a concern about an NHS funded service

Everything we do is free to people who live in the Southend on Sea area.

For more information, visit www.healthwatchsouthend.co.uk

About our public events

As a part of our remit to involve patients, service users, carers and the general public in the design and commissioning of health and social care services, we are running a series of public events locally on specific themes. These are intended as opportunities for people to come together, share thoughts and ideas, hear direct from commissioners and providers of services, ask questions and have their views heard.

Each event lasts for approximately three hours and is based around short presentations from guest speakers. These may be people who commission services in Southend, people who are involved in shaping health policy, or people who provide care, either under the umbrella of the NHS, the council, or through a charity or a support group. We also try to include speakers who have personal experience of the issues that are being discussed.

At the end of the event we open the discussion to comments and questions from the audience.

Our goals in holding these events are as follows:

- Where we are discussing a specific health issue we hope that everybody leaves with a better understanding of the challenges faced by those who live with the condition.
- We hope to shine a light on the problems that members of the public are experiencing with health or social care services in Southend. We hope to provide some insight into what is being done to address these problems and drive forward improvements.
- We hope that our guest speakers, along with any other professionals in attendance, leave with a broader understanding of how the public is engaging with local health and social care services and what their concerns are.
- In the longer term we hope that the events are useful for identifying problems, gaps in services and areas where improvement is needed. Healthwatch Southend can follow-up on these issues and keep the public informed of any progress that has been made.

[\(Click here to return to the contents page\)](#)

Why we held this event

Background

In March, 2013, the findings of the independent *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* (CIPOLD) were published.

The CIPOLD reviewed the deaths of 247 people with learning disabilities in south-west England in the period between 2010 and 2012 and uncovered some very alarming statistics on life expectancy:

“Men with learning disabilities in the CIPOLD study died on average 13 years earlier than in the general population, while the women with learning disabilities died 20 years earlier. Nearly a quarter of people with learning disabilities in the CIPOLD study were under the age of 50 when they died, compared with approximately 9% of the general population.”

(Confidential Inquiry into premature deaths of people with learning disabilities, Final Report, page 28)

97% of the people included in the study had one or more long-term or treatable health conditions. Furthermore the inquiry identified a number of health problems disproportionately affecting people with learning disabilities, such as weight loss and epilepsy. It highlighted the difficulties people with learning disabilities experienced with communicating their pain and the problems of engaging them in preventative healthcare programs. For example, it was noted that only 9% of people included in the study had undergone a cardiovascular disease risk assessment. Of the 53 people with learning disabilities whose underlying cause of death was related to the heart and circulatory system, only 15% had a cardiovascular disease risk assessment documented in their health records.

[\(Click here to return to the contents page\)](#)

The importance of the annual GP Health check

If carried out properly, a regular check-up from a GP is a simple and direct way of monitoring the health and improving the quality of life of a person with learning disabilities.

Since 2008 everyone who has been diagnosed with a learning disability is entitled to a free annual health check from the NHS. The service was initially offered to those over the age of 18. As of April 2014 it has been expanded to include 14-17 year olds. In most cases these check-ups will be carried out by a GP, however it is not mandatory for GPs to provide this service. Instead GP practices are encouraged to adopt annual health checks for people with learning disabilities as an enhanced service which they are paid for on delivery.

Health checks of this kind should be performed by an experienced doctor. They should be conducted in a manner that places the patient at ease, that allows them ample time to discuss their health and voice any concerns they have, and that includes them, as much as is possible, in the decisions affecting their healthcare.

In the CIPOLD study 71% of people with diagnosed learning disabilities had received an annual health check in the year prior to their death. 12% had never received an annual health check.

Despite the relatively high number of people receiving these examinations, the report acknowledges that the quality and the recording of the health checks varied tremendously and was often extremely poor:

“There was no particular type of approach taken, some did not cover key aspects of care (such as asking about post-menopausal bleeding, or assessing cardiovascular risk factors), and many were so poorly documented that it was difficult to be sure that a full health assessment had been conducted.”

