Annual Health Checks
For
Adults with Down's syndrome

Down's Syndrome Association
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ANNUAL HEALTH CHECKS FOR ADULTS WITH DOWN'S SYNDROME

Summary

This study focused on people with Down's syndrome, living in England, Wales and Northern Ireland, to investigate their experience of annual health checks. Since people with Down's syndrome have poorer health and a higher prevalence of unmet needs than the general population, they would benefit from the annual health checks which have been introduced for people with learning disabilities to address the inequalities in health care.
GP practices have been advised to base their health checks on the Cardiff health check protocol, available through the Royal College of General Practitioners or a similar protocol agreed with their PCT.

The study found:

- Uptake of annual health checks remain patchy, with some members not knowing of their existence;
- Health checks are not being conducted in line with the Cardiff protocol;
- Sufficient time is not always being given to conducting a thorough health check;
- Basic checks which are critical for the health of people with Down's syndrome are being missed.

Introduction

People with learning disabilities have poorer health than the general population, yet are less likely to access regular health checks or routine screening[1]. People with Down's syndrome are predisposed to certain medical conditions, including cardiac disease, thyroid disorders, hearing impairment, visual problems, coeliac disease and Alzheimer's disease, most of which are treatable. If left untreated, these conditions can cause secondary complications and seriously affect the overall well-being of the individual, as well as resulting in unnecessary costs, which may be avoided.

It is thought that the medical management of children with Down's syndrome is more effective than for adults. The Down's Syndrome Medical Interest Group (DSMIG) and the American Academy of Paediatrics have drawn up a set of guidelines for the medical management of children with Down's syndrome, and the majority of paediatricians follow these guidelines. [2]

However, this comprehensive system of medical management does not apply to adults with Down's syndrome. From being under the care of a single paediatrician or a team of paediatricians for their medical surveillance, some 18 year olds will be referred to the appropriate adult medical specialist for their medical problem, some to several specialists for a range of problems, but most will transfer to the surveillance of their GP for their general care.

[1] Michael J. (2008) Healthcare for All. The findings of the Independent Inquiry into the health inequalities of people with learning disabilities. *Department of Health.*
[2] Noble SE, Leyland Kin et al (2000) in Henderson, A, Lynch, S et al (2007) 'Adults with Down's syndrome: the prevalence of complications and health care in the community' *British Journal of Medical Practice,* 57(534):50-55

This change in medical responsibility at adulthood has meant that the health of adults with learning disabilities has been neglected. Annual health checks were introduced to address the inequalities in health care.

The current policy and guidelines for the medical management of adults (aged 18 and over) with Down's syndrome are outlined below:

- The DES (directed enhanced services) is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced in 2008 to improve healthcare and provide annual health checks for people on the local authority learning disability register. To participate in this DES, staff at GP practices need to attend a multi-professional education session run by their PCT. £101.74 is paid for every health check undertaken.[3]

The NHS recommends that the annual health checks are conducted in line with the regulations stated in the 'Clinical directed enhanced services (DESs) for GMS Contract: guidance and audit requirements for 2010/2011'. Furthermore, annual health checks should follow the Cardiff Health Check protocol which is endorsed by the Royal College of General Practitioners. However, as page 9 of the DES guidelines states, practices can use a similar protocol approved by their PCT, as long as it covers all elements of the health check as set out in the Statement of Financial Entitlement.[4]

Previous research[5] has highlighted a number of concerns regarding the annual health checks for individuals with learning disabilities, recording that 48% of adults with Down's syndrome (from their sample) had not seen a doctor in the last 12 months, and 33% (from their sample) had not had a medical assessment in the previous 3 years.

There are also concerns regarding the flexibility of the current system, which does not enforce any specific requirements for what tests should be included. Chauhan et al suggest 'a more targeted approach focused on incentivising Intellectual Disability (ID) specific health issues such as vision, hearing, behaviour, feeding, bowel and bladder function assessment along with current Quality of Outcomes Framework (QOF) targets (recording carer details, ethnicity, and specific clinical data such as blood pressure) might be more appropriate in primary care for improving care for people with ID than an executive ID health check'.[6]

Lastly, there are concerns regarding the approach taken by health practitioners in treating people with learning disabilities which may influence the overall effectiveness of the health check. Earlier research has suggested that negative attitudes of GPs lead to inaccurate diagnosis and inadequate medical management for individuals with learning disabilities[7]. However, more recent research suggests that negative perceptions alone do not fully explain

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[3] National Health Services, 'Directed Enhanced Services', *<http://www.nhsemployers.org/PayAndContracts/GeneralMedicalServicesContract/DirectedEnhancedServices/Pages/DirectedEnhancedServices.aspx>*, (accessed 17th February 2011).

[4] National Health Service, 'FAQS: Clinical directed enhanced services', *< http://www.nhsemployers.org/SiteCollectionDocuments/Clinical_DES_Guidance_mh23032009.pdf >*, (accessed 17th February 2011).

[5] Henderson A, Lynch S et al (2007), 'Adults with Down's syndrome: the prevalence of complications and health care in the community' *British Journal of Medical Practice,* 57:534 50-55.

[6] Chauhan, U. Kontopantelis, E. Campbell, S. Jarrett, H. Lester, H. (2010) 'Health checks for adults in primary care for adults with intellectual disabilities: how extensive should they be?' *Journal of Intellectual Disability Research* 54:6 479-486.

