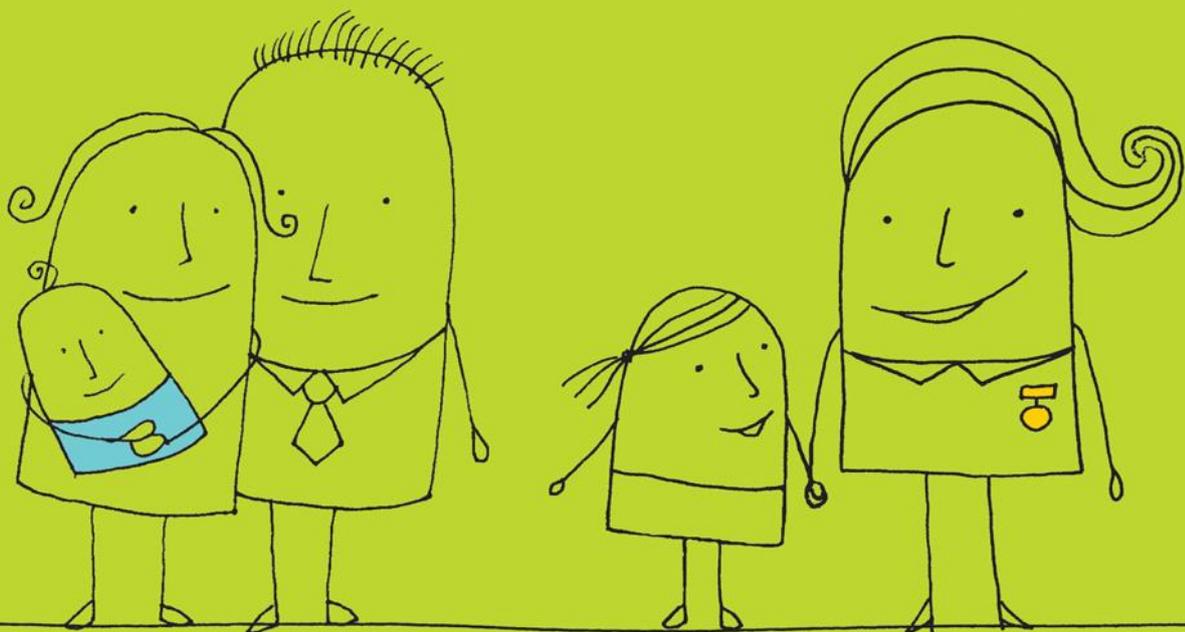


Annual Health Checks

The experience of service users and carers of annual health checks for people with a learning disability



The Patient and Client Council through the work of the Bamford Monitoring Group will engage with service users who have a learning disability and carers to understand their experience of annual health checks.

1. Introduction

1.1 Current context

Following the Bamford Review – which made over 700 recommendations in total, the Department of Health Social Services and Public Safety (DHSSPS) launched a consultation document known as *Delivering the Bamford Vision*. *Delivering the Bamford Vision* was superseded by the *Bamford Action Plan (2009-2011)*. The Action Plan set out how changes to reform services for people with a learning disability would occur.

The first action within the Bamford Action Plan emphasised the need to:

“ensure that persons with a learning disability have equal access to the full range of services to improve physical and mental health inequalities experienced by them.”

It also stated that a directed enhanced service would be created to include GP annual health checks and individual health plans. The plan stated that:

“the directed enhanced service will be rolled out regionally for adults with learning disabilities and provided in 90% of GP practices.”

In Northern Ireland, health checks were introduced somewhat later than in other parts of the UK. 2011/12 was the first year complete data was available across the region whereas in England the service commenced in 2008. Between 2011 and 2014 the number of GP practices signed up to perform annual health checks rose from 77% to 92%. The number of health checks performed by Trusts in Northern Ireland also rose from 4478 in 2011/12 to 5376 in 2013/14.

One of the features of Northern Ireland’s implementation of annual health checks is the introduction of health facilitators. These are trained learning disability nurses whose role it is to liaise with GPs to help identify patients with learning disabilities in

the practice, encourage attendance to the health checks and follow up any further actions.

1.2 Background to the project

As part of our work with the Bamford Monitoring Group; the Patient and Client Council (PCC) held the 'Healthy Minds Workshop' in June 2017. This was an opportunity for people with a learning disability to share their views and experiences of health and social care services including access to mental health services.

