



**Experiences of Annual Health Checks:
Voices from the Learning Disability
Community**

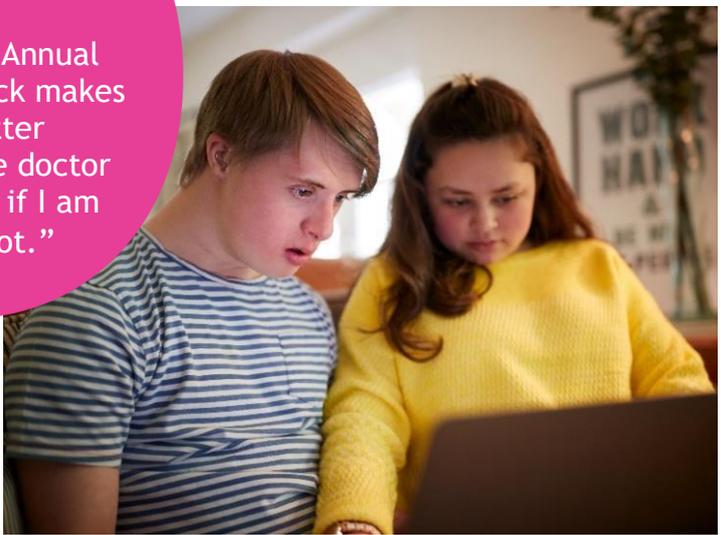
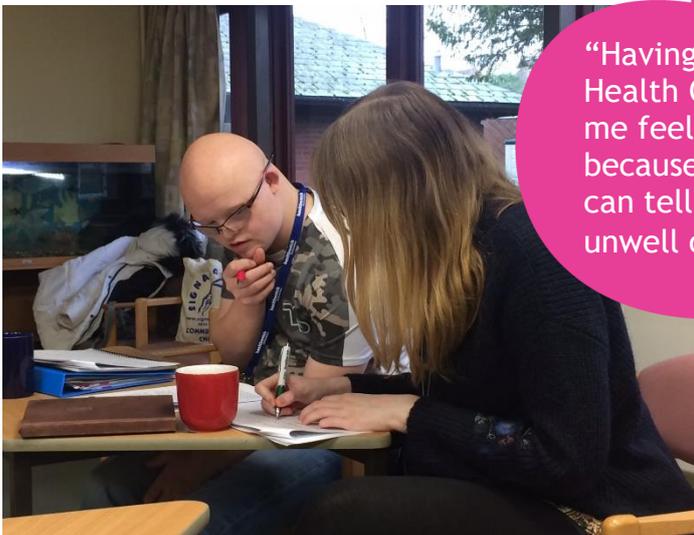
**Engagement: November 2019 - January 2020
Published: August 2020**



“There is not much point going to an Annual Health Check as they don't really check anything.”



“Having an Annual Health Check makes me feel better because the doctor can tell me if I am unwell or not.”



Contents

Executive Summary	1
1. About Healthwatch Hertfordshire	2
2. Introduction	2
3. Aims and background.....	3
4. Methodology.....	4
5. Key themes: Respondents who had an Annual Health Check.....	5
5.1. Satisfaction	5
5.2. Quality	8
5.3. Support	11
5.4. Information	12
6. Key themes: Respondents who have never had an Annual Health Check.....	14
6.1. Awareness.....	14
6.2. Provision.....	15
6.3. Understanding.....	15
6.4. Barriers	16
7. Conclusion	16
8. Updates relating to Covid-19	17
9. Recommendations	17
10. Response from Hertfordshire County Council	19
11. Response from Herts Valleys Clinical Commissioning Group and East and North Herts Clinical Commissioning Group	19
11. Appendix	20

Foreword and Acknowledgements

Annual Health Checks were introduced with the aim of reducing premature mortality and improving the physical and mental health of people with learning disabilities. Feedback from the learning disability community in Hertfordshire highlighted concerns about the uptake and predominantly, the quality of Annual Health Checks locally. In response to concerns raised, Healthwatch Hertfordshire worked with its Learning Disability Service Watch Group to co-produce a questionnaire to hear directly from the learning disability community about their experiences of Annual Health Checks.



Steve Palmer, Chair

The findings provide a very rich picture of local concerns and issues, particularly around the quality and comprehensiveness of Annual Health Checks. Our report demonstrates that, despite some good practice, this is not always the case and makes clear recommendations for change. As Chair of Healthwatch Hertfordshire, I hope readers find this report informative and helpful but more importantly, I want Annual Health Checks to help make lives of people with learning disabilities healthier. I hope that service providers in Hertfordshire use the report and its findings as a platform for improvement, and I hope that positive change can be made.

I should like to thank the Learning Disability Service Watch Group for co-producing this questionnaire. I would also like to thank the Learning Disability Forums and Purple All Stars for speaking to us about their experiences. Many thanks also to our partners for supporting this work and for distributing and completing the questionnaire with the learning disability community.

A final thank you and appreciation must go to all of those who participated by sharing their experiences of Annual Health Checks with us. By speaking to us, you have helped to make Annual Health Checks better for you and other people with learning disabilities.

Steve Palmer, Chair of Healthwatch Hertfordshire

“On behalf of Hertfordshire and West Essex Integrated Care System, I welcome Healthwatch Hertfordshire’s report ‘Experiences of Annual Health Checks.’ Annual Health Checks were established to address the health inequalities that people with learning disabilities so often face. It is therefore vital that we ensure everyone who would benefit from such an annual review experiences a thorough and satisfactory one. The checks need to be offered in a way that gives people choice and also encourage them to bring a relative or carer if this would be helpful for them.

The findings will certainly shape the work that is already underway to improve the uptake of Annual Health Checks as well as the steps to improve the quality of them.”

The Right Hon Paul Burstow, Independent Chair for Hertfordshire and West Essex Integrated Care System

Executive Summary

Background

Research has shown that people with learning disabilities have a much lower life expectancy and significantly poorer physical and mental health outcomes compared to the general population (Learning Disability Mortality Review (LeDeR), 2019).

To address these health inequalities, Annual Health Checks were introduced with the purpose of reducing premature mortality and improving the health of people with learning disabilities.

The aim of this project was to better understand the uptake and quality of Annual Health Checks locally, by hearing directly from those who are entitled to this service - the Learning Disability Community.

Methodology

Our engagement phase ran from 4th November 2019 to 31st January 2020.

With the help of statutory organisations, learning disability nurses and local support groups, we engaged with **491** service users, carers and support workers within the learning disability community:

- **138** people spoke to us through their local Learning Disability Forum.
- **353** people completed the questionnaire - either online or via hard copy.
- Of the 353 people who completed the questionnaire - **20%** were service users aged 14-17 years old.
- **75%** of the people we spoke to were service users and **25%** were carers or support workers.
- The Learning Disability Community fed back on **86** GP practices across the county.

What we found

Of the respondents who completed the questionnaire, **69%** (242) had an Annual Health Check since May 2017 and **31%** (111) have never had an Annual Health Check.

- For those who had an Annual Health Check, positive experiences reflected the friendliness and patience of clinicians. However, concerns were raised regarding the quality of Annual Health Checks.
- Issues regarding quality related to the length of appointments offered, affecting the comprehensiveness of the Annual Health Check.
- Few GP practices provided information in an easy read format and/or communicated with service users in a way that was accessible for them.
- Some GP practices did not allow service users to bring support with them and in some cases, staff in supported living accommodation refused to accompany service users.
- Of the respondents who have never had an Annual Health Check, **80%** said this is because they were not aware Annual Health Checks existed and/or because they had not been offered an appointment by their GP practice.
- **20%** of service users questioned the importance of having an Annual Health Check, and/or noted barriers such as time or confidence.
- Those aged 14-17 years old were less likely to have an Annual Health Check. For those who had, they were given greater choice in terms of their appointment time and clinician.

1. About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

2. Introduction

Hertfordshire County Council (HCC) distributes its annual survey to adults with learning disabilities living in Hertfordshire to help the Council understand how services can better support those with a learning disability. The survey focuses on the wellbeing of people with learning disabilities through asking questions about communication, involvement in the community, living locally and staying healthy.

To complement this survey, HwH co-produced a questionnaire with its Learning Disability Service Watch Group (LD SWG)¹ which focused specifically on hearing people's experiences of Annual Health Checks. This was in response to the LD SWG's concerns over the quality and uptake of Annual Health Checks locally.

What is an Annual Health Check?