[7] Gill F. Stenfert Kroese, B. Rose, J. (2002) 'General practitioners' attitudes to patients who have learning disabilities' *Psychological Medicine,* 32(8):1445-55.

the inadequate healthcare they receive[8]. Other factors should be addressed such as the need to adapt the format of the consultation, and the quality of interface between GP and the carer accompanying the patient.[9]

A systematic review of the impact of health checks for people with learning disabilities[10] concluded that it was 'clear from the results of these studies that introduction of health checks for people with learning disabilities typically leads to:

- the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia);
- targeted actions to address health needs.'

In light of recent research, the focus of the 'Annual Health Check Survey' was to investigate whether:

- people with Down's syndrome are accessing annual health checks;
- the health checks cover the medical conditions, to which individuals with Down's syndrome are susceptible, conducted in line with the Cardiff protocol.

Methodology

A survey was conducted amongst adults with Down's syndrome (aged 18 years or older) who are living in the UK to better understand their experiences of annual health checks. The survey was conducted in July 2010, and 219 responses were received by the Down's Syndrome Association.

The survey was sent electronically to 102 adult members of the Down's Syndrome Association with email addresses and a further 500 by post. This represented a third of our adult membership with Down's syndrome. The 500 members who received the survey by post were selected randomly by constituent ID from the DSA database of members. The responses received by post were entered manually into the 'Survey Galaxy' software so that the data from both the electronic and paper responses could be analysed together. 22 of the emails sent were undeliverable.

In addition, the 'Annual Health Check Survey' was also posted for completion on the Down's Syndrome Association website. Therefore it should be noted that not all the responses received were necessarily **members** of the Down's Syndrome Association, the inclusion criteria for the 'Annual Health Check Survey' being adults with Down's syndrome (aged 18 years or older) living in the UK.

Responses were analysed to investigate the experiences of the annual health check procedure and to determine the extent to which the procedure appeared (to the users) to adhere to the Cardiff protocol.

The data collection method used was a structured online questionnaire using proprietary internet-based survey software (Survey Galaxy). Some questions had a range of possible answers and allowed the participant to select one or more answer. The participant was able to enter additional free-text data regarding improvements. The data were collected in July 2010.

[8] Gill F, p. 1445.
[9] Gill F, p. 1445.
[10] Robertson J, Roberts H & Emerson E (2010) Health Checks for People with Learning Disabilities: A Systematic Review of Evidence http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf (accessed 3rd February 2011)

Ethical considerations
Responses to the questionnaire were collected anonymously. All ethical principles in relation to confidentiality of data and anonymity of participants were adhered to, in line with DSA guidelines. It was decided that formal ethical approval was not needed as no intervention was being undertaken. The purpose of the survey was made clear to participants in the invitation email and by self-selecting to complete this they gave their informed consent.

Data analysis
The survey software (Survey Galaxy) was used for initial analysis of the results. To enable more in-depth analysis and exclusion of participants who did not meet the required criteria, the responses were imported into Microsoft Excel and analysed by one of the researchers. Owing to the nature of the data and sample size, descriptive statistics only were undertaken.

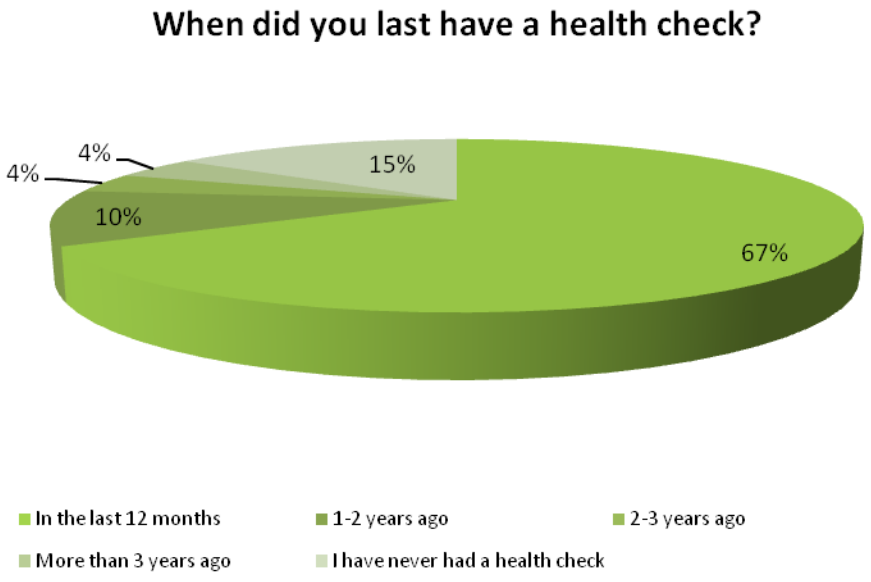
It should be noted that not all contributors responded to every question. Analysis figures, therefore, refer to percentages of people who replied to that particular question, rather than to the total number of respondents.

Findings

Of the 219 responses received for the 'Annual Health Check Survey', 147 (67%) were between 18-29 years of age, 40 (18.18%) were between 30-39 years of age, 25 (11%) were between 40-49 and 7 (3%) were 50 or older. 120 (56%) respondents were male and 100 (45%) female.