(Confidential Inquiry into premature deaths of people with learning disabilities, Final Report, page 47)

[\(Click here to return to the contents page\)](#)

The importance of Health Action Plans

When an annual health check is carried out a health action plan must drawn-up with the patient. This should communicate in plain English the main points that were discussed during the health check. It should identify specific health issues, detail plans for any further treatment and name the person who is responsible for ensuring that these objectives are carried out. It can also be used to identify any goals or objectives that were agreed on by the GP and the patient. The health action plan should be shared with other healthcare professionals who are involved in a patient's care so that there is a clear understanding of their current state of health and of what their individual needs are.

In the CIPOLD study a health action plan had been completed in roughly a third of all cases (34%). The inquiry found evidence to suggest that these had been effective in giving patients better control over their healthcare and reminding them of the steps they needed to take to ensure their good health. The plans were also useful for communicating other information such as decisions on end of life care.

However the inquiry noted that the health action plans were not widely shared with other healthcare providers and as a consequence pertinent information about patient health was not passed on.

[\(Click here to return to the contents page\)](#)

The situation in Southend

Healthwatch Southend was very concerned by the low uptake for health checks in the area. At the time of the event 87% of GPs in south east Essex (which includes Southend, Castle Point and Rochford) offered this service. (Since the event took place it has been confirmed by NHS England that all GPs in Southend have signed up to provide annual health checks).

However, according to figures from NHS England, only 27% of the people diagnosed with learning disabilities received an annual health check in 2013/14*. The National target is 70% and ideally everybody who has been diagnosed with a learning disability in Southend should be offered a yearly health check and encouraged to take advantage of the service.

We wanted to address the reasons behind this extremely low figure and look into how the number of people with learning disabilities receiving annual health checks could be increased. We also wanted to know whether these check-ups are being carried out properly and how well regulated they are.

To explore these issues from a variety of perspectives we invited three guest speakers to the event:

- Paula Pearl - a health facilitation nurse at SEPT - talked about the health checks from a community nursing perspective.

- Ian Ross - Enhanced Services Lead, Commissioning Directorate, Essex Area Team, NHS England - talked about how the health checks worked.
- Jenny Gilliat, the manager of SHIELDS Parliament (a charity that helps people with learning disabilities), who has learning disabilities herself, described her own experience of the annual health check.

*(Source: NHS England, Essex Area Team. Learning Disabilities Overview (July 2014))

[\(Click here to return to the contents page\)](#)

Useful Links

[Shields Parliament Facebook page](#)

[Confidential Inquiry into Premature Deaths of People with Learning Disabilities \(CIPOLD\)](#)

[Confidential Inquiry into Premature Deaths of People with Learning Disabilities \(CIPOLD\) Easy Read Edition](#)

[\(Click here to return to the contents page\)](#)

About this report

In this report we have included links to the presentations from the learning disabilities event. If you do not have access to the internet and would like printed copies of the presentations then please get in touch.

We have also added a summary of the points that were raised during the questions and answers session that took place at the end of the event, along with details of any other discussion that took place.

The evaluation section of the report contains comments taken from the event feedback forms that were giving to everyone who attended. We take these comments into consideration when organising future events.

Finally, we have included a summary of what happened after the event along with details of any follow-up work that we are planning to carry out in the future.

We will post news of any progress that has been made on our website and in our monthly newsletter.

If you wish to discuss any of the issues raised in the report, or if you would like any messages passed on to any of the speakers at the event, please contact us.

[\(Click here to return to the contents page\)](#)

What happened on the day

The event took place on Tuesday 15th July, 2014, between 1pm and 4pm. It was held in the large conference room at the Southend Association of Voluntary Services headquarters.

On the day there were over 50 people in attendance. Each speaker addressed the floor for between twenty minutes and half an hour. After each talk there was time for a few questions. At the end of the event there was a longer questions and answers session.

[\(Click here to return to the contents page\)](#)

Presentations

Where possible we have provided links to presentations from the event. To access these click on the underlined pink text. These are PDF files and will open in a new window.