Annual Health Checks are for people aged 14 years or over with a learning disability. They are provided by GP practices with the aim of reducing premature mortality and improving the health outcomes of people with learning disabilities. All GP practices in Hertfordshire are signed up to the Quality Outcomes Framework (QOF) register² and therefore should carry out Annual Health Checks and make reasonable adjustments for people with learning disabilities in line with this. More information about Annual Health Checks is provided later in the report.

Approximately 1.5 million people in the UK have a learning disability (NHS, 2018), of which less than 300,000 are registered on the learning disability register (NHS Digital, 2018). The learning disability register, formally known as the Learning Disability QOF register is a list of people with learning disabilities held by each GP practice in England (Public Health England, 2017). To receive an Annual Health Check an individual must be listed on the learning disability register. Therefore, being recorded on the learning disability register is essential for enabling people with learning disabilities to receive support from their GP practice.

According to HCC, there are an estimated 21,000 people with a learning disability living in Hertfordshire, of which only 5,000 are listed on the learning disability register. This means a significant proportion of people with a learning disability are unlikely to be receiving an Annual Health Check - an important part of detecting, treating and preventing new and

¹ The LD SWG ran until 2018 and was made up of service users, carers and representatives from voluntary, statutory and NHS organisations that support and provide care for people with learning disabilities, as well as commissioners.

² The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP practices in England. It is not about performance management but resourcing and rewarding good practice.

unmet health needs (Blair, 2016). The local Learning Disability Mortality Review (LeDeR)³ is aware of these issues and stated that the main reason people with learning disabilities are not recorded on the learning disability register is because they have not asked their GP practice if they can be put on the register, and/or have not been identified by their GP practice as having a learning disability.

Leading on from the above, as part of the Hertfordshire Learning Disability Strategy, HCC is working with services to improve the uptake of Annual Health Checks by focusing on increasing the number of people with learning disabilities recorded on the learning disability register. As part of this strategy, the Council also identifies a need to prioritise efforts in improving the quality of Annual Health Checks (as supported by the LD SWG) to ensure that every person with a learning disability receives a comprehensive examination of their health. Our work aims to inform how this can be achieved by evidencing lived experiences of how Annual Health Checks work in practice.

3. Aims and background

The aims of this research were:

- To understand from the patient's perspective their experiences of Annual Health Checks.
- To evaluate how patients with learning disabilities are supported to attend, receive and feedback on Annual Health Checks.
- To assess the barriers of Annual Health Checks and identify how these can be addressed.
- To identify and share good practice as well as learning relating to Annual Health Checks, communication and support.

Background to Annual Health Checks

Annual Health Checks were introduced in 2008 as part of a Direct Enhanced Service (DES) provided by GP practices with the purpose of reducing premature mortality and improving the health of people with learning disabilities (Emerson and Baines, 2015). This is primarily through identifying unrecognised medical conditions and implementing preventative measures such as screenings, vaccinations and blood tests to safeguard the health of people with learning disabilities (Turner, 2017). GP practices can choose whether to participate in this service and in return they are financially remunerated for each completed Annual Health Check (Welch et al, 2014).

Research by the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) has shown that people with learning disabilities have significantly poorer physical and mental health outcomes compared to the general population. Often this is because people with learning disabilities are unaware of the implications of the symptoms they experience and can have difficulties communicating their health needs (Walmsley, 2011). This can lead to challenges identifying health conditions and delays in diagnosis and treatment (Public Health England, 2016). Diagnostic overshadowing is also recognised as contributing to the health inequalities faced by people with learning disabilities, whereby clinicians misattribute symptoms to an individual's learning disability, leaving co-existing medical conditions undiagnosed and untreated (Javaid et al, 2019). The above, along with people with learning disabilities being more susceptible to a

³ LeDeR reviews deaths of people with learning disabilities aged 4 years and over with the aim of improving the standard and quality of care for people with learning disabilities, thereby reducing health inequalities and premature mortality. It is made up of representatives from service users, and representatives from voluntary, statutory and NHS organisations.

certain range of diseases, makes it even more crucial that their health needs are identified and addressed by clinicians early and that they are given the appropriate care, treatment and support (McConkey et al, 2015).

In 2018, LeDeR reported that the median age of death for people with learning disabilities in Hertfordshire is 63 years old. This compares favourably to the national average of 58 years old, however this is still considerably lower than the median age for the general population which is 81 years old. This is often because people with learning disabilities are more likely to suffer life-limiting conditions (Brown et al, 2010). According to LeDeR, over 50% of people with learning disabilities in Hertfordshire have died prematurely as a result of pneumonia, aspiration pneumonia and sepsis, all of which are preventable diseases. Sepsis in particular has been identified as a local priority in Hertfordshire to address. In efforts to tackle this, services in Hertfordshire have adopted an inter-agency approach to prevent the occurrence and prevalence of sepsis in those who have a learning disability.

Uptake of Annual Health Checks

In 2018-2019, nationally around 53% of people with learning disabilities who are listed on the learning disability register had an Annual Health Check (NHS Digital, 2019). Though it is important to remember that not everyone with a learning disability is recorded on the learning disability register. Positively, in Hertfordshire around 70% of people with a learning disability who are listed on the learning disability register received an Annual Health Check in 2018-2019 which is considerably higher when compared to the national average. In addition, GP practices in Hertfordshire have added approximately 1,500 people with learning disabilities to the learning disability register since 2012.

Although these are positive steps towards improving the standard of care for people with learning disabilities, as stated earlier in the report, within Hertfordshire less than 25% of people with a learning disability are recorded on the learning disability register. This indicates that a significant number of people with learning disabilities have not been identified by their GP practice and are therefore not receiving an Annual Health Check. This signifies that actions need to be taken to improve the identification and registration of people with learning disabilities on the learning disability register.

Intelligence from the Learning Disability Service Watch Group (LD SWG)

It was important to use anecdotal feedback from service users to inform the focus of the project. Feedback from members who were part of the LD SWG acknowledged that the uptake of Annual Health Checks was higher than the national average and instead raised concerns regarding the **quality** of them. For an Annual Health Check to be effective, clinicians must provide a *thorough* examination of the individual's physical and mental health which requires providing an appointment which is longer than a routine GP appointment. However, some service users reported only receiving a 5-10 minute appointment with the clinician carrying out basic health checks such as height, weight and blood pressure. It was highlighted by the group that this type of examination is unlikely to detect health needs or enable an opportunity to discuss an individual's wellbeing, which is particularly important when you take into account barriers around communication that some people with learning disabilities face.

4. Methodology

HwH originally worked with its LD SWG in late 2018 to co-produce a questionnaire which focused on the quality and uptake of Annual Health Checks. The group consisted of service users, carers and representatives from HCC, Herts People First, Carers in Hertfordshire

and Watford Mencap. The group determined the content and wording of the questionnaire as well as the research methods used. In early 2019 the project had to be paused due to the staff capacity issues. The project was restarted in June 2019 when issues eased as we grew the team.

When the project restarted, in collaboration with HCC and Herts People First⁴, a guidance document for carers and support workers was produced to help service users to complete the questionnaire as independently as possible. An online version of the questionnaire was also created for those service users who prefer this format as well as for carers and support workers to complete with, or on behalf of the service user.

The engagement period ran for 13 weeks from 4th November 2019 until 31st January 2020. The online version of the questionnaire and hard copies were sent to specialist schools for people with learning disabilities and services across Hertfordshire to distribute and complete with service users. These services included: East and North Herts Clinical Commissioning Group (ENHCCG), Herts Valleys Clinical Commissioning Group (HVCCG), Herts and West Essex Sustainability Transformation Partnership (STP), Hertfordshire Community Trust (HCT), Hertfordshire Care Providers Association (HCPA), Oaklands College, Carers in Herts, Guideposts, Hertfordshire Carer Involvement Programme (HCPI), Kids Herts Hub and Supported Activities Programme.

HCC distributed physical copies of the questionnaire and promoted the online version via social media through their services. These services included: Health Liaison Team, Young People Health Liaison Team, Purple All Stars, Special Educational Needs and Disabilities (SEND) and YC Hertfordshire.

From November 2019 to January 2020, HwH also attended Learning Disability Forums across the county. Activity at most of the forums involved completing the questionnaire with service users on a one-to-one basis. Some forums entailed holding a focus group discussion with service users, carers and support workers and professionals to learn about their experiences. In total we engaged with 138 service users, carers and support workers and professionals at these forums. This feedback has been incorporated into the questionnaire findings.

5. Key themes: Respondents who had an Annual Health Check

This section will discuss key themes by respondents who had an Annual Health Check. This includes findings from the questionnaire and local Learning Disability Forums.