The majority of respondents of the survey 168 (77%) were living with parents, whilst the remainder were either in supported living 22 (10%), in residential care 17 (8%), alone 2 (1%) or in an 'other' living situation 10 (5%). The high number of adults living with parents should be considered in the further analysis as it may influence how frequently they have a health check.

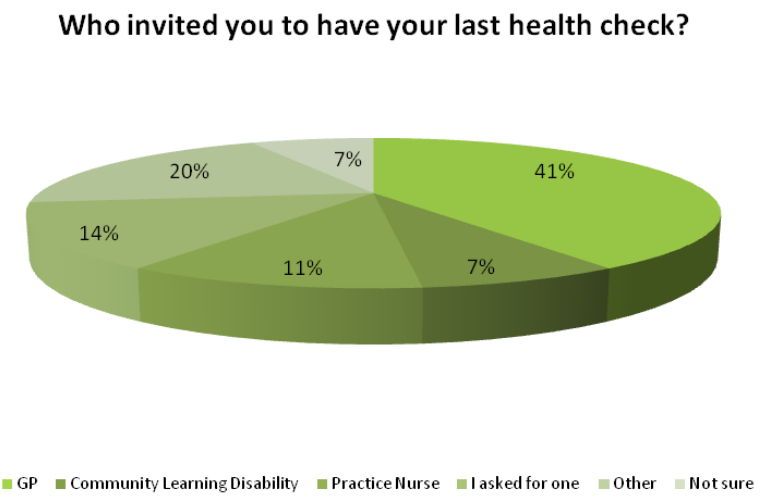
216 respondents went on to provide further information. The results indicate that two thirds 144 (67%) of respondents had a health check within the past 12 months and that 33 (15%) have never had a health check.



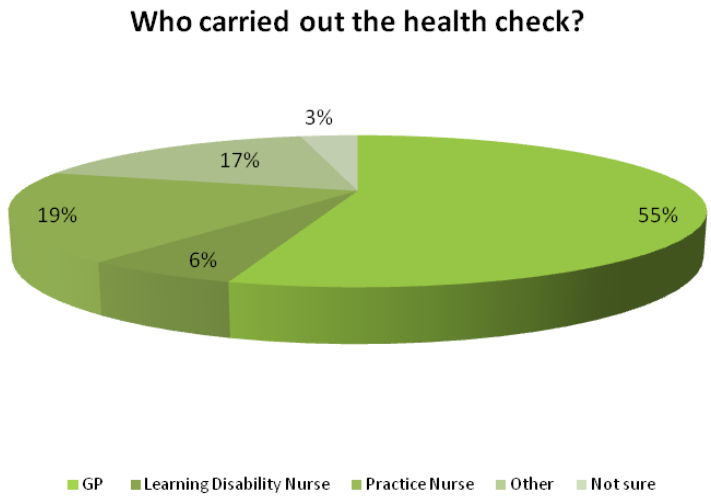
Of the 33 that had never had a health check, most 27 (84%) responded that this was because they were not aware annual health checks were available. Comments indicated that many thought it would be useful to have more information about where and when to go for a health check, to make them better known/available to those who can benefit. Only 1 respondent had difficulty getting an appointment and only **1** respondent did not want an appointment. (N.B other respondents chose an 'other' reason for not having a health check).

"We have never had notification about a "health check" for my son. I will be looking into this, checkups have been related to everyday illness, or when requested."

The Annual Health Check Procedure



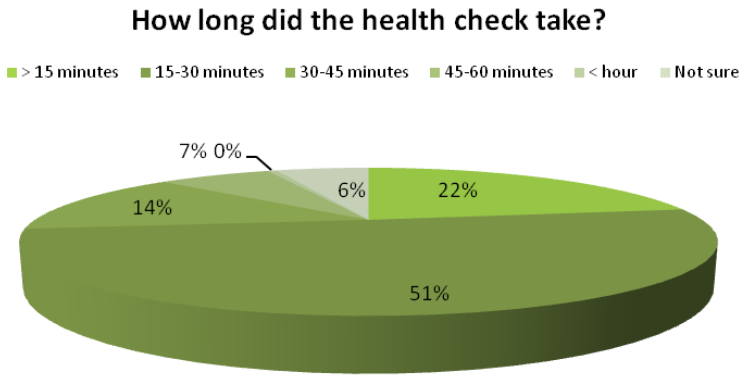
95 health checks were carried out by GP's (55%) and 33 (19%) by a practice nurse. 30 (17%) chose the 'other' option and comments indicated that consultants also carried out some of the health checks. (See the 'Further Analysis' section for additional investigation into this issue.)



Following investigation into the duration of the health checks, intended to give an indication as to the standard of care received, 88 (56%) health checks lasted for between 15-30 minutes.

However, 39 (22%) lasted for less than 15 minutes- a concerning figure as it is unlikely that less than 15 minutes would be adequate time to cover all the aspects of the suggested Cardiff protocol. The recently published guidance document[11] for GP practices recommends that the health check should be carried out over 2 half-hour sessions.