Participants told us that in addition to their family and friends, they would be most likely to contact their GP to seek support for a mental health issue and highlighted the importance of the relationship that people with a learning disability and their carers have with their GP. Annual health checks were an important part of this relationship for some of the participants.

One of the actions agreed at the workshop was that the Bamford Monitoring Group would undertake a small study aimed at understanding the experience of service users and their carers of the GP annual health check.

1.3 Literature scoping

Following the workshop a literature search was undertaken to identify if the findings of any previous work exploring annual health checks for people with learning disabilities in Northern Ireland had been published. One key paper, published by McConkey and colleagues was identified. The paper focused on reviewing Northern Ireland statistics on the number of GP practices registered to provide health checks, along with the total number of patients with intellectual disability known to the practice. Statistics related to the number of people who received an annual health check, the characteristics of this group and their satisfaction of the service based on a brief questionnaire completed by individuals after they have an annual health check were also analysed.

The study found that 87% of adult persons with intellectual disability in Northern Ireland registered with a practice that offers an annual health check, the authors stated that there is fairly clear evidence that this level of coverage can be attributed to the appointment of Health Facilitators.

Another key finding was that certain sub-groups of people with intellectual disability appear to be missing out on having health checks: namely younger persons, those living with family members or independently and persons resident in more socially deprived areas.

McConkey and colleagues were able to determine that despite the impressive coverage and uptake figures, fewer than 50% of people with intellectual disability are receiving a health check every year in Northern Ireland. They proposed possible explanations for this as being: GPs may decide that an annual check is not needed for younger patients who present with no problems; patients themselves may feel there is no need for them to attend another check as nothing untoward was found previously, or that many patients with a mild intellectual disability may not be known to services and are therefore not flagged within the health service system records.

The data related to people's experience of annual health checks was limited with the authors reporting on findings from a brief patient satisfaction questionnaire which was only returned by an average of 58% of practices in 2012/13. The findings showed that almost without exception people rated the checks highly: 100% were happy with it; 100% reported they had enough time; 96% reported they had been told how their health could be better and all were willing to come back next year.

2. What we did

As the literature review did not identify any work within Northern Ireland that had explored the experience of people with learning disabilities of having an annual health check the following objective was included in the PCC Business Plan 18/19:

The Patient and Client Council, through the work of the Bamford Monitoring Group, will engage with service users who have a learning disability and carers to understand their experience of annual health check.

2.1 Initial scoping

To help shape the project the PCC project co-ordinator of the Personal and Public Involvement team met with three learning disability groups. Lilli put Theatre Company, Derry/Londonderry, Compass People, Ballymoney and Positive Futures, Newry. The project co-ordinator also met with one of the Trust Health Facilitators and corresponded with others via email. The purpose of these conversations was to get a better understanding of the service and to help shape the topic guide for further in-depth interviews.

2.2 In-depth interviews

Ten in-depth interviews were conducted with 14 participants, five service users and nine carers. Interested individuals were identified through contact made with local Health Care Coordinators across Northern Ireland. The interviews were transcribed and four have been presented as case studies, written consent was obtained for their inclusion in this report.

3. What people told us

Of the 14 people we spoke to, 13 had direct experience of the annual health check service either as a service user or as a carer in attendance with a family member. One carer was interviewed as their family member was unable to access the service due to the severity of their learning disability.

3.1 The annual health check appointment

It appeared from the interviews that the annual health check service was valued by participants. Carers explained that it provides them with peace of mind that a thorough health check of their loved ones is completed

“...it really does seem to go over everything so it does and they really do seem to do 100%.”

Respondent E (carer)

When asked about communication between the service user and GP during the appointment participants told us they were happy with how they were communicated with one respondent stating that they felt their family member who has a learning disability was communicated with effectively and given the respect and time he needed and another saying that the GP would always make sure to use words that their family member could understand. Another participant, a service user, also emphasised that they never felt rushed during their annual health check.

“Yes, oh yes definitely 100% em yes I do think they do give enough time. They don't rush you, that if there is a problem that you want to sit and discuss they are quite happy to do that.”

Respondent E (carer)

It was noted that outside of the AHC many service users did not have regular contact with their GP.

“...before this started I could say that it was maybe several years were going past before [family member with LD] would see her doctor. Because as I say she doesn't get sick. She is rarely ill in any way.”