Overall 353 respondents completed the questionnaire, of which 75% (265) were service users and 25% (88) were carers or support workers responding on behalf of a service user. Of the respondents, 69% (242) had an Annual Health Check while 31% (111) have never had an Annual Health Check. These findings resonate with the data produced by HCC which found that 70% of people on the learning disability register had an Annual Health Check in 2019.

5.1. Satisfaction

79% (191) of respondents emphasised that they would attend an Annual Health Check again, along with comments we received, conveys that the majority of service users value having an Annual Health Check and recognise it is an important initiative to help manage

⁴ Herts People First is a user-led, rights based, self-advocacy organisation run by and for adults with a learning disability.

their health and wellbeing. Some respondents also noted that having understanding and knowledge of their health gave them reassurance.

“It is important for me to have an Annual Health Check.”

“It is important to be checked regularly, it’s like a car going for a MOT, and any problems can be picked up in my yearly check.”

“Having an Annual Health Checks makes me feel better because the doctor can tell me if I am unwell or not.”

Attitude of clinicians

Of the respondents who had an Annual Health Check, 71% (172) said their experience was either good or very good, while 19% (46) thought their experience was neither good nor bad. Only 10% (24) of respondents found their experience bad or very bad. A key reason as to why service users found having an Annual Health Check a positive experience was because they thought the clinician was approachable and reassuring, with 84% (203) of respondents stating that the doctor and/or nurse was friendly and patient. Understandably, service users found having an Annual Health Check far less daunting when the clinician was supportive and treated them with respect.

“The staff at the surgery are kind to me, they treat me well.”

“The attitude of the doctor and nurse was very supportive, friendly and helpful.”

Service users also stated that they particularly value when clinicians are patient and take the time to listen and explain information to them. When asked what was good about their Annual Health Check, a number of service users said they trust their doctor and/or nurse and felt comfortable enough to ask questions and raise concerns they have in terms of their physical and mental health.

“I was able to have a good, private talk with my doctor.”

“The GP listened to what I had to say.”

“If I have any problems I feel I can speak to my doctor.”

10% (24) of respondents felt that their doctor and/or nurse could have been friendlier and more patient, expressing concerns that their clinician did not listen to them or was dismissive.

“The doctor smiled when I said that I was angry all the time as if it was funny.”

“The service is dreadful. [The GP practice] they don’t believe you have a learning disability despite being under them for 16 years and all the evidence. I have since changed GP practice as they had no idea and didn’t care about me at all.”

Communication

When asked what could have been better about their Annual Health Check, 25% (61) of respondents thought that the doctor and/or nurse could have better explained what an Annual Health Check is and what they doing. Some service users said they could not understand what the clinician was explaining to them, often because the clinician did not take the time to explain information to the service user in an accessible way. In some cases, the clinician excluded the service user from the discussion and relied on the carer or support worker for information.

“I only understood my doctor a little bit.”

“I was given medical information and actions that I did not understand. This happens a lot. It would help me if the doctor would explain medical information and actions or give it to me in easy read information.”

“The doctor needed to speak a bit louder.”

Choice and access

Providing continuity of care for people with learning disabilities was raised as particularly important to this community to help both the service user and the clinician build good communication, trust and rapport. Service users who did see their usual doctor and/or nurse valued this familiarity and appreciated when the clinician recognised them and remembered who they were. However, we found that 24% (58) of respondents did not see the doctor and/or nurse of their choice.

“I saw my normal doctor and I was pleased with this.”

“I don’t see the same GP I end up seeing lots of different ones.”

“It was good that the nurse knew me well.”

It is considered good practice for the service user to be able to choose when their appointment is. This allows the service user to ensure a carer or support worker can support them at their appointment if they want this. It enables the service user to choose times which are less busy, reducing unnecessary anxiety. It also allows the service user to keep their routine with social activities.

Most respondents said they had a positive experience when organising their Annual Health Check as the majority of GP practices were flexible and addressed the needs of the service user. Though 35% (85) of respondents said they were not offered an appointment time that was right for them.

“I was told the Annual Health Check appointment can only be made two weeks in advance.”

“[I] waited a long time in the waiting room before my appointment.”

“[The GP practice] they called me to choose my appointment and we agreed it together.”

5.2. Quality

71% (172) of respondents rated their Annual Health Check as either good or very good. However, the findings conveyed that the majority of service users did not know what to expect from their Annual Health Check and/or did not know what the appointment should include when they provided this rating.

Length of the appointment

Annual Health Checks are distinctive from a routine GP appointment to allow enough time for the service user to ask questions about their health and for the clinician to carry out the relevant tests and examinations. A 5-10 minute appointment is problematic as it only allows enough time to conduct a basic health consultation which is not the purpose of an Annual Health Check.

When HwH spoke to individuals at the Learning Disability Forums, the majority of service users said their Annual Health Check only took between 5 and 10 minutes, despite national guidelines advising that the appointment should take between 30 minutes and 1 hour. Likewise, most service users and support workers who responded to the questionnaire were not aware that an Annual Health Check should be longer than a standard GP appointment.

Similarly, when asked what could have been better about their Annual Health Check, 33% (80) of respondents said the length of the appointment (10 minutes) was not right for them.

“The Annual Health Check was only 5 to 10 minutes.”

“The appointment felt rushed.”

“The appointment was really short.”

These respondents identified that they would have appreciated more time to discuss their health and wellbeing in more detail with the clinician, and that having a short appointment meant that the service user was unable to do this. Having this opportunity becomes especially important when potential communication barriers and diagnostic overshadowing explained earlier in the report are considered.

“I would have liked more time to say what I needed to.”

“I find it hard to talk to my doctor in such short time.”

“I didn’t have time to speak about the worries I have.”

Service users who were given a longer appointment found this beneficial as it gave them more time to process the information they were given and the ability to ask the clinician questions if there was information they did not understand.

“The length of the appointment was longer than usual so I didn’t feel rushed like I do at ordinary appointments.”

“I saw the doctor who I felt gave me enough time.”

Examinations

The majority of service users we spoke to at the Learning Disability Forums were not aware that an Annual Health Check should involve a thorough, detailed examination of the service user's physical and mental health. This includes providing screenings for cancers such as bowel, breast, cervical and testicular cancer, vaccinations and blood tests. These checks and examinations play a vital role in detecting health conditions, some of which could prove life-threatening for the service user.

Most of the service users we spoke to at the Learning Disability Forums, and a significant number of respondents said the clinician only carried out a basic health examination which involved measuring their height, weight and blood pressure.

"There is not much point going [to an Annual Health Check] as they don't really check anything."

"The doctor did not do all the checks."

A large number of respondents also said the clinician did not ask the service user all the questions related to their health and wellbeing, despite this being a requirement of the Annual Health Check. In particular, clinicians did not ask questions about mental health, sexual health, alcohol consumption and/or drug use. In terms of mental health, respondents felt this can often be because clinicians will attribute symptoms to the service user's learning disability, rather than emotional wellbeing. In terms of alcohol consumption, drug use and sexual health, respondents stated that clinicians often assume that the service user does not participate in these behaviours, meaning that some health, social and/or emotional needs are missed or neglected.

"Conversations about mental health are non-existent."

"The doctor didn't ask if I drink alcohol, the answer is no I don't drink alcohol but the doctor didn't ask me this and I might have started drinking alcohol, they don't know!"

"The nurse or doctor did not ask if I used drugs or some of the other checks on the checklist."

However, service users who did have a comprehensive examination of their health and wellbeing thought this was a valuable way of understanding how to stay healthy.

"When I had my Annual Health Check it was really good and thorough."

"It was good to have the Annual Health Check and have all my tests and checks done."

Purple folder

The purple folder scheme was designed to help clinicians deliver person-centred care for people with learning disabilities. The purple folder contains information that clinicians need to know in order to understand the health of the service user and ensure the appropriate treatment is provided. The purple folder also enables the clinician to see

what care, treatment and support the patient currently or has previously received and aids with communication between services and the patient.

When asked what did not work at their Annual Health Check, 37% (90) of respondents said the doctor and/or nurse did not look at their purple folder, despite the service user taking it to their appointment. Some service users found that the clinician simply signed their purple folder, rather than using it as a tool for recording information or for understanding essential health and behavioural information related to the service user.

“I took my purple folder with me but they never check it.”

“They looked in my purple folder but did not write in it.”

“They didn’t ask to look at my purple folder.”

A small number of respondents said the doctor and/or nurse did not know what a purple folder was or how it should be used.

“My doctor did not know what my purple folder was.”

“My carer had to explain to [the clinician] them what my purple folder was.”

A few respondents said they either do not own a purple folder or were not aware they existed. Most service users who had never heard of purple folder only found out they existed via completing the questionnaire or at a local Learning Disability Forum we attended.