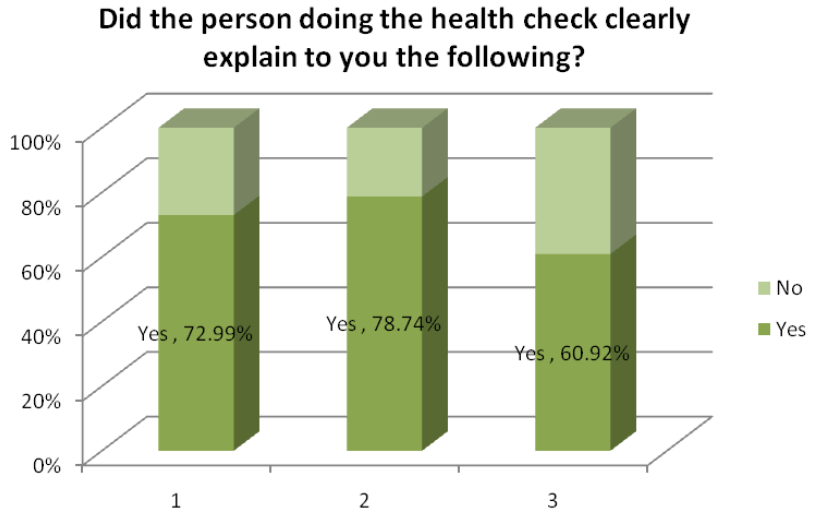
"Usually doctors are very busy. They are required to see maximum numbers of patients in minimum time. Probably they are under directions to do so."



Overall, our data suggest that communication between health professional and patient is fairly good. More than 60% of respondents believed that the health professional conducting the health check had clearly explained (1) why the procedure was going to happen, (2) what was going to be done during the procedure and (3) what the possible outcome might be.

However, some comments referred to unhelpful approaches:

"The nurse spoke to my mum/carer most of the time-wrong. The nurse referred to my (mum) as mummy. The nurse looked to my mum and asked "is he sexually active"."



[11] RCGP (2010) A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability

Tests and Checks

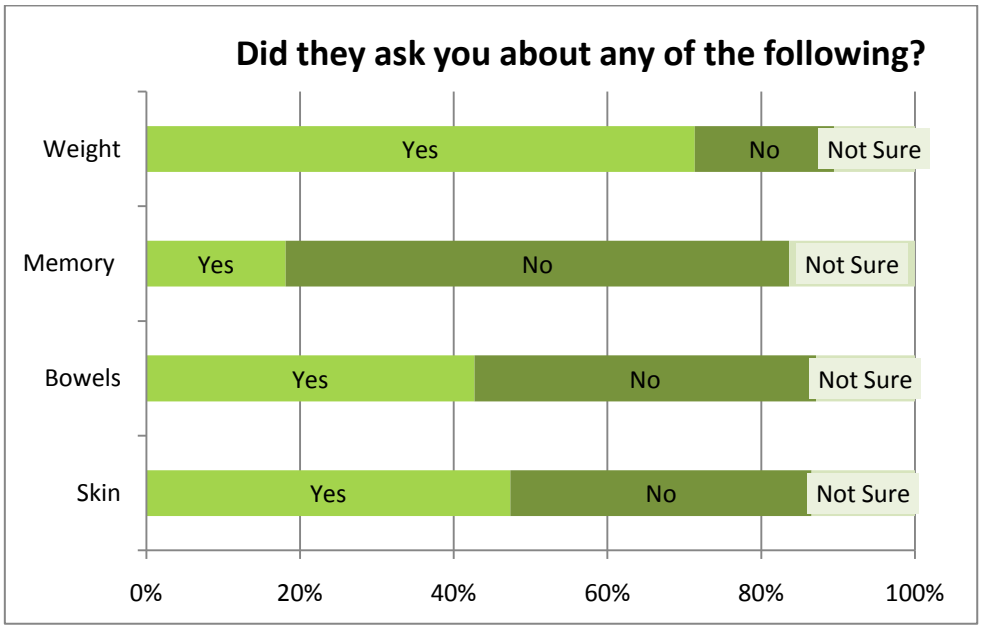
The aim of this next section of the survey was to determine which aspects of health care were covered by the health practitioners. Basic health checks were audited; 171 participants responded and were included in this section.

In 106 (62%) of cases, current medication was discussed between the health practitioner and patient, although 48 (28%) were not taking any medication. In 135 (79%) cases, reference was made to medical records, and another 23 (13%) were 'not sure'.

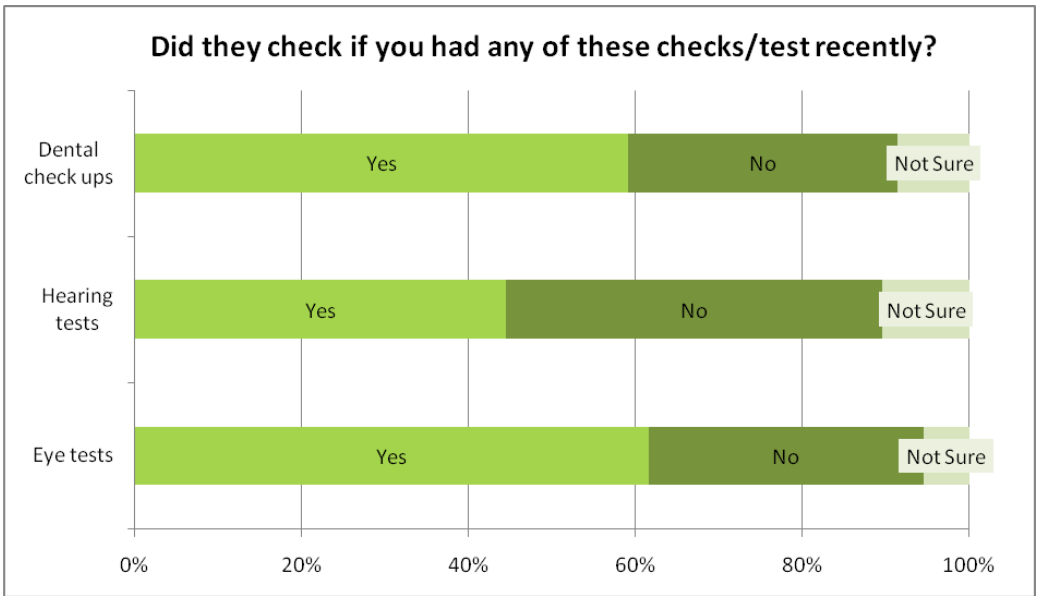
Skin conditions, bowel conditions and memory were checked or tested for in less than half of all 171 health checks. It should be noted that individuals with Down's syndrome are susceptible to skin and bowel conditions and therefore such low percentages (47% and 43% respectively) is concerning.