Respondent E (carer)

“...he is very healthy. Very seldom would he be in during the year with them (GP).”

Respondent G (carer)

3.2 The role of the Health Facilitator

From the feedback provided by participants the role of the Health Facilitator appeared integral to the overall positive experience of the annual health check appointments. The Health Facilitators seem to be a valued, trusted contact and a source of continuity across the health care process as identified by the service user and carers interviewed. Some service users told us that they “really like” or “love” their Health Facilitator which demonstrates the impact this person had on them.

In addition, Respondent F (carer) highlighted the value of the Health Facilitator as an important advocate in having a concern taken more seriously:

“What I found was that initially when the problem developed I was able to phone [Health Facilitator] who was that link with the health check and said to her what was happening and through the learning disability team we moved dentist and got the condition taken more seriously I think.”

Carers unanimously said that Health Facilitators were good to have as a point of contact.

3.3 How the annual health check experience could be improved

Provision of more information prior to the annual health check was identified as something that would be beneficial to help explain what will take place and prompt people to be ready to raise any concerns they might have. This would especially be of benefit to people living independently. Respondent D (service user) who lives in

supported living accommodation highlighted that no information was given ahead of the appointment nor were there any questions asked around how they would prefer to be communicated with.

The value of receiving a copy of the annual health check documentation was noted by carers, with one identifying that they had found it difficult to get a copy of the documentation from their family members most recent annual health check.

The "...GP has agreed that I can have it so what the problem is I don't know but I have always kept a copy of all repots and it is very handy as well for looking back, if something did crop up with [family member]...wee things that slip your mind".

Respondent E (carer)

3.4 Additional issues related to annual health check

Whilst the annual health check both as a concept and the appointment itself were favourably commented on, Respondent E (carer), did share concern that there is no opportunity to talk to health professionals privately. They said that often carers or parents may not wish to share their concerns with health professionals in front of the person with a learning disability to prevent stress. Respondent E (carer) explained:

"if mammy or daddy says, 'I need to speak to you in private', that they need to take it on board that while you know that there, really I know there is an equality and confidentiality (issue), but with people with a learning disability, with their carer there isn't really confidentiality". In the past the respondent felt that issue of confidentiality had been used as an excuse not to share information.

4. Case studies

Participant A: Male carer for brother and cousin

I care for my brother and my cousin and our GP explained to me that it was an opportunity for him to pay attention to people with special needs who in the past didn't see their GP unless they had some ailment or were ill and it helped him keep tabs on their health on an annual basis.

We get a letter from the practice manager to tell us that on a particular day and time an appointment has been made. You usually get it about a fortnight beforehand in case it doesn't suit and you can make other arrangements. The Health Facilitator would be there and the GP from the practice. It would be a two part process.

There would be a range of activities at the health check including blood pressure, weight and asking questions about their general health. There would be particular questions the Health Facilitator would ask regarding anything flagged up from the last annual health check. A note was made and that would have been flagged up with our GP, just in case it did not necessitate us seeing him for that ailment.

The GP would then give them a physical examination and if they are on medication which my brother is as he is a diabetic, he would do his annual check on his medication. His medication is also reviewed six monthly at the clinic. So it is thorough it is not just a cosmetic exercise. I would be very positive about our experience.

Blood tests are also conducted and if anything is highlighted, other decisions are made. That is happening to my brother at the moment actually. He is now going for his third set of blood tests. We were not aware or he didn't display any sign of infection but his bloods showed that he had an infection. They are on the ball. I would have to say that they are very proactive at looking after their wellbeing.

The Health Facilitator would ask about mood swings, any change in habits or if we had noticed anything visibly different from the previous time and how that was

impacting him or how it was affecting him. I can also get in touch with the Health Facilitator after the health check. In fact on another issue I was able to get her details from the practice and rang and left her a message and she got back to me. The Health Facilitator knows him, she has past knowledge of him and that provides continuity. She flags up the Mental Health issues that the GP would not necessarily be on the ball with. She is given her place as a professional in that area and bringing that to bear in the process.

We are fortunate that the Health Facilitator would know them from away back and this is a big, big plus. My brother and cousin are at ease going in and speaking to her and as I said she has background knowledge of their history so it makes life a wee bit easier. She is very, very good. There is no doubt that attention is given to mental health because the Health Facilitator would be proactive in questioning. She would not leave it all coming from us. She herself would know what triggers to ask about and would prompt you with a question and different aspects of mental health such as moods being one, sleeping patterns, daily routine and diet.