“I was asked about a purple folder but I’ve never heard of one.”

“I’m not aware of what a purple folder is.”

Health Action Plans

Health Action Plans (see Appendix A) are personalised plans for people with learning disabilities and detail what help an individual needs in order to stay healthy. This includes support in managing physical and mental health conditions and practical actions to improve an individual’s lifestyle such as exercise and healthy eating. A Health Action Plan should be discussed with the service user during an Annual Health Check appointment, and provided to them when they leave.

The majority of service users we spoke to at the Learning Disability Forums, and 45% (109) of respondents to the questionnaire said they did not receive a Health Action Plan at their Annual Health Check. Additionally, respondents flagged that they did not know what a Health Action Plan was. Once aware, service users emphasised that they would value receiving a Health Action Plan as it would be a way for them to improve their health with the advice and support of clinicians.

“It would help me if I knew what a Health Action Plan was, this would help me manage my own health.”

“I would have liked to have a Health Action Plan.”

Service users who were given a Health Action Plan spoke about the benefits of receiving one as it gave them practical advice and solutions for managing and improving their health and wellbeing.

“I was given a Health Action Plan with a diet sheet and they spoke about it with me and I have stuck to it.”

“My Health Action Plans over the years have shown me that my health has got better and they have given me direction.”

5.3. Support

88% (213) of respondents said they had wanted to take their carer or support worker to their Annual Health Check, in comparison to 80% (194) service users taking their carer or support worker with them to their last appointment.

The majority of service users said they wanted to take someone to their Annual Health Check so they could be supported during their appointment, particularly if they struggle to communicate or understand information. However, some of these service users said they do not have a carer or support worker so they would have liked to have been supported by a professional, such as a learning disability nurse.

A large number of service users we spoke to at the Learning Disability Forums were not aware that they could take a professional with them to their Annual Health Check. Where service users did not have access to support, they were at a higher risk of not being able to communicate with the clinician or ensuring that the relevant examination was carried out.

“For the [Annual Health Check] to be better I would have liked to have had support.”

“I need support go to an Annual Health Check and so far I haven’t had the support I need.”

“I wanted to take my learning disability nurse.”

A number of service users were not told or reminded that they could take a carer or support worker with them to their Annual Health Check.

“It would help me if I had my support worker who knows me well to come to the Annual Health Check with me. When the surgery called me to make the appointment they could have asked me if I wanted someone with me.”

“I was not reminded to bring my carer.”

A smaller number of service users said their GP practice did not allow them to take a carer or support worker with them to their Annual Health Check. Additionally, some service

users stated that staff in their supported living accommodation refused to accompany them to their appointment, despite the service user asking for their support.

Some respondents also noted that at times, staff in supported living accommodation and support workers made independent decisions about their capability and capacity to attend the appointment without support which had an adverse effect on the service user.

It should be noted that anyone with a learning disability should be provided with the option to take a support worker or carer if they want this, and this request should not be denied by GP practices or any other service.

“It would help me if I had my support worker with me but the surgery did not understand that this would have helped me.”

“I am told I cannot have support from staff where I live because I am too capable.”

“I wasn’t allowed to bring support with me.”

One way of GP practices supporting service users with a Learning Disability is to have a Learning Disability Champion as part of the practice. Learning Disability Champions play an important role in improving the quality of care people with learning disabilities receive. They are a valuable source of information and support and can even be an advocate for someone with a learning disability and their family, should this be required.

When engaging with the Learning Disability Forums, we found that 100% of service users we spoke to did not know if their GP practice had a Learning Disability Champion. Furthermore, 80% of respondents to the questionnaire were not aware. Lastly, those who were aware of their Learning Disability Champion stated that they had very little or no contact with them.

““[I have] never heard of a Learning Disability Champion.”

“[I have had] no contact with the Learning Disability Champion.”

“I don’t know if my GP surgery has a Learning Disability Champion but it sounds like a good idea.”

5.4. Information

Preparation

Most of the individuals we spoke to at the Learning Disability Forums, and a significant number of respondents said they were not given any information on how to prepare for an Annual Health Check. Carers and support workers were also not given information on how they can help the person they care for prepare for their Annual Health Check.

HCC has produced a Carer Preparation Tool (see Appendix B) which helps service users, carers and support workers prepare for their appointment by writing notes about the service user’s health and wellbeing. This checklist can be found on HCC’s website and good practice suggests that it should be provided with the appointment letter sent by the

GP practice. However, respondents said they either did not receive the Checklist or were not aware that this resource existed. Most service users, carers and support workers heard about or received the Checklist at support groups such as the Learning Disability Forums.

“I didn’t get a Carer Preparation Tool.”

“It would be good if I had my own Carer Preparation Tool that I could use to prepare for my Annual Health Check as I go on my own.”

HCC has produced an Easy Read Annual Health Check Checklist (see Appendix C) which has a list of all examinations and questions service users should anticipate at their Annual Health Check. However, similarly to the Pre-Annual Health Check Checklist, most service users, carers and support workers only became aware of this resource after attending a community or support group, suggesting this resource is not widely known.

“I have an easy read Annual Health Check Checklist that I picked up from a health day run by the Purple Star Strategy.”

“I’ve never had an Annual Health Check Checklist but I think this would help me.”

Appointment information and results

It is good practice for GP practices to book, organise and remind service users of their appointment, as people with learning disabilities tend to need more support with this, especially if they do not have a carer or support worker.

25% (66) of service users, carers and support workers said there was poor communication from their GP practice when organising their Annual Health Check. Often service users and their carer or support worker are not reminded when their Annual Health Check is due and are expected to arrange this appointment independently. Service users, carers and support workers who received text messages and appointment letters reminding them to make this appointment found this very beneficial.

“My supporter had to arrange my Annual Health Check, the surgery did not come directly to me”

“I have no one to help me make my appointment and the surgery does not remind me.”

The majority of service users, carers and support workers emphasised that appointment letters, text messages and other modes of communication did not include practical information about the Annual Health Check. Prior to the appointment, GP practices did not explain what an Annual Health Check is, what the appointment will entail, how long the appointment will be and what tests and examinations might be carried out by the clinician. Having this information would be useful for service users and their carer or support worker as it will help them understand why the appointment is important and what they should expect.

A small number of service users said that after their Annual Health Check, they were not informed about the results from blood tests, screenings and other examinations. Service

users were unsure if they were expected to find out this information independently or with the help of their carer or support worker, causing anxiety.

“I was not informed about the results of my blood tests. I had to phone up and get the results myself.”

“We have not had any feedback or outcomes from tests done.”

Easy read information

58% (140) of respondents and most of the service users we spoke to at the Learning Disability Forums said they did not receive their appointment letter in easy read. Providing information in easy read is important for people with learning disabilities as typical appointment letters are often not accessible. Service users and their carer or support worker can ask for information to be given in easy read, however, clinicians also have a responsibility to be proactive in asking service users if they need information to be given in an alternative format. Likewise, service users who were given a Health Action Plan said it was not provided in easy read, meaning the service user could not understand the actions that clinician had suggested.

“I would like more information in easy read from the GP.”

“I would like an easy read Health Action Plan so I can check what my actions are.”

6. Key themes: Respondents who have never had an Annual Health Check

31% (111) of respondents who completed the questionnaire have never had an Annual Health Checks - reasons for this will be explored in this section.

6.1. Awareness

42% (47) of respondents said they have never had an Annual Health Check because they did not know what Annual Health Checks existed. From attending the Learning Disability Forums, we found a reason for this could be because the service user does not receive support from social care services and/or regularly attend support groups for people with learning disabilities.

In one case, HwH met a family at a local Learning Disability Forum who have never heard of Annual Health Checks, despite the service user having regular contact with their GP practice. It was not until attending the Learning Disability Forum that the family learnt about Annual Health Checks and how important they are for people with learning disabilities. This suggests that service users who are more independent or do not receive support from social care services are less likely to be aware of Annual Health Checks and other services available to people with learning disabilities.

However, lack of awareness could also be because the service user is not recorded on the learning disability register, meaning they have not been offered an Annual Health Check from their GP practice.

“What is an Annual Health Check?”

“I never knew my child could have an Annual Health Check, I never knew they even existed!”

6.2. Provision

38% (42) of respondents said they have not had an Annual Health Check because they have never been offered one. Most service users said that although they understand what an Annual Health Check is, they do not know how to organise this appointment independently. This conveys that there needs to be more guidance for how service users, carers and support workers can arrange an Annual Health Check if they have not been offered an appointment via their GP practice. Having this information is particularly important for service users who are more independent as they will not have the support to assist with this.

