# Optimising the uptake of health checks for people with intellectual disabilities

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**Introduction**

The health inequalities experienced by people with intellectual disability[[1]](#footnote-1) is well attested nationally in the UK as well as internationally (Emerson and Hatton, 2013). Taggart and Cousins (2014) reported that they are more likely to experience a range of secondary or chronic health conditions, such as constipation, thyroid problems and diabetes, many of which can be prevented and managed more appropriately, thereby improving quality of life, increasing longevity and reducing care costs. There is also evidence that people with intellectual disability are less likely to receive checks for breast and cervical cancer compared to their non-disabled peers. However it is now a legal duty within the UK under the Disability Discrimination Acts (1995, 2005) and the Equality Act (2010) for primary and secondary services to make reasonable adjustments to ensure equality of access to healthcare (Disability Rights Commission, 2006).

One response has been the introduction of annual health checks undertaken by community family doctors such as general practitioners (GP) in the UK National Health Service. This is supported by a body of literature from the mid-1990s onwards and the development of screening tools such as the Cardiff Health Check (Baxter et al, 2006). A systematic review of international evidence on health checks for adults with intellectual disability has been recently undertaken by Robertson et al. (2010) which concluded that the introduction of health checks had resulted in ‘*the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia) p. 24’.* The health checks also led to targeted actions to address health needs such as the promotion of healthier lifestyles. Moreover health checks also seem to be cost-effective as early detection reduces the costs associated with managing chronic conditions (Buszewicz et al., 2014).

In England, the uptake of health checks has been documented by Public Health England (2013) since their introduction nationally in 2008. By 2012/2013 there had been nearly a four-fold increase from 27,000 to over 93,000 checks undertaken. Nevertheless only a minority of adult persons with an intellectual disability are receiving a health check although the proportion has risen from 19% to 46%. A striking feature of the English data is the regional variation across the 10 Strategic Health Authorities. Although all showed some progress in the proportions of people with an intellectual disability screened, the patterns were very stable over time: the better regions continue to screen more people while the rates in poorer performing regions remain low. Thus by 2012/2013 the best performing region screened 64% of persons with an intellectual disability known to GP practices compared to 37% in the poorest region. A similar regional variation in the provision of health checks has been reported for Wales from 23% to 60% (Perry et al., 2010).

To date, relatively little attention has been given to examining the implementation nationally of health checks and especially the resulting inequities across regions that are now clearly apparent. In Northern Ireland, health checks were introduced somewhat later than in other parts of the UK. 2011/12 was the first year in which complete data was available across the region for the Direct Enhanced Scheme for Learning Disability under which payments are made to GP practices for the provision of an annual check. However given the smallness of the region (1.8 million people) and the data emerging from England and Wales, a major concern was to encourage the uptake of health checks and to monitor equity of provision across the region. The paper reports the findings from a three-year review that aimed to discover possible factors affecting the provision of health checks and the contribution that the appointment of a cadre of dedicated staff known as Health Facilitators could make to this. All were registered learning disability nurses and members of community intellectual disability teams. They were seconded to these new posts to liaise with GP practices.

**Method**

**Country context**

Northern Ireland operates a National Health Service in common with other parts of the UK. General Practitioners (GPs) provide free primary health care to a panel of patients mostly resident in their locality. There were 351 GP practices in 2013/14 (353 in other years) with around 1,100 GPs employed in total. In 2013 the average number of patients per practice was around 5,200 of whom 3,800 are adults aged 20 years (based on figures provided by the Department of Health, Social Services and Public Safety: http://www.dhsspsni.gov.uk/gp-w-f.pdf ). In addition Health Boards may contract with GPs to provide additional services to subgroups of patients such as those with diabetes under what is known as Directed Enhanced Service (DES).

As in other parts of the UK, a DES for Learning Disability was introduced regionally in 2010 with GPs entitled to claim £75 for each patient with intellectual disability who had a health check. Guidance was provided on the type of checks to be undertaken based on the Cardiff Health Check (Royal College of General Practitioners, 2010). This includes a physical examination by the doctor and information obtained from the patient or an accompanying person such as a family carer or service staff.

Further monies were made available in Northern Ireland by the commissioning Health and Social Care Board so that community learning disability nurses who were employed by Health and Social Care Trusts could be seconded or recruited to act as Health Facilitators. In broad terms their role was to liaise with GP practices to identify patients with intellectual disability, encourage their attendance for health checks, to assist at screening clinics and follow-up on actions needed. Due to financial pressures, the number of Health Facilitators that were appointed varied across the Trusts and over the years. However this provided the opportunity to assess the impact that the Health Facilitators might have on the uptake of health checks.

**Information gathered**

This study was an audit of anonymised data held by Health and Social personnel and as such ethical approval was not required.