- [What health checks are and the role of SEPT](#)
Paula Pearl, health facilitation nurse, SEPT
- [My experience of the annual health check](#)
Jenny Gilliat, manager, SHIELDS Parliament
- [How it works and what your doctor should do](#)
Ian Ross, Enhanced Services Lead, Commissioning Directorate, Essex Area Team
NHS England

[\(Click here to return to the contents page\)](#)

A summary of the questions and answers session

Our speakers sat as a panel at the front of the room. The discussion was moderated by the Healthwatch Southend manager, Jonathan Keay, who was event chair for the day.

Anyone in the audience who wanted to ask a question, make a comment or share an experience was able to do so. Our audience comprised members of the public, along with representatives from local government and various health or social care organisations and charities.

The following represents the notes we were able to take during the discussion. We have endeavoured to make these as complete and as accurate as possible, but recognise the difficulty involved in accurately recording live and animated debate. If you feel we have misrepresented any aspect of the discussion and points raised, please get in touch and let us know. Where possible we have included the name of the person who was responding to the question in brackets.

What is SHIELDS Parliament? The letters 'SHIELDS' stands for Supporting, Helping, and Informing Everyone with Learning Disabilities in Southend. SHIELDS is a group of people who have learning disabilities, that speaks up on behalf of other people with learning disabilities. (Jenny Gilliat)

Who arranges the health checks? The GP practices are encouraged to identify all patients who are 14 and over with learning disabilities, maintain a health checks register and offer them an annual health check, which will include producing a health action plan. (Ian Ross)

How many GP Surgeries are offering the service, because not all are doing so? Providing health checks for people with learning disabilities is not part of GPs core contract. It is an optional enhanced service. Currently 87% of GPs in south east Essex (which includes Southend, Castle Point and Rochford) have signed up to deliver the service for this year.

However, at present only a minority of learning disabilities patients are getting their health checks: In Southend the number of patients recorded with learning disabilities is 621 and only 172 (27%) of these received a health check in 2013/14. GPs do have to put in an action plan and submit it to NHS England. We will check again in September/October this year to make sure they are doing this. If GPs

aren't undertaking the health checks the responsibility for carrying them out could be passed to another organisation like SEPT. (Ian Ross)

(It was also mentioned during the discussion that the 27% figure may not be accurate. One local GP surgery had been performing the checks but had experienced difficulty in reporting them). (Ian Ross)

Are GPs paid to do the health checks? Yes, GPs do get paid for doing them, but they are categorized as optional enhanced services. They are not mandatory. GPs are only paid for the health checks that they perform. (Ian Ross)

Who actually does the health check, is it the doctor or the nurse? Usually the responsibilities are shared between both. (Paula Pearl)

If 87% of GPs have signed up to do health checks what happens to the 13% of learning disability patients who are registered with a GP who hasn't signed up? We need to encourage more GPs to sign up or talk to SEPT about meeting the shortfall. (Ian Ross)

A lot of GPs deliver health checks later in the year and the numbers undertaken aren't included for that year. What can be done about that? We are going to be a lot more pro-active in seeing where GPs are with their plans and encourage them not to leave the health checks until February or March. (Ian Ross)

Southend Hospital 'flag' patients with learning disabilities but we are aware that our lists are not up to date. Will you provide us with updated lists? Absolutely.

There are people in the community who have not been registered as learning disability patients and who may not want to be 'labelled'. What about them? If they aren't identified as having learning disabilities then they won't be called in for a health check. All we can do going forward is to speak to friends, family advocates, etc, and hope they pass the information on. SEPT Health Facilitation Service also does a lot of promotions in the community. (Paula Pearl)

There is a difference between GPs, SEPT and the council's definition of learning disabilities. The co-ordination/structure between SEPT, Public Health and GPs regarding learning disability health checks is something Jonathan could take up with the Health & Wellbeing Board. With any of the enhanced services none of them is mandatory. GPs can sign up but only get paid when they deliver the service.

We are finding it harder and harder to book GP appointments for learning disability health checks. NHS England is looking to work on that this year - probably in about September. We will be asking GPs if they are offering appointments and look into whether they need to offer appointments at more convenient times.