“I’ve never been invited for an Annual Health Check and I never knew I could have one.”

“I was aware of Annual Health Checks but I’m not really aware of how to have one.”

“How do I organise an Annual Health Check? How do I ask for one?”

“An Annual Health Check was not offered to me.”

However, a few carers were told by their GP practice that their child cannot have an Annual Health Check because they are under the care of a consultant elsewhere.

“I have asked and been told it is not necessary due to ongoing input from ULCH - although this does not provide a full health check.”

“I was told my child cannot have an Annual Health Check as they are seen by medical specialists at GOSH.”

Similarly, a couple of service users were told by their GP practice that they do not provide Annual Health Checks, even though the GP practice does provide this Direct Enhanced Service (DES).

“I was told they do not offer [Annual Health Checks] them.”

“[I] asked at my surgery and they don’t do Annual Health Checks.”

6.3. Understanding

10% (11) of respondents said they have never had an Annual Health Check because they do not think they need one. For most respondents, this is because they do not believe Annual

Health Checks are important so as a result, they do not ask for an appointment or accept appointments offered to them. Some service users stated that they are sceptical of whether Annual Health Checks are necessary and whether they will benefit from attending the appointment. Other service users said they already see their GP practice for other health reasons so they do not understand the necessity in having an Annual Health Check as well. This indicates that more could be done to communicate the importance of Annual Health Checks, as well as the difference between these appointments and routine GP appointments.

“I don’t think I need [an Annual Health Check] it.”

“I feel like I am at the GP for lots of different reasons so I don’t see how an Annual Health Check is going to help me.”

“Why do I need an Annual Health Check?”

“Is [an Annual Health Check] it necessary?”

6.4. Barriers

10% (11) of respondents have not had an Annual Health Check because of barriers and challenges preventing them from attending the appointment. Key barriers mentioned included: confidence, not having enough time to organise or attend an appointment, and not feeling comfortable having certain tests and examinations carried out. To build confidence, service users should be reassured that someone can support them at their Annual health Check and will be treated with dignity and respect by the clinician.

“I have too much on my plate.”

“It’s too hard to get an appointment.”

“I don’t like being touched.”

7. Conclusion

The findings identified in this report convey that the majority of service users understand the importance of having an Annual Health Check and found the appointment valuable. Primarily this is because service users thought the clinician was reassuring and approachable, with examples of good practice reflected in this report. Although this feedback is positive, the findings showed that most service users rated their Annual Health Check as good, without knowledge and understanding of what to expect and/or what the consultation should include.

The findings raise concerns regarding the quality of Annual Health Checks, with a large number of service users not receiving a thorough examination of their physical and mental health - this included service users not having the relevant tests carried out and not receiving a Health Action Plan to help them manage their health. Information accessibility was also highlighted as a key issue, with a number of service users stating that their clinician did not provide information in easy read and/or communicate with the service user in a way that is accessible for them.

Although the majority of service users were supported at their Annual Health Check, some service users said their GP practice did not allow and/or remind them to take support with them and in some cases, staff in supported living accommodation refused to accompany service users at their appointment, despite the service user asking for their support.

For service users who have never had an Annual Health Check, most service users said this is because they were not aware that Annual Health Checks existed and/or because they have never been offered an appointment. Some respondents have not had an Annual Health Check because they do not think they are important, or found that barriers such as time and confidence prevented them from attending.

Similar findings were found among the 14-17 age group, however this group were less likely to have an Annual Health Check. For respondents who did have an Annual Health Check, they were given more choice in terms of appointment time and choice of clinician.

8. Updates relating to Covid-19

At the time of finalising and publishing this report, a new Annual Health Checks pathway has been developed in response to Covid-19. This new pathway will aid healthcare professionals to safely continue Annual Health Checks during this time.

The pathway has three phases, phase one suggests more of a requirement for the Carer Preparation Tool (see **Appendix B**) to be completed ahead of the appointment. There is also an additional phase being a video link or telephone call ahead of a physical examination to be carried out when it is safe to do so. More details about the phases is shown in **Appendix D**.

In light of the new pathway, our recommendations have been amended to reflect any changes.

9. Recommendations

Based on the key findings outlined in this report, it is recommended that GP practices consider the following recommendations:

Awareness

1. All staff to be aware of the Direct Enhanced Service (DES) for the learning disability Annual Health Check and The Equality Act (2010) under which all people with learning disabilities have access to reasonable adjustments.
2. GP practices, Community Learning Disability Nurses and the Purple Star Strategy to raise awareness of and promote the QOF learning disability register and Annual Health Checks to all individuals with a learning disability.

Information

3. All clinicians to adhere to the Accessible Information Standards (2016) and ensure care is delivered to service users in a way that is accessible for them.
4. All service users to receive an appointment letter and/or be communicated with in a way that is accessible for them when their Annual Health Check is due. The appointment letter and/or alternative communications should include:
 - (a) Information about what an Annual Health Check is
 - (b) What the appointment will involve
 - (c) How long the appointment will be

- (d) What tests and examinations might be required
- (e) The Carer Preparation Tool (see Appendix B)
- (f) An Easy Read Annual Health Check Checklist (see Appendix C) to help service users and their carer/support worker prepare for the appointment

Quality

- 5. Clinicians to allow 30 minutes to 1 hour for the consultation dependent upon prior completion of the Carer Preparation Tool (part of this time could be virtual rather than face to face).
- 6. The Annual Health Check must provide a full examination of the service user's physical and mental health.
- 7. All clinicians provide service users with a Health Action Plan (see Appendix A) at their Annual Health Check which provides the service user and their carer/support worker with actions for managing their health and wellbeing. The plan should read in an accessible format and the contents should be discussed with the service user and their carer/support worker.
- 8. GP practices to have systems in place to monitor the quality of Annual Health Checks and ensure clinicians are held accountable for poor practice.
- 9. All clinicians to be aware of purple folders and advised on how they should use the resource appropriately to benefit the service user.

Support

- 10. If/when the service users asks for support to attend an Annual Health Check appointment, this request should not be denied by the GP practice.
- 11. All communications (e.g. appointment letters, text messages and telephone calls) to service users should remind them of their right to take a carer/support worker with them to their Annual Health Check. In case the service user does not have a carer/support worker, communications should signpost service users to the Health Liaison Team who can organise the appropriate support.
- 12. If a GP practice has a Learning Disability Lead/Champion, this service should be signposted to service users and their carer/support worker.
- 13. All GP practices are recommended to have a Learning Disability Lead/Champion if they do not already.

Choice

- 14. Efforts should be made by GP practices to ensure service users see their usual clinician to provide the service user with both continuity in care and familiarity.
- 15. Efforts should be made by GP practices to allow service users to choose their appointment time to enable the service user to (a) be able to arrange for someone to support them at their Annual Health Check (b) take account of situations that might cause anxiety e.g. busy times (c) to keep their usual routine.

10. Response from Hertfordshire County Council

“The Integrated Health & Care Commissioning Team welcomes this report and its recommendations which will support our ongoing support with key partners to increase the uptake and quality of Annual Health Checks for people with learning disabilities. In particular the Health Liaison Team are working closely with GP practices to ensure reasonable adjustments are made to enable people with learning disabilities to access good quality healthcare and support. However, as this report has demonstrated there is still room for improvement.

The recommendations highlighted in this report will be shared with members of our Improving Health Outcomes Group (IHOG). Chaired by the GP lead for learning disabilities (Herts Valleys Clinical Commissioning Group), the role of this group is to address health inequalities in order to improve the health outcomes of people with learning disabilities. The recommendations will be addressed by this group and will also be referenced in the Action Plan Year 2 of the Learning Disability Strategy 2019-2024.”

Hansa Nariapara, Commissioning Officer for Hertfordshire County Council

11. Response from Herts Valleys Clinical Commissioning Group and East and North Herts Clinical Commissioning Group

“We commend the report produced by Healthwatch on the Annual Health Checks. The research and report are invaluable to enable our care and services to improve following feedback from those at the heart of our work. We need to ensure the health inequalities experienced by people with a learning disability are addressed through the Annual Health Check and without their feedback it would not be possible to ensure this is effective. We are grateful to Healthwatch for this work and also to those who participated in the research.

The report and recommendations will be shared with all members of the Improving Health Outcomes (IHOG) and with all GPs in Hertfordshire. The recommendations will be addressed through IHOG and actions taken forward. We will continue to monitor the uptake of the Learning Disabilities Annual Health Check. There is also a Covid-19 pathway which was developed to ensure these can be completed safely this time.”