The Health and Social Care Board provided information on the claims made by GP practices for reimbursement for the checks they had undertaken in the three financial years: 2011/12; 2012/13 and 2013/14. This data also identified the number of GP practices that had agreed to provide health checks – a potential source of inequity – along with the total number of patients with intellectual disability known to the practice. The number of patients who had been checked could also be identified and the variations over the three years and across Trusts could be monitored.

However these summated data gave no personal details of the people attending health checks. Thus an analysis was made of the anonymised patient records kept by Health Facilitators within one Health and Social Care Trust. These records were held for all the patients with intellectual disability who were known to the practices. Thus comparisons could be drawn with those patients who had a health check and those who had not. Chi Square Tests or T-tests as appropriate were used to assess the statistical significance of differences.

**Results**

**Information on practices**

Northern Ireland has 351 GP practices (353 in years 2011-13). Over the three years the number of practices signed up for the DES has increased from 77% in 2011/12 to 79% in 2012/13 and 92% in 2013/14. However not all practices undertook health checks in any one year. Figure 1 illustrates the variations in the percentage of practices in each Trust undertaking health checks over three years as well as the total for Northern Ireland overall.

*Insert Figure 1 about here*

As Figure 1 shows, the overall percentage of practices had risen to 84% by 2013/14. The highest uptake over the three years was in the Northern Trust which has had a full team of three Health Facilitators for the longest period with the lowest uptake in Belfast which started with only one part-time Health Facilitator (0.6 WTE) in 2011/12 but this complement has been increased to a full-time post. Likewise in the Western Trust the two WTE Health Facilitators only became fully active in 2012/2013 when there was a marked increase in the number of participating practices. In the two other Trust areas Health Facilitators have been active since 2011/12 and again the proportion of participating practices is high in that year. However the fall in the proportion of practices undertaking checks in 2012/2013 is not necessarily reflective of a drop in the number of practices participating in the DES but the Health Facilitators reported that certain GPs in the Southern Trust area in particular, felt that an annual health check was not necessary for their patients with an intellectual disability.

**Patients registered with practices**

*Insert Table 1 about here*

Details on the number of patients who received a health check in GP practices needs to be set against possible differences in the prevalence rates for these patients across the five Trust areas in Northern Ireland. The first row of Table 1 presents the number of adult persons resident in each Trust area. The second row gives the number of persons with intellectual disability identified in GP practices. As there is no centralised data-set in Northern Ireland that registers people with intellectual disability, the Health Facilitators when they came in post worked with practices to match people known to Trusts with those known to the practice and also to verify if those recorded in the practice did in fact have an intellectual disability using agreed criteria when the DES was introduced. The resulting prevalence rate is shown in the third row. The regional prevalence rate of 7.16 is close to that previously reported of 7.06 (McConkey et al., 2006) and the higher proportions of people with intellectual disability in the Western and Southern Trusts is a well-established finding from studies undertaken in Northern Ireland over the past 40 years (McDonald and Mackay, 1994). The fourth row of Table 1 gives the number of patients with intellectual disability recorded in the GP practices within the Trusts that took part in the DES programme in 2013/14 and expresses this as a percentage of people identified in the practices. Thus regionally around 87% of people with intellectual disability are covered by participating practices, with the Northern Trust having the highest coverage and Southern the least.

The final row in Table 1 shows the mean number of patients with intellectual disability in participating practices and the range in each trust area. The larger numbers of person with intellectual disability in some practices probably arises from their proximity to residential and nursing homes which accommodate sizeable numbers of residents. It might be expected that higher proportions of people with intellectual disability might be screened in practices with smaller number identified. This was not the case as comparison of rows 4 and 5 illustrates.

Overall the proportion of patients with intellectual disability is generally small in GP practices: an average of 19 per practice (which represents around 0.5% of the total number of adults on GP lists). If around 30 minutes is assumed for each health check, then the time investment for an average of 19 patients is 10 hours per annum for Northern Ireland per practice.

**The number of patients who had health check**

*Insert Figure 2 about here*

The number of health checks undertaken across Northern Ireland has risen from 4,478 in 2011/12 to 5,084 in 2012/13 (a 13.5% annual increase) and 5,376 in 2013/14 (a further 5.7% annual increase). Likewise the number of people with intellectual disability identified by practices has also increased over this time. In 2013/14, 64% of the number of people with intellectual disability known to practices had received a health check which is significantly higher than comparable percentages of around 46% reported for England (Public Health England, 2013). However as Figure 2 shows, the proportions of people with intellectual disability who received a health check varied across the Trusts as a whole but with less variation by 2013/14 (ranging from 56% to 70%). Comparable ranges across Strategic Health Authorities in England were from 37% to 64%.