The GP communicates well with them particularly when he has them up on the couch. I would turn away and he would chitter away to them and talk to them and tell them what he was doing.

About a fortnight to a month after the appointment you get a copy of the annual health check paperwork. We were given very clear information of what everything was about and the purpose of it and any decisions that were reached or future appointments. They made it very clear what they were and why.

It's not as good in the hospital though. They talk to us instead of talking to my brother. The clinics were fine but that would be our experience of staying in hospital. They don't care, they really don't care and I don't say that in a dismissive way. We had an instance when my brother was admitted to hospital from A&E and we were left sitting outside waiting to get in for nearly two hours. The communication was poor. The initial reaction should have been that this gentleman with a learning disability has no one with him; but we were sitting outside waiting. He wouldn't have settled and would have been frightened. When we eventually got in, they did

apologise. We calmed him down and reassured him that we would be back in the next day but that was bad.

I don't think I would change anything about the annual health check. I am being personal about it. The knowledge and knowhow of our family that the Health Facilitator has gathered over the years from our family, from knowing them in different situations in their different environments, you will never replace that. The appointment is as long as it needs to be. You may be given a slot but you are given the time you need. There is nobody sitting clock watching and saying; "well that's me finished" or "your time is up". There is none of that. It begins naturally, it goes through naturally and it has a natural end. So that is what I liked about it too. I think it is a valuable service and it can only be for good for my brother and cousin and anyone else in that situation.

Participant E: Mother caring for adult daughter

My daughter has had an Annual Health Check for a number of years. It is normally scheduled around the same time every year and usually I would get a phone call from the surgery reminded me that it is time to make an appointment.

The first time we went for the check we had a conversation about how my daughter likes to be communicated with but she has changed a lot in her communication over the past few years. While she is very verbal and can speak very well, her comprehension has deteriorated quite a lot. Plus she seems to have a lot of problems now misinterpreting what people say.

At the appointment they basically give her a complete health check. The GP would check blood pressure, height, weight, check her bloods and if the person hasn't had gender specific checks done, they are willing to do that during the appointment too. She would also speak with the Health Facilitator about any concerns, even outside the medical domain. I have also been able to raise her interpretation and her mental health at the health check. She would also have a physical exam with her GP.

I do feel that my daughter's mental health could be covered in more depth. Usually within the appointment mental health would be approached in an informal way and they ask if I have any concerns or worries about my daughter. The GP would pick up on anything raised. I understand here are so many different areas to cover at the annual health check that sometimes wee things can slip through. But in general the health care professionals are very thorough and the Health Facilitator is there if you have any concerns.

As my daughter is a reasonably health girl she wouldn't be at the GP throughout the year. I do feel this annual check is of major importance for this very reason. Before it started I would say that sometimes several years went by before she would see her doctor.

My daughter doesn't understand everything the GP and Health Facilitator say all the time and that is why I would always accompany her. It's not so much of a problem

with our GP or the annual health check but it is a problem that I come up against quite regularly with other professionals. While confidentiality is important, I feel there can be challenges when it comes to people with a learning disability. My daughter is an adult and she is entitled to be able to go in and sit and talk to the doctor on her own if she wants to. However, I estimate that at least three quarters of professionals do not take into account that people like my daughter have a problem with misinterpretation. An example of this issue of confidentiality is in relation to the mental health services which my daughter uses. If I was to discuss certain issues in front of my daughter it would cause her major distress yet if I ask to speak to the doctor alone I am told that as my daughter is their patient they can't really talk to me without her being there. I think that is a major issue as the implication is issues aren't being raised.

Another issue I experienced was when my daughter was once in hospital. I had repeatedly asked staff to wait until I was present to ask her questions but there was an instance when a doctor had questioned my daughter by herself and when I returned she was very distressed as she was worried she had said the wrong thing. They had been discussing sexual activity and she didn't understand what he had been asking. It did turn out that she had provided the wrong information. Sometimes professionals simply don't understand because my daughter is so normal looking and has no physical disabilities. It is just assumed there is no major problem and that there should be no problem with comprehension. It must have taken me the best part of fifteen years to have it marked on the front of my daughter's file that she has a learning disability, because it is not obvious. This is a very, very big issue. I would see a benefit for the Health Facilitator in that area.