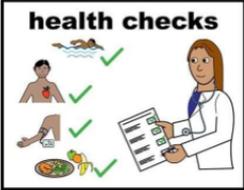
Dr Victoria McCulloch, Learning Disability Clinical Lead for Herts Valleys Clinical Commissioning Group

Dr Anindita Saha, Learning Disability Clinical Lead for East and North Herts Clinical Commissioning Group

11. Appendix

Appendix A: Health Action Plan

Learning Disability – Health Check Action Plan

Details of person completing this form		Name	TEST, Emis (Dr)
	Date form completed	15-May-2017	
	Position		
About Me		Forename	James
	Surname	Harry	
	Date of Birth	27-Mar-1945	
	Gender	Male	
	Registered GP	TEST, Emis (Dr)	
	NHS Number		
Allergies	Allergies	Allergies No allergies recorded.	
			
Health Goals for me to do			
	Diet		
	Exercise		
	Weight		
	Smoking		
	Drugs		
	Alcohol		
	Sexual Health		
	Contraception		
	Mental Health		
Other Goals			
Health Goals for my Doctor to do			
			
Extra Advice from my Doctor			
Help for me at the end of my life			
			



Go Prepared for the Annual Health Check

The purpose of this checklist is to enable paid carers / care practitioners, family members or friends of someone with a learning disability [age 14 and over] to ensure that the person attends their annual health check with all the information the GP may need to be able to fully assess their current health needs.

It is known that people with a learning disability die up to 20 years younger than the rest of the population and we want to change this. Having a good annual health check and using the Purple Folder will help stop this from happening.

Reduced communications skills mean that some people may not be able to explain a change / a pain / a new sensation they are feeling. They may not understand fully that these changes may have a significant impact on their health, if it is not checked out. As you complete this form make sure you empower the person to understand and take an interest in their health. If they are able to learn to spot changes that the Doctor should be asked about this will help stop delays in diagnosis.

LOOK AT THE LEARNING DISABILITY NURSE WEB PAGES FOR TOOLS AND EASY READ INFORMATION ON THE KEY HEALTH ISSUES and to print an Easy Read Annual Health Check checklist.

WWW.HERTFORDSHIRE.GOV.UK/LDMYHEALTH

This Preparation tool should be completed 2 weeks before the Annual Health Check

Injections / immunisations which help to keep you healthy

Flu injection - ALL people with a learning disability can have the free Flu Vaccine. This is usually given in September, October or November. Chest infections is one of the highest health risks for people with a learning disability and can be life threatening. Have they been asked if they want the Flu Jab? If they really will not have injections then a nasal spray can be given instead; Talk to the doctor.

Notes

Hep B - ALL people with a learning disability who live with other service users can have this series of injections to help stop them getting Hepatitis B. Hep B is an infection of the liver caused by a virus that's spread through blood and body fluids. Have they had this one?

Notes

Pneumococcal - All people with a learning disability who have or are at risk of respiratory, heart, kidney or liver issues or who are diabetic can have this injection to help them stop getting infections like meningitis, pneumonia and bronchitis. This is an injection they have just once. Have they had this injection ever? Talk to the doctor about whether they should have this?

Notes

Allergies

Is there anything that the person is allergic to or think they might be? An allergy could be something you eat or a medication that makes you ill or gives you a rash when you have it. If they have a known or suspected allergy make sure you tell the doctor so they can keep a record of this.

Notes

Communication

Make sure the doctor is aware of how best to communicate with the person to make sure they understand the Annual Health Check questions as much as possible. They should talk to their patient directly and not through you as carer. You can help the doctor to talk to person in a way they will understand. If you have any communication tools you use with the person then make sure you take this with you.

Under the **Accessible Information Standard** all Health and Social Care providers have a duty to **ASK** the persons preferred means of communication [both face to face and notification of appointments etc.] they need to **RECORD** this, **FLAG** it and **SHARE** when they refer them to another Health or Social Care provider and **USE** it every time they contact this person. Please help the person prepare by supporting them to think about what they want recorded and shared about their preferred communication methods.

What is their preferred way of being communicated with? Have they understood and agreed for this to be recorded and shared

The GP may want to store information on the persons **Summary Care Record additional information page** which is an electronic record of important patient information i.e. preferred communication methods plus other info such as significant medical history, medication and reason for taking it, management of long term conditions, immunisations and end of life care plans. This can be seen and used by authorised staff in other areas of the health and care system. Please discuss the benefits of this with the person before you go. If you have concerns over their capacity to understand and consent then discuss with key people in their lives whether it is agreed that this medical information sharing is in their best interest.

Notes

**Have they ever had Speech and Language Therapy?
Date, name and where were they from?**

Mobility

Do you think their ability to move around and their stability has changed at all in the last year?

Notes

**Do they use any walking aids?
Have they been seen by Physiotherapy? Date, name and where were they from**

Body and Lifestyle

What is their height?

What is their weight? If a record of weight is kept then take this with you. It is important to tell the doctor if they have lost or gained weight without any big changes to their diet as this could be an indicator of something being medically wrong

Waist circumference - If you have a tape measure and someone can check then write down what the measurement is around their waist.

Blood pressure - If they have a blood pressure record, where someone has been checking it for any reason, please bring it. If not the doctor will check their blood pressure because this helps to check their heart is healthy

Diet - write down what they ate yesterday for breakfast, lunch and dinner and all the snacks and drinks they had too. Be honest.

Exercise level - write down what they do each day of the week in a normal week. Where they go, how much they walk, whether they do any activities.

Unhealthy Habits

Smoking - If they smoke write down how many cigarettes they have each day. If they vape write this down too. The doctor will talk to them and you as their carer about what help they can get to try and give up smoking and the reasons why.

Alcohol - If they drink alcoholic drinks write down what they drink and how often.

Substance Abuse - if they take any drugs or smoke cannabis it is good to tell the doctor because they can make sure they get help to understand the impact of their life decision and use the services to help them stop.

FOR WOMEN

Breast checks - This again might seem embarrassing but it is very important to check breasts [boobs] and arm pits to see if there are any lumps in them. A lump might be cancer and if this is found early it can easily be treated. Do they know how to check their breasts for lumps and do they check them? If they don't, then you should tell the doctor so that they can talk to them about whether they are happy for the doctor to check them. Before you go prepare the person by helping them understand the importance of the doctor checking their breasts. If they don't have capacity to understand, discuss with key people in their life whether you feel it is in their best interest so that you can support the GP in assessing their capacity to consent and making the best interest decision for this check to be done. If they are supported with their personal hygiene then make sure you regularly make visual checks [changes in shape, colour, discharge etc. - search online for visual checks]

Notes

Periods and Menopause - consider their menstrual cycle. Is it regular? Have there been any changes? Has any changes in behaviour been noted which link with their cycle? Do they have any signs of the menopause [become more anxious, change in sleep pattern, hot flushes, mood changes, irregular cycle]

Notes

Breast Screening - If they are a lady aged over 50 or if they have a family history of breast cancer have they been invited to breast screening and did they go? This is very important - 1 in 8 women will be diagnosed with breast cancer in their lifetime. [Cancer Research UK 2014] 78% will survive it [Cancer research UK 2010 - 11] so early detection is critical. For women who can't self-check thoroughly this is even more critical. If they haven't been, discuss this with the GP.

Notes

Cervical Screening [Smear Test] - If the person is, or ever has been sexually active then discuss this with the GP. Have they ever been screened? If not then has this been fully considered and have they been given all the information to make an informed decision to understand and weigh up the risks and benefits?

Notes

FOR MEN

Testicle checks - This again might seem embarrassing but it is very important to check testicles [balls] to see if there are any lumps in them. A lump might be cancer and if this is found early it can easily be treated. Does the person know how to check their testicles for lumps and do they check them? If they don't then you should tell the doctor so that they can talk to them about whether they are happy for the doctor to check them to make sure they have no lumps that should not be there. If they are supported with their personal hygiene have you noted a change in size to their testicle or noted an increased tenderness when washing? Before you go prepare the person by helping them understand the importance of the doctor checking their testicles at the annual health check and if they don't have capacity to understand, discuss with key people in their life whether you feel it is in their best interest so that you can support the GP in assessing their capacity to consent and making the best interest decision for this check to be done.

Notes

AAA Screening - If they are a man aged 65 to 74, have they been invited to abdominal aortic aneurysm screening? Did they go? If they haven't been invited you can look up the AAA screening service and request an appointment for this. This is a very simple check to see if they have a large valve in their chest. If they do have this enlarged valve, this can be treated. If it isn't treated it can burst which is instantly life threatening which is why it is very important to get it checked. Talk to the doctor about this.