People who should be getting appointments and aren't should get on to their Healthwatch. Patients can also contact SEPT but GPs should also be doing this on behalf of the patient and asking SEPT to do it for them. (Ian Ross)

Within this scheme will we be looking to see that the Health Action Plans are also being done? Yes, there is no point in doing the Health Action Plan if it isn't done in the correct way. It is another part of the NHS England work stream for this year. We need to work with the providers to see what we can do to make it better. It is a national directive. We can feed back common themes to the centre and hopefully they can take these on board. (Ian Ross)

How many Health Action Plans have been done? I don't know but will check. (Ian Ross)

(Healthwatch Southend has attempted to follow-up on this question but has yet to receive a response.)

What about the wider issues, e.g. offenders' health services and health checks? Prisons and the military are regional and are another region's responsibility. We will start to liaise more directly with local contacts, e.g. Glyn Jones, SBC, Sarah Haines, Southend Hospital and SHIELDS etc.

Some health checks are only 5 minutes and others 45 minutes will you look into this? Yes, but it can depend on the needs of the person and the first health check does take longer.

This year the age for the health check has been brought down to 14 but SEPT is only commissioned to work with those from age 18. What will be done about this? I don't know but will find out. (Ian Ross)

(Healthwatch has attempted to follow-up on this question but is still awaiting a response)

What about the practicality in contacting a person with a learning disability? Health facilitation services do work with the surgery to help contact them. We need to look at the way we are doing things. One suggestion is to hold a meeting

at Southend football club or have a presence at different types of events; go to various groups e.g. Mencap and bring health checks to the service users.

(Ian Ross)

Shouldn't it be about making GPs more accessible? It will be hard getting the balance right.

GPs tend to talk to the support workers or carers but not to the person with learning disabilities themselves. Jenny Gilliat said that when she went to the doctor for her health check he spoke to her, not to Paula (Paula Pearl, SEPT). On this issue Sarah Haines, Specialist Nurse for Learning Disability at Southend Hospital, said that the General Medical Council website has excellent information about communicating with patients who have learning disabilities on their website.

[Click here to access the GMC guidance for doctors](#)

We have also added this link to the GP Health Checks for Patients with Learning Disabilities page on the Healthwatch website.

[\(Click here to return to the contents page\)](#)

Additional discussion

- Ian Ross attended the training which is offered to all practices who want to offer this service. We arranged it on behalf of all GPs across Essex. Although it is useful it is quite generic.
- Sue Geiss, Health Facilitation Nurse, Castle Point & Rochford said that they had been asked by NHS England to do some training and a couple of dates were booked.
- Chinn (a long-term supporter of Healthwatch Southend) said people are encouraged to speak to Healthwatch if they aren't getting their health checks; their service is very good. Jonathan added that if people let us know on 'speak out' forms or by giving us a call we will pursue any trends.
- J Barrie Andrews observed that family doctors used to know the family, but now people rarely see the same doctor.

[\(Click here to return to the contents page\)](#)

Evaluation of the event

[Click here](#) to download information gathered from our event feedback forms. This includes comments from those who attended the event regarding how successful they thought it was, whether we addressed everything we should have, and what we could do better in the future.

Comments on the event

Do you have any experiences or comments about health checks for people with learning disabilities that you would like to share with us?

- “I told everyone today about my experiences. My doctor was really good.”
- “Of five people we support with learning disabilities (Local Authority register), only three are registered at GP as having learning disabilities. We have supported people to go to their health checks since 2008 and we’re finding it more and more difficult to get these health checks. The Health Action Plans the GP produce are very short compared to the Health Action Plans we have to provide as a Provider for the Local Authority & CQC.”

[\(Click here to return to the contents page\)](#)

Follow-up Work

On the 30th September, 2014, Healthwatch Southend received an email from Ian Ross (Enhanced Services Lead, Commissioning Directorate, Essex Area Team NHS England) which stated that all GPs in Southend have signed up to provide directed enhanced services. This includes providing annual health checks for people with learning disabilities.