In the Belfast Trust, not only were fewer practices offering health checks but smaller proportions of patients known to the practices were receiving the checks. By contrast the highest proportions of people receiving health checks was in the South-Eastern area which has had a longer history of providing health checks (Marshall et al., 2003).

It is noticeable though that the proportions of people with intellectual disability who received a health check had fallen in the most recent year. In part this is due to increased numbers of people being identified by practices but it could also arise from practices not calling people annually for a check if there were no concerns from previous checks. A similar drop had been reported for some English Health Authorities (Public Health England, 2013). Even so within the five Trusts in Northern Ireland there was wide variation on the proportion of patients receiving a health check by practices; ranging from 6% to 100% of all the patients known to them with intellectual disability. Moreover there was no apparent relationship between the number of patients with intellectual disability known to the practice and the proportion who received a health check as summarised in Table 1. This was further confirmed when Pearson Product Moments correlations were calculated between the proportion of persons who had a health check in each practice with the numbers of patient with intellectual disability known to that practice. None of the correlations within each Trust or for the region as a whole were statistically significant (p>0.05). Thus practices with smaller numbers checked the same proportions of their patients than practices with large numbers.

**The characteristics of patients who had a health check**

No details are available from GP records of the demographic characteristics of people checked. In order to obtain this information, the records of patients held by the Health Facilitators in the Northern HSC Trust were analysed. This Trust has the longest established provision of health checks and has achieved the highest enrolment of practices and percentage of persons checked within practices. Although this data may not be typical of other Trusts, it could indicate possible trends in the people being checked that might be more marked in areas with lower uptake of checks.

The Health Facilitators had acquired information on 1,944 adult persons with a reported by GP practices which was 1,714 persons and is accounted in part by the omission of a few practices from the DES. In all 1,371 persons (71% of the total) had received at least one health check in the period 2010 to 2013 which accords well with the claims made by practices and shown in Figure 2. Comparisons can then be drawn between those who had a health check and those who had not.

There was no significance difference by gender. More males (54%) than females (46%) had a check which is in keeping with the overall demographic for this client group. Likewise differences in terms of level of disability were not significant. Around half the persons checked (50%) were considered to have a severe intellectual disability; just under one-third (30%) a mild intellectual disability with around 20% undefined which again was similar to the overall proportions in the population. The mean age of those who had a check was 44.7 years which was significantly higher than those who did not have a check (mean 41.7 years) (t=3.1; p<0.002). Likewise people living in nursing or residential homes (82%) or in supported living arrangements (75%) were more likely to have a health check than those living with family carers (72%) or independently (63%) (Chi Sq 24.4 p<0.001). Also people who had health checks tended to live in more affluent areas based on postcode of their residence. Of the people checked, 15% lived in the top 20% of areas with least deprivation with only 7% living in top 20% of the more deprived areas (Chi Sq 8.4:p<0.02).

In summary, this data suggests that there may be some biases among those who received a health check. People more likely to do so were: older persons, living in residential accommodation and in areas of less deprivation. By contrast, people less likely to have a health check are younger people, those living with families or independently and in more deprived areas.

**Number of checks undertaken for each patient**

The data submitted by GPs does not identify the people who were checked so it not possible to determine the extent to which people are having repeat check: (a similar problem is present in the English data). The Health Facilitator’s database was used to determine this. Over the period from 2010 when the Health Facilitators commenced work in the Northern Trust, the number of health checks reported to them for each person was as follows: No health check, n=550 (29%); one health check, n=587(31%); two checks, n=319 (17%); three checks, n=386 (20%) and four checks, n=79 (4%). This data suggests that by the fourth year of operation, fewer than 50% of people have had more than one health check and this was in the Trust with the highest uptake of checks. In future years this figure should rise as long as health checks continue to be provided but it is an indication of the length of time required for this to happen.

**Patient Satisfaction**

As part of the DES, a brief patient satisfaction questionnaire on the health checks is completed at the end of the appointment (see below). From the returns made by practices in 2012/13, 58% of them had done this (range 49% to 74% across the trusts). An audit was undertaken of 408 questionnaires drawn from 22 practices across the Trusts. 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.

**Discussion**

Although confined to one small region of the United Kingdom, this study provides the most detailed information to date on the uptake of health checks for people with intellectual disability. Compared to England and Wales (Perry et al., 2010, Public Health England, 2013), it would seem that greater coverage has been attained in Northern Ireland with around 87% of adult persons with intellectual disability registered with a practice that offers an annual health check. There is fairly clear evidence that this can be attributed to the appointment of Health Facilitators given the variation that existed across the five Trusts. The more Health Facilitators there were and the longer they have been in post, the greater was the number of practices that provided health checks. Their role in supporting practices to provide health checks may have overcome some of the barriers these patients may have encountered previously (Lennox et al, 1997). GPs may value the benefits that health checks can have above routine appointments, they are more confident to undertake health checks and there is clarity around the eligibility criterion of who can have a health check (Turner and Robinson, 2010, Chauhan et al., 2012).