Notes

Eyesight

Do you think the person's eyesight has changed in the last year? Think about whether they have stopped being interested in things they used to be e.g. reading / looking at books / watch TV etc. Could they have eye pain [rubbing eyes or other behavior changes] Consider whether these changes could be because they can't see as well as they used to? People with a learning disability are 10 times more likely to have serious sight problems than the rest of the population and 6 in 10 people with a learning disability need glasses. [BNIB] Poor eyesight can impact a person's mood, lethargy, interest in activities as well as cause headaches. Remember - SeeAbility has a wide range of eye care resources and easy read material for people with learning disabilities

**Do they have prescription glasses and do they wear them?
When was last eye test and were there any issues achieving this?**

Hearing

Do you think the persons hearing has got worse in the last year? Do they need the TV to be louder? Have you ever thought that they have started ignore you?

Notes

Do they show any signs that they get ear ache or may have lots of wax in their ears?

Have they been seen by audiology? When and where and what was the outcome?

Dental

Consider how good are they at brushing their teeth? Do they regularly brush? Do their gums bleed? What condition are their teeth and gums in? Poor dental hygiene leads to gum disease and Gum Disease can increase the risk of health conditions such as strokes, diabetes and heart disease.

Notes

When and where did they last visit the dentist and what was the outcome? Are there any issues with receiving dental care?

Chest / Lung Health

Respiratory disease is the lead cause of death for people with a learning disability causing around 50% of deaths compared to approx. 15% for the rest of the population [CIPOLD 2013] So make sure you always get any of these symptoms checked out promptly.

Have a think about how they have been for the last month or two - Have they suffered from any of these?

- A cough that just won't go away
- Coughing up sputum [slimy stuff]
- Blood in their sputum
- Breathlessness - feeling like they can't get enough air in when they breathe
- Wheeziness - when it makes a squeaking noise when they try to breath in
- Do they often get chest infections?

Notes

Eating and Drinking

Do they have any problems with swallowing? Has anything changed in the last year? Do they get indigestion or heartburn [symptoms may be feeling sick or bloated after eating, burping a lot or get bad wind] Do they get acid reflux, have you noticed they have bad breath? Have you noticed that they find it harder to swallow or keep food in their mouth longer? Do they cough or clear their throat when they are eating or drinking? [This may mean that their swallow isn't as good as it should be and bits of food and drink are going into their lungs and not their stomach. This is not good because they can get chest infections which can become life threatening] People with learning disabilities have a significant risk of suffering from Dysphagia [swallow problems] and GORD [esophageal reflux]

Have they had any of the above symptoms?

Have they had a dysphagia [swallowing] assessment?

When was this done and what was the outcome?

Notes

Bladder Continence [weeing]

Have you noticed any changes when they wee? Tell the doctor if they have started to go more often, started to go at night, started having wet underwear, not been able to get to the toilet quickly enough or if you have noticed signs that it might be painful when they wee or it is very smelly and dark in colour. A change in someone's weeing can be a strong indicator of health changes that may not have been spotted so make sure you inform the GP

Have you noticed any symptoms above?

Have they been seen by continence nurse?

Date / who saw them and what was the outcome?

Notes

Epilepsy

Take seizure records with you so the Doctor can review this. [Especially important if you don't see a Neurologist or psychiatrist for this?]

Take a record of when the medication was last reviewed if you have this and when they last had blood tests. Make sure you consider bone health as this can be affected by some epilepsy medications.

Do they see a Neurologist or psychiatrist or any other epilepsy specialist?

Date / who saw them and what was the outcome?

--

Additional Notes

--

Heart and Lungs

Has the person had any signs of the symptoms which may indicate a problem with their heart and lungs [Cardiovascular system]?

- Do they get puffed out easily?
- Do they get pains in their chest?
- Do they get swollen ankles?
- Do they get palpitations [when it feels like your heart is beating really fast?]
- Do they get giddy or feel faint ever?

Notes

--

Diabetes

Type II Diabetes can develop at any time. If they are overweight or have a high sugar and fat content diet then they are at a higher risk level, so please make sure you tell the doctor about this so they can consider checking this out.

Has the person shown any of the following possible symptoms of developing diabetes?

Excessive thirst

Tiredness

Frequent weeing, especially at night

Unexplained weight loss

Notes

--

If they have a diabetes diagnosis

Make sure you take relevant information summaries of their blood sugar records, who they see to monitor this, what their diet is like and any issues with managing this.

Have they been invited to the Diabetic retinal eye screening? When did they last go? [This is really important as eye health is a significant issue with diabetes and needs close monitoring]

Notes

--

Muscle and Skeletal

Have you noted any changes to their muscle tone and bones and how they move? Have they slowed down? Have joints become stiffer? Has their ability to bend / move/ hold things etc. changed?

Notes

Foot Health

What are their feet like? Can they manage their own toe nails? The Doctor should check their feet in the health check.

Notes

Date last seen by podiatrist and what was the outcome?

Skin

If possible have a check of their skin before the appointment. Make a note of any bruises or sores and note any moles and whether they are scabby / changed colour or shape. If the person has lots of moles, it is good to keep a body map record of what their moles look like so you can see if there are any changes. Changing moles may indicate skin cancer so needs picking up early to be treated.

Notes

Mental Health Review

Consider whether there have been any significant changes in their behaviour., sleep pattern etc. Take a summary of records of incidents [please don't take a whole file as the GP won't be able to analyse all incidents but just needs a summary from the people who know them well.]

Consider whether there have been any big life events which may have impacted their mental health. [A death, a move, loss of house mate, loss of key staff or day activity etc.]

Notes

Consider whether they have a history of self-harming or suicide attempts and whether there is any information the GP needs to be updated on [safeguarding]

Notes

If they are on any medication and / or any "use when needed" medication please bring along a record of when it has been used and why it was needed. If they have been on a medication for their mental health for a long time and are not under a psychiatrist, please see if you can find any information about why it was originally prescribed so the GP can review it and make sure they aren't being over medicated [STOMP-LD]

Dementia

Have you noticed any possible signs of memory changes? Have they lost interest in activities they used to enjoy? Do they become confused about instructions they previously would have been able to follow? Do they have mood swings which are new to them? People with Down Syndrome have higher risk of early onset dementia. The Community Learning Disability Nurses carry out a dementia screen assessment from the age of 30.

Notes

Have they had a Dementia assessment? When was this done, who by and what was the outcome?

Checks the GP May Want To Do

Please do the ground work to help the person understand what checks the doctor may want to do and why these are important. Please look for easy read resources online too. This will help the Doctor to be able to assess their capacity to understand and then make a best interest decision about whether to complete these checks if they are not able to consent.

They will want to:-

Check the feet and skin

Check the Blood Pressure, Pulse

Listen to the chest and heart

Do an abdominal check of the digestive system [feel the tummy]

Look in the eyes and mouth

Do a breast or testicle check

Do a blood test

Any other health checks specific to syndrome

If the person has a specific syndrome then look up what the specific health issues may be and record and signs or symptoms of these to tell the GP

Downs Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Early menopause

Early onset dementia

Hypothyroidism [signs may be weight gain, tiredness, depression, memory issues]

Celiac disease [signs relate to issues with bowels and stomach pains]

Arthritis

Hearing and Eyesight

Heart related health issues

Blocked Nasal passage

Lower airway disease

Atlanto axial instability [signs would be neck pain and reduced neck movement]

Fragile X Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Anxiety

Signs of menopause [Ovarian failure can be from the age of 30]

Joint dislocation

Hernias

Muscle tone

Williams Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Constipation

Heart related health issues

Weight gain



Carers and Patients Provide the Clues for Detecting Health Needs

Go To www.hertfordshire.gov.uk/ldmyhealth for more info on how to help with health

Remember - You are the provider of the Health Clues. For any health provider to be able to make a timely diagnosis and treatment they need all the information for them to be able to piece the clues together. You are the people who know this person best. Any changes in their behaviour, lifestyle, sleep pattern, movement, mood, appearance etc. may all be indicators of a hidden change in the health.

Before you attend have a discussion with any key people in this person's life about any changes anyone has noted in the last year.

Also consider the End of Life Planning question

"would you be surprised if this person dies in the next 12 months?"

If the answer is NO - then raise this at the annual health check so that a positive end of life plan can be put in place.