Only 18% of people from the sample were tested for memory issues, and weight was discussed in 122 (71%) cases; however comments indicate that more discussion/advice on health management would be preferable.

"More help to do with weight control."



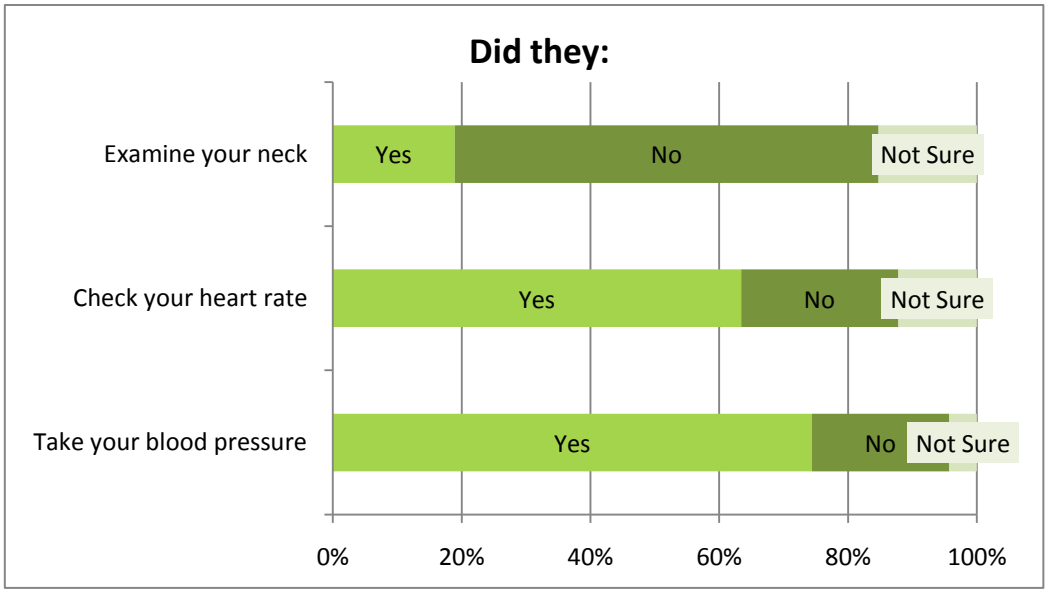
The annual health check should ideally provide a holistic approach to the overall wellbeing of the patient. Therefore although dental checks, hearing tests and eye tests are not expected to be conducted as a part of the procedure, attention should be paid to each to ensure that hearing, vision and oral health have been considered. 97 (59%) of health checks covered discussion of oral health or dental checkups, 73 (45%) covered discussion of hearing tests and 101 (62%) discussed vision or eye tests.



Although both blood pressure and heart rate checks were carried out in many cases (74% and 63% respectively), these basic tests should be conducted in every annual health check for an adult with a learning disability. One particular comment refers to this:

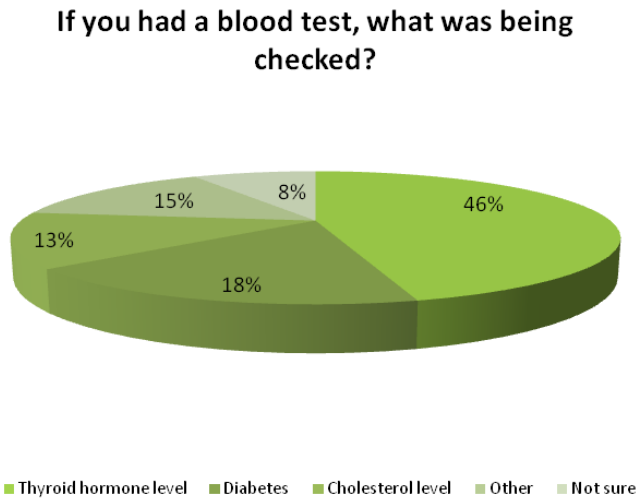
"I think the health check should include: blood pressure, heart rate as standard practice."

Furthermore, 21 comments were related to the necessity for more routine tests and checks to be done.



Only 31 of the 164 assessable responses had reported having either a smear test (5), pelvic exam (1), breast exam (12) or testicular exam (13). As per the Cardiff protocol guidelines, each of these tests should be conducted (dependent of gender) therefore the figures are significantly lower than might be expected.