NHS England has contacted all GP practices in Southend requesting information regarding:

- The number of learning disabilities patients they have on their register
- The number of patients with learning disabilities who have been invited to attend an annual health check
- The number of annual health checks that have been completed
- The number of patients who have declined to attend a health check
- The number of patients who did not respond to an invitation to attend a health check
- The number of patients who did not attend their annual health check and the number of times they did not attend.

They have asked for two sets of figures - one relating to the period between the 1st April 2014 - the 30th September 2014, and another covering the period between the 1st October 2014 - 31st March 2015.

Healthwatch Southend will contact NHS England in early December. It is hoped that, by this time, they will have received responses from GPs and will be able to provide data on annual health checks in Southend between the 1st of April 2014 and the 30th September, 2014. We will study this information and take action or engage in more follow-up work depending on what these figures tell us.

To compliment the quantitative data that NHS England is compiling, Healthwatch is keen to develop a more detailed picture of the situation locally. In particular we want to know:

- Details of how the annual health checks for patients with learning disabilities are actually being carried out at practices in Southend, the kind of examinations that are performed and whether any preventative screening is included as part of the check (such as cardiovascular disease risk assessment/bowel screening, etc). We would like to know more about the training and guidance that is offered to GPs and whether there is a template that they are required to follow when carrying out the health checks.
- How GPs in Southend are approaching the logistical challenge of providing this service: When scheduling appointments for annual health checks, do they set aside blocks of days at certain times of the year, or do they perform the checks throughout the year?
- Whether GPs in Southend are able to carry out health checks in a home setting if a patient is unable to attend a surgery.

- What the procedures are when a learning disabilities patient does not respond to an invitation to attend an annual health check, or accepts an appointment but then does not attend.
- The procedures that are in place to ensure that any further treatment specified in the health action plans that are generated by the annual health checks is carried out.
- The steps they are taking to ensure that the health action plans are accessible and are shared with other providers who are involved in the care of a patient.
- The opinions of GPs or Practice Managers regarding how the annual health checks are commissioned and managed.

In attempting to broaden our understanding on these points Healthwatch Southend will come up with a short list of questions which we will send to practice managers during October. We will publish a summary of any responses we receive.

The *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* noted that “there was little evidence that Health Action Plans were used as a mechanism to link people with the range of services and supports that they received, or to share information about them effectively.” (page 51)

On this matter we will be contacting SEPT and Southend Hospital. We will ask them whether community health services and departments within the hospital are able to easily access Health Action Plans for patients with learning disabilities and whether this information is useful and of good quality.

Healthwatch Southend will send this report to Healthwatch England, NHS England, the Care Quality Commission, the local Clinical Commissioning Group, the Health and Wellbeing Board and to local MPs - James Duddridge and David Amess.

[\(Click here to return to the contents page\)](#)

Thank you

We would like thank everyone who attended our GP health checks for people with learning disabilities event, whether you were one of our speakers, or a member of the public who turned up and listened, asked questions, shared experiences and

raised issues. We would also like to extend our gratitude to those healthcare professionals, representatives from charities and support groups, and members of local government who attended and were able to add their expertise to the conversation. Last, but by no means least, we would like to thank the volunteers at Healthwatch Southend who helped out at the event and with compiling the information for this report.

We hope what was discussed at the event will set an agenda for the improvement of this service, leading to more people with learning disabilities receiving their annual GP health checks and ensuring that these checks are fit for purpose and of a standard that meets their needs.

We genuinely believe events of this kind are a great way to facilitate discussion that is targeted on specific issues. They provide opportunities for learning and information sharing but, most importantly, give people the chance to air concerns and questions, and have these answered by key people in our local services. In this way we can break down barriers of communication and learn to listen to each other without preconceptions or prejudices.

There is nothing that cannot be improved if people have the will to cooperate and share ideas. If you are a commissioner or service provider, please read the comments in this report carefully and think about how you might be able to contribute to positive change.

Many thanks for your continuing support,

Your local Healthwatch team.

[\(Click here to return to the contents page\)](#)

Amendments

This report was amended on the 10th October 2014 .

- It was noted that the health check service was initially only provided to those aged over 18. However in April 2014 it was expanded to include 14-17 year olds.
- Clarification was made with regard to one of the speakers in the Q&A session.