Remember - it may not seem significant to you, but for the GP these Clues pieced together may form a diagnosis

Notes of Any Changes

Remember to make sure the person is given a Health Check Action Plan at their annual Health Check and Store this in their Purple Folder

Some of ways the Community Learning Disability Nurse can help

- Support with needle phobia issues to help the person understand the reason for blood tests / injections and then support the mental capacity and possible best interest decision making process.
- Provide **easyread info on flu vaccines** and liaise with people who aren't attending re the benefits and options of nasal spray where injections will not be tolerated
- Share any known accessible means of communication for the person, to enable health professions to build a better rapport and to improve their ability to deliver health care to them.
- Act as link between GP, HCT and carers to embed health messages through easyread info and creative thinking re diet and exercise and help overcome barriers to success.
- Educate people on constipation and the risks through enabling people to understand what is a healthy poo and what they should do if this changes - we have easyread info and a **clay Bristol stool chart model** we can use.
- Support people to understand importance of completing bowel screening
- Educate people in importance of checking breasts. This can be down, to some level, for absolutely everyone. We have developed a **breast pack and have breast models**. This should be in all ladies care plans.
- Educate ladies re the risks of not having cervical screening and prepare them for what the process entails through use of **cervical screening model**.
- Support with breast screening preparation and planning.
- Educate people in importance of checking testicles. This can be done to some level, for all men. We have developed a **testicle pack and have testicle models**. This should be in all mens care plans.
- Support with enabling successful AAA screening - this screening service has the Purple Star Award
- Support with enabling eye tests - we can loan opticians **eye test tools** that enable testing on people unwilling to engage and people who are non verbal.
- Support with dental through close links with specialist dental service. This service has the Purple Star Award. We have **easyread info and a teeth model** to help educate on the additional health risks beyond the teeth, with poor dental hygiene
- Liaising with HPFT regarding any concerns re swallowing to ensure a full assessment is done.
- Completing urine testing with people who wear pads through in pad test kits
- Supporting with epilepsy through our specialist epilepsy nurses.
- Enabling better understanding of diabetes through joint work with HCT in developing an **adapted DESMOND** for people with learning disabilities.
- Enabling access to Diabetic eye screening. This is a **Purple Star Awarded service**.
- Providing information in easyread regarding Bone Health
- Support with completing a risk assessment and history gathering to enable careful planning in reducing unnecessary medication which may be proving more harmful than beneficial. [STOMP - LD]
- Carrying out baseline dementia assessments [from age 30 for all people with Downs Syndrome] and support at point of diagnosis with monitoring where medication is newly prescribed and enabling carers to understand and adapt their care delivery. **[Additional Purple Folder Pages for dementia are available]**
- End of Life Planning - the nurse can support with this - a number of Herts hospices are awarded their **purple Star and additional purple Folder pages are available**

Appendix C: Easy Read Annual Health Check Checklist



Name :
Date :

Annual Health Check Checklist - page 1

Make sure the doctor or nurse talk about all of these and



<p>Important Injections you might need</p>  <input type="checkbox"/>	<p>Things you might be Allergic to</p>  <input type="checkbox"/>	<p>How you like to be communicated with</p>  <input type="checkbox"/>	<p>Any changes to your mobility</p>  <input type="checkbox"/>	<p>Your height and weight and any health risks</p>  <input type="checkbox"/>
<p>Your blood pressure (BP) and Pulse to check your heart</p>  <input type="checkbox"/>	<p>What foods you eat and any health risks in your diet</p>  <input type="checkbox"/>	<p>What Exercise you do and ways to get fitter</p>  <input type="checkbox"/>	<p>Whether you Smoke, drink alcohol or take drugs and ways to help stop</p>  <input type="checkbox"/>	<p>The free Flu vaccine and how you can have nose spray if you can't ever allow injections</p>  <input type="checkbox"/>
<p>Talk about safe sex and about Sexual Health and periods</p>  <input type="checkbox"/>	<p>Talk about what is healthy Bowels (poo) and Bowel screening</p>  <input type="checkbox"/>	<p>For women -talk about checking Breast for lumps and about having Cervical screening</p>  <input type="checkbox"/>	<p>For Men - do you know about checking Testicles for lumps</p>  <input type="checkbox"/>	<p>Whether you Eyesight has changed.</p>  <input type="checkbox"/>



Annual Health Check Checklist page 2

Make sure the doctor or nurse talk about all of these and



<p>Whether you think your Hearing might have got worse</p>  <input type="checkbox"/>	<p>Your Teeth, and dentist and the health risks from having bad teeth and gums</p>  <input type="checkbox"/>	<p>Listen to your Chest and ask about whether you have been coughing</p>  <input type="checkbox"/>	<p>Talk about your Swallowing - Do you cough when you eat or find it hard to swallow?</p>  <input type="checkbox"/>	<p>Has your Bladder (weeing) changed - do you go more often or is it smelly or a dark colour?</p>  <input type="checkbox"/>
<p>If you have Epilepsy talk about how many seizures you get and how often</p>  <input type="checkbox"/>	<p>Check your heart and lungs</p> <p>AAA screening</p>  <input type="checkbox"/>	<p>See if you are at risk of diabetes or check your diabetes if you already have it</p> <p>Diabetic eye screening</p>  <input type="checkbox"/>	<p>Check your Muscles and Skeleton (bones) because they can get weak as we get older</p>  <input type="checkbox"/>	<p>How you look after your Feet and cut your toe nails?</p>  <input type="checkbox"/>
<p>Talk about and check Skin for sores and moles</p>  <input type="checkbox"/>	<p>Talk about what you do and about your thoughts and feelings to check your wellbeing</p>  <input type="checkbox"/>	<p>See if you are at risk of getting Dementia and whether you need an assessment</p>  <input type="checkbox"/>	<p>Look at your Medication and see if it should be reviewed (STOMP LD)</p>  <input type="checkbox"/>	<p>At the end have you been given an Annual Health Check action plan</p>  <input type="checkbox"/>

How To use the Annual Health Check checklist



The checklist has most of the things the Doctor or Nurse should talk to you about at your Learning Disability Annual Health Check.



Before you go to your Annual Health Check it is good to get someone who helps you to complete the Careers preparation Tool. This will help your Doctors to see if there are health needs you have that hadn't been spotted before.



Remember, some illnesses hide so it is important to Check it out. The Check it Out symbol on the checklist means that you might be asked to go to a screening test to make sure you don't have illnesses hiding.



Before you go to your Annual Health Check look at all the boxes on the checklist and highlight anything you want to talk to the Doctor or Nurse about. If you need to write some notes to help you remember what you want to ask then take these notes with you too.



Take the checklist and your notes to the Annual Health Check and tick each section off to make sure all the important things are talked about.



At the end you should be given a Annual health check Action Plan. This will say all the things that the Doctors need to do, all the things that you and your careers need to do and also the things that you can ask the Community Learning Disability Nurses to help with.



If you want to talk to someone about Annual Health Checks then your GP Surgery has a learning disability link nurse who can help.



Ask the surgery for the learning disability link nurses information.

Appendix D: New Annual Health Checks Pathway

PATHWAY TO COMPLETING LEARNING DISABILITY ANNUAL HEALTH CHECKS DURING COVID 19 PANDEMIC

In order to reduce the risk of increased unnecessary deaths in people with learning disabilities during the Covid 19 Pandemic a Phased Annual Health Check can be carried out.

This should include:-

1. **Pre-Annual Health Check Carer Preparation Tool** – to be completed in advance by the patient/carer/family member and returned to the practice. The clinician can review the preparation tool to establish the key areas of health that may require additional focus (both medically and educationally for the patient and carers). Carer Prep and Easy Read Tool are at <https://www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/annual-health-checks.aspx> If the patient/carer does not have access to the internet send out a printed copy of the carer's preparation tool. **IF THE PERSON HAS NO SUITABLE CARERS OR FAMILY YOU CAN SEEK LD NURSING SUPPORT**
2. **Identify access to technology/video consultation and capacity for video consultation.** If felt this is not suitable schedule Face to Face AHC when clinically appropriate.
3. **Phase 1 – Virtual Annual Health Check** – focus on the key areas identified from the Preparation Tool and any concerns from the patient/carer/family member. The **Annual Health Check Action Plan must be completed, stating when physical assessments can take place via face to face consultation** (document when and where these should be done and who is responsible for booking these). The Health Check Action Plan should also have **additional educational/health monitoring actions for the patient and carers to act on** [referencing the LDMYHEALTH web page information].
4. **Phase 2 – Face to face Assessment** – This should be completed when agreed appropriate, as per the Virtual Annual Health Check. If Triggers are identified (which may include symptoms or unsure of capacity to decide about treatment) this may be a Priority F2F, Routine if felt safe to continue with F2F or Delayed if no triggers are identified and the risk is felt to be greater. **Try and co-ordinate all F2F assessments to be completed during 1 visit to the practice.**

Learning Disability Annual Health Checks – Guidelines during COVID-19