At the annual health check they don't rush you. If there is a problem that you want to sit and discuss, they are quite happy to do that. I really do feel involved as a carer. I can't fault the annual health check, I really can't because it really does seem to cover everything. They really do seem to do one hundred percent. My daughter is happy enough with the whole process. Although from the start I have explained in depth to her the purpose, that it is because she doesn't see the doctor very much and there are wee things that you have to get checked every year, and she has come to accept that and is quite content with it.

The Health Facilitator is a benefit to the process, they are really able to bring in the side of the mental health issues and simple things like eating habits. These are things that a GP wouldn't normally touch on. I feel GPs really aren't up to date with dealing with people with learning disabilities as they don't have an understanding of the problems people with a learning disability have. It is even more difficult when we can't get to see our own GP. I don't mean this in a bad way, but some GPs do tend to treat people with learning disabilities just the same as you and I. They can forget that there are other issues there and think that just because someone is perhaps fairly articulate that they don't have a problem.

I am involved with a learning disability group and have experience with many people with learning disabilities so I know that there are people who would definitely benefit from more information ahead of the annual health check. More information could avoid a situation where people are thinking "I am not sick so what do I need to go to the doctor for?"

I would strongly promote the Annual Health Check.

Participant B: 29 year old, male service user

I get a letter from my GP to go for my annual health check once a year. I have been getting this for about the last six years. I go down with my Mum or Dad and wait for a minute. Then I go in and they check my weight and my chest to see how my breathing is. They pump my arms to check my blood pressure too.

Sometimes I get blood samples taken. The one thing I don't like at all is giving blood. I was very annoyed that the last couple of times I did, my bloods were lost. I had to go back down and have them taken again, which I hate doing. Apart from that, I don't mind going to the health check at all.

Now that I am a bit older I am more confident and if there is something I think of or want to say, I just say it. I have the right to talk to people.

The last time I went for my health check I saw a nurse first. That took about twenty five minutes and then went straight in to the doctor. It depends what way they talk to me; if they talk nice to me, I will be nice back. They focus on my physical health but I don't remember them talking too much about my mental health.

After the appointment I get some papers on eating healthy food. It was good to get this to look over. I am quite active and walk a lot. That keeps me healthy. I am happy enough with what I get so I just say; move on. Just don't ask me to come back to give more blood. Last time they lost them, I refused to go back.

Participant F: Mother caring for adult son

I think we have been receiving an Annual Health Check for around five years, normally the Health Facilitator would phone us and try and get a date organised and we put it in the diary.

Generally my son wouldn't be a regular attendee of the doctor but he has been going to his GP a bit more often of late because he developed a skin condition. It was of such a serious nature that I thought we might need some advice to help my son so the learning disability nurse came on board and I also asked for a little bit of help from the Psychology team. He got to see someone who was very good with him and brought a lot of things down to his level.

At the annual health check they would do his height and weight and talk about what is healthy to eat and drink. Then we go to the GP and there is a general review. They take their time; it is not just a cursory exercise. He had glasses as a child but didn't need them. At the annual health check they suggested we get an appointment with the optician. So that was a good thing because we might not have bothered. Thyroid problems can be an issue for people with Downs syndrome so they would do a check and do bloods every other year for that. They also promote healthy eating and there is a small action plan and they check if he is involved in activity.

Mental health wouldn't have been to the forefront because in general he is a very content young man. However, given the health issues that have cropped up with my son I was able to phone the Health Facilitator who was that link with the health check and could say to her what was happening. Through the learning disability team we were referred to appropriate services and got the condition taken more seriously. So although that wasn't a direct result of the annual health check, I was able to communicate with the Health Facilitator. It is good to have that contact.

I think that is the annual health check is even more important for people who are not backed up by someone 24/7. It would give support workers an opportunity to raise any concerns they have about people they work with.

It is not uncommon for adults with a learning disability to have their symptoms minimised because they cannot really explain their level of pain. In my sons case his recent condition had developed a little bit because of that reason. Although he got treatment, maybe it could have been prevented, had the level and nature of the condition been considered a bit more at the very early stages. But that's not to do with the health checks because on this occasion when the symptoms developed the GP was very quick to refer straight for treatment and that was brilliant. Unfortunate that it arose but brilliant that it was dealt with quickly.

