



# Down's Syndrome Association

A Registered Charity No. 1061474

## Health Checks for People with Down's Syndrome An Evaluation of the Health Book

### Summary

This [evaluation report](#) assesses the impact the Down's Syndrome Association's (DSA) Health Book has had upon improving the uptake and quality of annual health checks for people with Down's syndrome. In 2010 the DSA surveyed its members to find out about their experiences of adult annual health checks. It was found that health checks were not being conducted in line with official guidance and basic checks critical for people with Down's syndrome were being missed. Less than 30% of people had both a blood and urine sample taken and not everyone who had a health check was given sufficient time for the check to be carried out thoroughly. 22% of checks took less than 15 minutes even though GP guidelines say people with learning disabilities should have two half hour sessions.

As a consequence of these findings the DSA developed an adult Health Book to be used by people with Down syndrome at their annual health check and other GP appointments. The Health Book was launched in March 2014 and is currently sent to all members with Down's syndrome over the age of 14. Our research in this area also showed that there was no single reference point for up to date reliable information about adult health issues for people with Down's syndrome. The DSA therefore produced an area on its website specifically [for GPs](#) to be used in conjunction with the Health Book.

The evaluation assessed information gained from two surveys (one for people with Down's syndrome and their carers and one for health practitioners) carried out in March 2016. Additional material is from surveys, focus groups, email and Facebook posts carried out between 2012 and 2015

### Main Findings for People with Down's Syndrome and their Carers

- The Health Book made them aware of the importance of an annual health check and the necessary checks which needed to be carried out
- Helped their GP identify new clinical needs
- Provided a useful checklist which also served as a record of the visit and memory aid for future visits
- Helped them talk with confidence to their GP and nurse about their health and how they felt
- Kept all their health information in one place
- Carers wanted a smaller resource; this was not a finding for people with Down's syndrome.

*I wouldn't have had a health check if it wasn't suggested in the Health Book. Now my GP says I will have one next year.*

*I am filling this in for my son. By using the book the appointment follows in order a pattern which is easier than random questions*

*Easy to use and read. Helps start conversations and answers questions if too shy*

*We've been using it since its pilot it is an invaluable health tool. Our GP has learnt so much too.*

## Main Findings Health Practitioners

- The majority of respondents (45/48) had either no experience or no knowledge of the Health Book
- A majority expressed interest in the Book and would consider using it in their practice
- respondents thought the book would aid communication between patient, carer and practitioner,
- It was thought that the book could provide structure to the appointment and ensure all the relevant areas were covered
- A third of practice nurses wanted a pan disability document.

*Has highlighted some conditions more commonly related to DS that I was not aware of. As a practice we already offer annual health checks to all our patients with Learning Difficulties. The book mentions some areas not necessarily looked at in our current checks.*

*Patient able to think about various health matters in advance. She left the book in prior to the appointment so I had opportunity to read and see her concerns before we met which was helpful*

*It's helpful to have a structured format during the annual health review.*

## Recommendations

- To develop a series of focus groups involving people with Down's syndrome, family carers, professional carers and health professionals to ascertain their views on how the form and content of the Health Book should be further developed.
- Work with the RRGCP and RCN on how to integrate the use of the Health book into their practice without losing its relevance in supporting the empowerment of people with Down's syndrome in their healthcare.
- Meet with other health professionals and their representative bodies identified through the survey to see how the Health Book can be incorporated in a variety of health appointments.
- Investigate the feasibility of making the Health Book an on-line resource
- Develop a health awareness campaign specifically for people with Down's syndrome which involves the creation of Health Advocates.
- Develop a training programme for care providers to support them in encouraging the use of the Health Book.
- Provide an article for relevant health professional journals which summarises the purpose of the Health Book, the evaluation and its conclusions and recommendations.

Further information about the Health Book and health issues can be found on our website. There are specific areas for [people with Down's syndrome](#), [families and carers](#) and [professionals](#). A video made by adults with Down's syndrome about the Health Book is also available.