As people with Down's syndrome often develop thyroid disorders, it is particularly important that blood tests are conducted, although obviously it is important to check a variety of other medical conditions such as diabetes and cholesterol level. However, out of the 164 assessable responses only 104 (63%) had a blood test taken, of which 82 (79%) checked for thyroid hormone level. 60 (37%) did not have a blood test taken at all.



Of the 163 assessable responses to this question, only 62 (38%) had a urine sample taken - another basic test which should be carried out as an integral part of the health check. Five of the comments related to ways in which the health checks may be improved referred to urine samples and tests being done as standard.

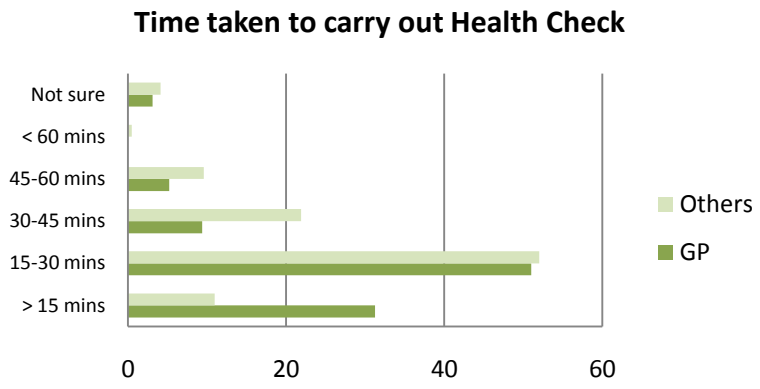
Overall, the responses to how useful in general the health check was are very mixed. 30 (18%) did not find the health check at all useful, 85 (52%) found it quite useful and only 48 (29%) found it very useful. Only half of respondents reported that any long-term health problems were discussed.

"…….. more question about long term health problems like this long questions about simple care and health questions GP ask if you need help with it. If someone can't deal with it go back to your GP or nurse."

Further Analysis

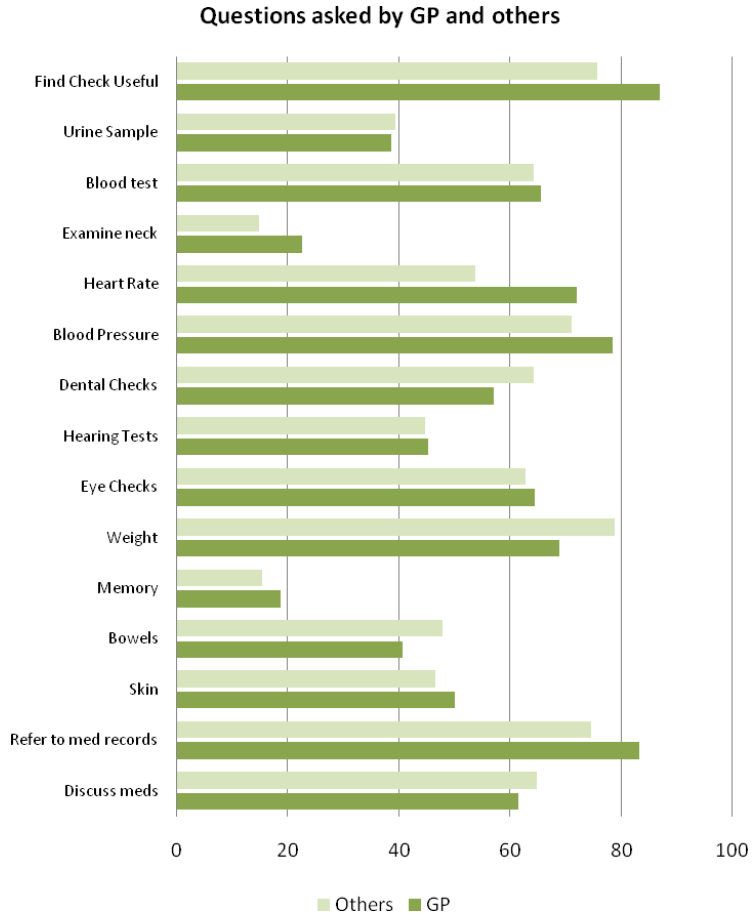
There was no significant difference to the numbers of people who had a health check in the last 2 years, in relation to their age, living arrangements or gender.

There were, however, some differences in length of time taken to carry out the health check dependant on whether or not the GP performed the test. In particular, many more GPs than other professionals spent less than 15 minutes on the health check, and were also less likely to spend more than 30 minutes.