The GP is very good. She would speak directly to my son and would refer to me for other questions around general health. I find that helpful and I think it helps him when he has to go and see her for other things. It means he is not so anxious. My son lives at home and his Dad and I are his primary carers. I think it is a very good routine for my son and it is a reminder to check things that are not run of the mill. Maybe someday he will move into supported living or when we don't just have the same capacity to look after him, so as a carer it's very reassuring to know services such as the annual health checks are available.

Some information ahead of the appointment might help, for both the patient and carer. It would maybe prompt people to be ready to ask questions during the check. It might also be a good idea to provide information about adult learning disability services, especially when people are transitioning from children's services. They could maybe provide contact details in case you ever needed to come back to ask any questions afterwards. Also on the appointment letter they could include a place to make notes to bring along with you as a reminder of anything you wanted to ask or have checked.

My son likes to know what is going on and what is happening each day so he can understand things. The learning disability team are very good at putting things into pictures for him and doing little social stories. One of them did a little booklet when he did have to go into hospital. So maybe there would be an opportunity for something like that for carers or parents to go through what is going to happen at the annual health check.

I think the annual health check works very well because you are going to a GP surgery with people you already know, so you are not in unfamiliar territory. When we go we are not waiting a long time to be seen which makes it easier. I think because of the way the staff deal with my son, makes it helpful. He is relaxed and if he needs an examination or anything he is not too anxious.

5. Conclusion and key messages

The majority of people we spoke to reported good health and a recognition that they would rarely visit their GP. This highlights the value of the Annual Health Check from a practical perspective to ensure that service users, particularly those in more rural areas or with less family support, do not miss this important check-up.

The value of a long-term relationship with Health Facilitators is a consistent message across the conversations we had. As a partner in the care process their consistent, trusted role is highlighted and noted as valuable. This is particularly relevant given the extended age profile of people living with a learning disability into later years. The role of Health Facilitators to support both service users and their carers to transition between services appropriately is an area that could be explored further.

Provision of information continues to be highlighted by people as an area which can be improved. The Patient and Client Council are told daily that good information is important to people. The value of information about the annual health check was particularly important for service users who lived in supported accommodation. They told us they would value more information prior to their appointment.

While time taken in the appointment itself and the dignity and respect afforded to service users was commended, the value of checking that information is clearly understood was highlighted. The value of using language that everyone can understand is again highlighted as something that continues to need attention across the system. It is important that information isn't misinterpreted in discussion. For service users who attend an annual health check alone, as is the case for two people we spoke to, this is vital. This reinforces the value placed on the Health Facilitator and their important role as a partner in the care process acting as an advocate.

5.1 Key messages

To our knowledge this is the first project that has explored with people with a learning disability, and their carers, their experience of having an annual health check. While the project was small it has led to some important insights.

- Previous evidence from within Northern Ireland has demonstrated that the role of the Health Facilitator is linked with the greater number of GPs providing Annual Health Checks in comparison to England and Wales. This study has also highlighted the role of the Health Facilitator on a personal scale. Participants shared how the role provides consistency, trust and a point of contact in the annual health checks process. The findings from this project would also suggest that there may be scope for a similar role beyond primary care to provide support and advice to people with a learning disability who have identified that they often find hospital visits and stays stressful.
- Given the consistent evidence supporting the importance of good health literacy it was encouraging to hear that both the GPs and Health Facilitators referred to by participants in this study were seen as ensuring dignity and respect for people with learning disabilities by allowing sufficient time for appointments and using effective communication to ensure the person was engaged in the process.
- One aspect of the annual health checks service that was identified from this work as requiring further development was communication prior to the appointments. The PCC is aware of pre-appointment questionnaires which are used elsewhere in the UK but from our conversations with Health Facilitators these do not seem to be common practice in Northern Ireland. In order to improve the uptake and experience of the annual health check more information should be made available in advance of the appointment. The aim would be to ensure people are aware they are eligible to have an annual health check and also to ensure people know what to expect and can make the most of their appointment. The PCC will work with the Bamford Monitoring Group and the Health and Social Care Board to improve the information available to people in advance of their annual health checks.
- In 2015, 50% of people who were offered an annual health check took up the offer. It would be helpful to understand if this figure has changed and to know the reasons why people don't take up the offer of an annual health check.

- It would appear, the annual health check could be made more comprehensive by extending it to include dental assessment, eye tests and hearing tests.