Yet despite the efforts of the Health Facilitators some GP practices have been reluctant to sign up, citing as their main reasons for not doing so, a lack of demand, scepticism about the value of screening and a wish to avoid extra paper work. Moreover some GP’s feel inadequately prepared to provide health checks (Phillips et al, 2004) although an earlier study in Northern Ireland had shown an increased willingness among GPs to participate in screening this population once they had experience of it (McConkey et al., 2002).

This study also provided details on the likely number of patients per GP practice although this can be inflated in certain practices that cover residential or nursing homes for people with intellectual disability. Across Northern Ireland, each practice has an average of only 19 adult patients which would require less than 10 hours of GP time to undertake the checks per annum. Against that, the extra income that comes to the practice is also small so the financial inducement is probably not a determining factor in practices offering checks. Informal feedback from those practices in Northern Ireland that offered checks suggested that the provision of a better service to their patients was a dominant concern.

Nonetheless it would seem that certain sub-groups of people with intellectual disability are missing out on having health checks: namely younger persons, those living with family members or independently and persons resident in more socially deprived areas. The latter parallels experiences in other screening programmes (Whynes et al., 2003). These factors too might also account for some of the regional variation reported across Trusts as certain areas have higher levels of deprivation (both urban and rural) than other Trusts. Nonetheless extra efforts might be required from Health Facilitators and GP practices to target sub-populations and encourage attendance at health checks for persons in these categories, as well as others persons not known to learning disability services who may be at greater risk of experiencing poorer health (Emerson, 2012, Emerson and Hatton, 2013).

This study suggests that despite the impressive coverage and uptake figures, fewer than 50% of people with intellectual disability are receiving a health check every year. This might indeed be clinically appropriate as a GP may decide that an annual check is not needed for younger patients who present with no problems. Likewise patients themselves may feel there is no need for them to attend another check as nothing untoward was found previously. Similarly many patients with a mild intellectual disability may not be known to services and therefore not flagged within the health service system records (Emerson and Hatton, 2013). Hence further research needs to be undertaken to identify those patients for whom an annual health check is considered essential so that more effective targeting can be undertaken.

Other significant questions remain regarding health checks that were beyond the scope of this study, notably the quality of the checks that are undertaken and their efficacy in identifying health issues (Turner, 2013). Also the follow-on from health checks could usefully be monitored especially in terms of health gains for people with disability (Felce et al., 2008, Emerson and Hatton, 2013). This should embrace changes in lifestyle as well as treatment for specific illnesses or ailments. As yet there is limited evidence for the medium to long-term impact of health checks, therefore future studies will need to examine both the long-term costs and also the financial gain of conducting these checks (Cooper et al, 2014). Finally a further role for the Health Facilitators is to stimulate health promotion within intellectual disability services although this requires co-ordinated planning which to date has proved elusive but it is vital that it occurs if health gains are to be obtained for these patients (Walsh and McConkey, 2011).

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***Note: \* 85 practices in 2013/14: ~ 351 practices in 2013/14***

**Figure 1: Percentage of practices providing the Learning Disability DES over three years by each Health and Social Care Trust in Northern Ireland.**

**Figure 2: The proportion of people with intellectual disabilities who had a health check over three years by each Health and Social Care Trust in Northern Ireland**

**Table 1: The number of people with intellectual disability (ID) in participating practice lists across the five HSC Trusts and for N. Ireland in 2013/14**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Belfast Trust** | **Northern Trust** | **South Eastern Trust** | **Southern Trust** | **Western Trust** | **NI Total** |
| **1.Adult population of Trust** | 263,588 | 345,751 | 261,479 | 262,859 | 214,877 | 1,348,554 |
| **2. Number of people with ID identified in Trust area** | 1,860 | 2,103 | 1,663 | 2,155 | 1,859 | 9,651 |
| **3. Prevalence rate ID per 1,000** | 7.06 | 6.08 | 6.36 | 8.20 | 8.65 | 7.16 |
| **4. Total number of patients with ID from GP returns in 2013/14 and percentage of identified number of persons with an ID as shown in row 2.** | 1,535  (83%) | 2,022  (96%) | 1,386  (83%) | 1,707  (79%) | 1696  (91%) | 8,386  (87%) |
| **5. Mean number (and range) of patients with ID per practice providing checks** | 13.1  (1-40) | 17.9  (1-61) | 21.9  (1-77) | 21.2  (2-59) | 21.5  (6-91) | 18.6  (1-91) |

1. The term intellectual disability is used to refer generally to this population and the term ‘learning disability’ when referring to the health services for this population. [↑](#footnote-ref-1)