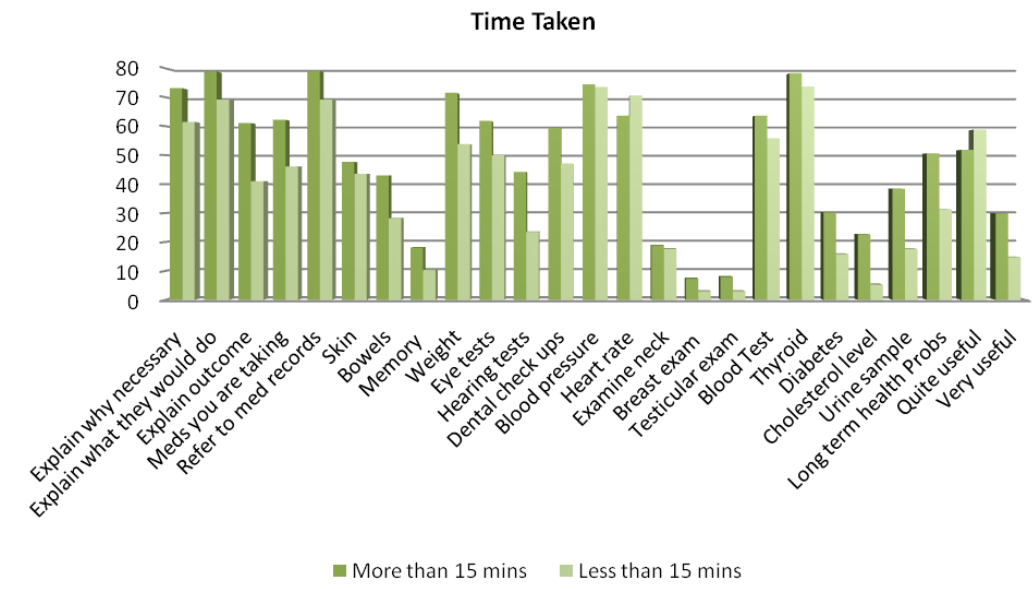


More GPs than other practitioners referred to medical records, took blood pressure and checked the heart rate. Fewer GPs asked about bowels, weight and dental checks.

Overall, fewer checks incorporated memory, neck examination, or urine sample.

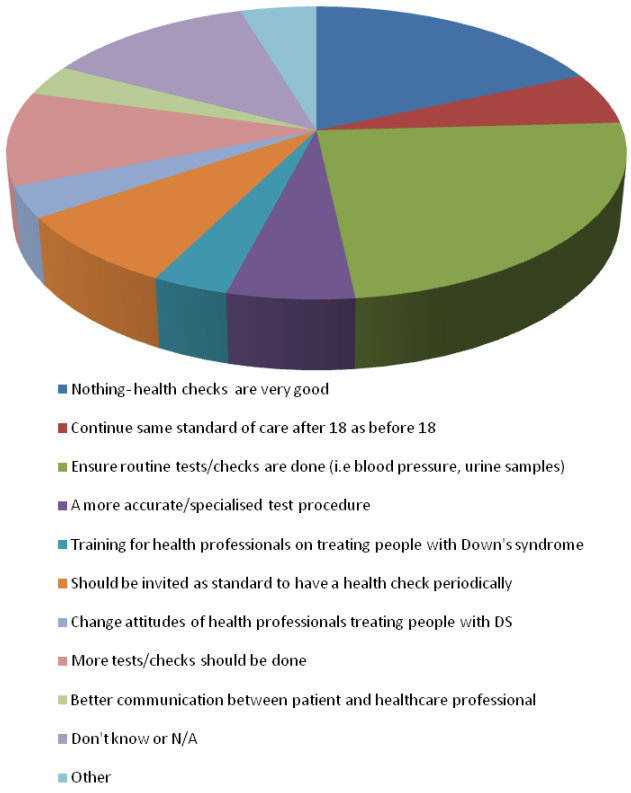


The time taken by any practitioner to perform the overall health check obviously affected the quality and quantity of checks. Whilst most individual checks were affected, significantly fewer of the shorter assessments recorded weight, asked about hearing tests, checked for diabetes, cholesterol, took a urine sample or referred to medical records.



Only 48 of 164 (less than 30%) people had **both** their blood taken and a urine sample checked at their last health check, both basic checks.

Respondents were asked to comment if they thought the health check could be improved in any way. A total of 87 comments were recorded, almost one in 5 (18%) identifying that no change was needed as the checks were very good. However, almost a quarter referred to the need for blood pressure and urine samples checks



Discussion

This study identified a patchy experience of annual health checks for adults with Down's syndrome, despite the availability of the recommended Cardiff protocol, with many basic checks not carried out.

It is encouraging to see that over 66% of those surveyed had received a health check within the last 12 months – up from the 48% identified by Henderson & Lynch in 2007. However, it should be considered that these figures are only an indication of the number of people eligible for the service, as the 216 respondents to this question cannot be said to be representative of the population of adults with Down's syndrome. Our members are advised through our website, journals and our internet forums of services available to people with Down's syndrome, and therefore this particular population could potentially be considered better informed than those who do not receive such information directly. Furthermore, as the majority of respondents were living with parents, this may have influenced the relatively high proportion of those who have had a health check within the past 12 months.

15% of the sample had never had a health check, and most of those responded that this was because they were not aware annual health checks were available. Furthermore, comments indicated that many thought it would be useful to be provided with more information about where and when to go for a health check, effectively to make them better known/available to those who can benefit.

Half of all health checks reviewed here lasted for between 15-30 minutes and almost a quarter less than 15 minutes - a concerning figure as it is unlikely that less than 15 minutes would be adequate time to cover all the aspects of the suggested Cardiff protocol. The recently published guidance document[12] for GP practices recommends that the health check should be carried out over 2 half-hour sessions.

Skin conditions, bowel conditions and memory were checked or tested for in less than half of health checks. It should be noted that individuals with Down's syndrome are susceptible to skin and bowel conditions and therefore such figures for those having these checks conducted is concerning.

More alarming perhaps is the very low number of people being checked for memory difficulties, although it is personality and behaviour changes that may initially indicate early stages in the development of Alzheimer's disease. People with Down's syndrome are particularly at risk of developing dementia, and early clues may signal the need for more regular screening. It is likely that these checks are not being considered by GPs, possibly due to poor awareness.

