Title of the study: Eye care in people with Down's syndrome: understanding the provision and the impact of COVID-19

End of study report – summary of results

Thank you again for taking part in our online survey study from the Aston School of Optometry, Aston University. Thanks to the help of all people who took part in our study we have found the answer to our question, and we now know more about current eye care in people with Down’s syndrome and how the COVID-19 pandemic impacted on their eye care.

This is a report with the summary of the study and its findings for your information.

Why was this study conducted?
People with learning disabilities have been estimated to be 10 times more likely to have vision problems than other people. In addition, it has also been suggested that people with learning difficulties often miss out on a number of health services including eye care. There is limited information about the experiences and accessibility of eye care for people with Down’s syndrome and that is why we wanted to investigate this. We also wanted to understand the impact of the COVID-19 pandemic on the eye care of people with and without DS.

Differences between the eye care of people with and without Down’s syndrome will be important to suggest ways to improve access to eye care in people with Down’s syndrome.

How did we study differences in eye care between people with and without Down’s syndrome?

To investigate whether or not the experiences and accessibility of eye care are different between people with and without Down’s syndrome
we conducted an online survey that was completed by people with and without Down’s syndrome. The survey was completed anonymously and included questions about:

1. The participants current eye care (for example when was their last eye examination, if they wear any glasses...)
2. The participants eye care experiences (for example how easy was it to book an appointment, the duration of the last eye test, the communication during the eye test...)
3. Any differences in the participants eye care as a result of the pandemic (for example if their eye test was cancelled during the COVID-19 pandemic, if they experienced any eye problems during the COVID-19 pandemic).

![Survey Questions Example](image)

Figure 1. Examples of the survey questions for participants with Down’s syndrome.
What did we find?

1. **The participants current eye care**: In general, most people who participated in the study and completed the survey (with and without Down’s syndrome) have attended an eye test in the last 12 months, but we found that adults with Down’s syndrome tend to attend eye tests more frequently than adults without Down’s syndrome. In addition, while not many people without Down’s syndrome attend the hospital eye services for their eye care, many people with Down’s syndrome do.

2. **The participants eye care experiences**: In general, most participants (with and without Down’s syndrome) found booking an eye test appointment an easy process and did not report any problems with doing so. Interestingly, when participants were asked about the duration of their most recent eye test, people with Down’s syndrome reported to have a longer eye test duration than people without Down’s syndrome (less than 20 minutes vs 20-40 minutes).

   A number of participants who completed the online survey (63% of participants without DS and 70% of participants with DS) reported having been prescribed spectacles in their last eye examination. Many of these participants reported to have chosen their new spectacles in the same place where they had the eye test. Those who chose spectacles on the same day and practice (from both groups), in general reported to be happy with their glasses on collection.

3. **Eye care during the COVID-19 pandemic**: In general, half of the participants from both groups (with and without Down’s syndrome) confirmed that they waited longer to attend their regular eye examination during the COVID-19 pandemic (61.5% of participants without Down’s syndrome and 57.9% of participants with Down’s syndrome). In addition, a similar
proportion of participants from both groups reported to have experienced an eye problem during the COVID-19 pandemic (27.6% participants without Down’s syndrome and 33.33% of participants Down’s syndrome) and most of these participants were able to find help and support for their eye problem at the time.

So, where does this leave us now?
This study has improved the understanding we had so far about the eye care provision of people with Down’s syndrome. In conclusion, our results suggest that there are small differences between eye care in adults with and without Down’s syndrome and that the COVID-19 pandemic had a similar impact on people with and without Down’s syndrome in relation to their eye care.

Thanks again for your help.

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