Carers have indicated through the comments that some people with Down's syndrome are not being given appropriate consideration or care:

"Not enough detail (tests etc). Too general- just a chat rather than specific health checks. Blood test done for diabetes-no results shared."

"It isn't a case of HAS D/S. you ARE D/S and it cannot be cured! Doctors say that everything is characteristic to D/S and we personally do not feel that enough attention is given to anything that concerns us. Its attitude that needs to be improved first."

[12] RCGP (2010) A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability.

The Adult Down's Syndrome Specific Annual Health Check list (RCGP 2010) contains, amongst others, the following checks that should be carried out, along with the survey findings (figures have been rounded):

Health Issue Checked	Survey	Health Issue Checked	Survey	Health Issue Checked	Survey
Weight	72%	Skin	48%	Urine	38%
Heart	64%	Hearing	44%	Diabetes	31%
Vision	62%	Bowel	39%	Memory	18%
Dental	59%	Blood tests 64% (of which 78% checked Thyroid levels)			

Obesity can also be a particular issue for people with Down's syndrome, and although weight was discussed in over 70% of health checks, comments indicate that more discussion/advice on weight management would be welcome.

Oral health/dental checks, hearing tests and vision or eye tests are all important as there are increased risks for problems in these areas.

Few responses indicated either a smear test (5), pelvic exam (1), breast exam (12) or testicular exam (13) had been conducted. The Cardiff protocol guidelines suggest that these tests should be carried out (dependent of gender) and so again, the figures are significantly lower than might be expected.

Individual comments related to ways in which the health checks may be improved referred to urine sample testing being carried out as standard. It is possible that gaining both urine samples and blood samples may meet with some anxiety or resistance, and this requires further investigation. Likewise, smear tests, breast examinations and testicular examinations may prove difficult.

Almost a quarter of respondents felt that communication could be improved, in particular comments were made in relation to the outcome of the checks, with suggestions that a written report would be helpful following the check. Ideally, this would be reflected in an Annual Health Action Plan.

Just less than one fifth of comments suggested that the health check was a good experience, and that nothing needed to change. More than a third of comments referred to the need for standard/basic checks to be carried out, and other comments referred to better training, communication and improved assessor attitude were required. Several people commented that the same level of care should be afforded to adults as was offered to children, and in particular, one respondent was requesting further information on his health check:

"If I, the patient could have a checklist to compare with the doctors, so I could make sure I will have a full checkup."

The checks that are recommended for the annual health check of people with Down's syndrome are very basic, but even these are not being comprehensively administered. Consideration should be given to issuing all adults with Down's syndrome with a personal health record booklet to maintain records of their ongoing checks and to ensure good communication of the results of each evaluation.

There are further checks that should be considered in order to ensure that people with Down's syndrome have the medical surveillance that is needed, for example a simple annual measure of activity levels, as decline in activity will often contribute to declining health. Any other checks that are undertaken (not necessarily part of the GP's remit) should be recorded as part of the health check and referred on where abnormalities are found. All adults with congenital heart defects should be under the care of an adult congenital heart disease service. Referral on for dental and chiropody care should be standard practice. Finally, differentiating depression from Alzheimer's in people with Down's syndrome is a specialist undertaking, but all adults should have a standardised annual assessment of mood such as the HAD score and be referred for evaluation if changes in this or memory function are noted.

Limitations of Survey

The survey requested information on health checks; it cannot be known whether all medical contacts reported were formal health checks or routine reviews for other purposes. Only 59% responded that the GP, community health team or practice nurse had invited them for review. Without patient initiated contacts or other checks that might reflect consultant reviews for specific chronic illness, it is possible that less than 50% would have recorded having had health checks.

The survey was not constructed to determine whether new health problems were identified during these health checks; however, from other survey data it would be anticipated that a significant number of individuals would have had previously undiagnosed thyroid disorders and cataracts identified if the health checks were being undertaken in a standardised fashion. Finally, the information gathered regarding the duration and nature of the health check is from the memories of the individuals and their carers. It cannot be known whether the information provided over or under estimates the quality of the actual health check. Nevertheless there are some areas such as blood investigations, duration of contact and intimate examination where the data are likely to be robust.

Conclusion

There is good uptake of annual health checks by our membership, but availability remains patchy, with some members not knowing of their existence. Health checks are not being conducted in line with the Cardiff protocol, and basic checks which are critical for the health of people with Down's syndrome are being missed. Sufficient time is not always being given to conducting a thorough health check. Results are often not shared.

Recommendations

A simple annual measure of activity levels should be conducted for all people with Down's syndrome, as a decline in activity will often contribute to declining health.

Differentiating depression from Alzheimer's in people with Down's syndrome is a specialist undertaking, but all adults should have a standardised annual assessment of mood such as the HAD score and be referred for evaluation if changes in this or memory function are noted.

All adults with congenital heart defects should be under the care of an adult congenital heart disease service.

Referral on for dental and chiropody care should be standard practice.

Such checks as recommended should be recorded as part of the health check and referred on where abnormalities are found.

Consideration should be given to issuing all adults with Down's syndrome with a personal health record booklet to maintain records of their ongoing checks and to ensure good communication of the results of each evaluation. An easy read format should be available.

Further research is needed to investigate the health check experiences of adults with Down's syndrome who do not live with their parents.