



'CAREVIS: Covid vaccine information with Books Beyond Words'
Lay Summary
(easy-read, long)

We are sharing the findings of the research project called 'CAREVIS: Covid vaccine information with Books Beyond Words'. We thought you would be interested in what we did and what we found out.

What did we do?

We helped develop a picture book for people with learning disabilities that explains, in pictures, about having an injection (the 'vaccine') for the Coronavirus (COVID-19). There was already a lot of information about the vaccine but it involves a lot of words. Sometime information uses words and pictures together in an Easy Read format. For some people, words are very hard to follow, to understand and to remember.

Our project helped develop a story to provide information in pictures about having the Coronavirus injection. We worked with a Charity called 'Books Beyond Words'. We asked people with learning disabilities to help us develop the book. They looked out how easy the book was to understand.

We worked with people who have learning disabilities on the project to make sure they agreed with what we did. We worked with the Purple All Stars group at Hertfordshire Council to design the picture book, and Experts by Experience. These people helped us write the research questions that should be asked. We also brought our findings to The Purple All Stars group to see what they thought of what we had found.

How did we do this?

The picture book was shared widely to people with learning disabilities and people who care for them. We asked family and friends, paid carers, nurses, social workers and other professionals who provide them with support. The book was free from a website and could be printed. We shared the book through the NHS, the council, GP surgeries, Books Beyond Words, the Royal College of Nursing and other groups.

We then looked at how useful the picture book was. We did this in different ways:

- 1) We interviewed (asked questions) people with learning disabilities who used the picture book. We asked if it was helpful for understanding the vaccine.
- 2) We interviewed carers (family and friends), paid carers, nurses, and other professionals. We asked them if the picture book helped people to talk about the Coronavirus vaccine.
- 3) We looked at how many people with a learning disability have their Coronavirus vaccines around Hertfordshire.

4) We sent out a national questionnaire (a survey) on the internet. We wanted to see if people used the booklet, and how. We sent this to people providing support for people with learning disabilities (such as nurses, doctors, social workers).

We are now at the end of the project and these are the initial findings from the study.

What did we find?

Interviews

We interviewed 35 people in total. 11 people had a learning disability. 10 people were carers of someone with a learning disability. 14 people were health professionals who look after people with a learning disability.

Nearly everyone could understand what the book was about. People were shown having a vaccine so they could get close to friends and family again. They could also start living their lives more normally again. But, the reason for why people were having the vaccine was not clear to everyone. Some people did not like the horse picture and found it confusing. Some people said photos might be better. Not everyone liked the needle pictures or the pictures of the coronavirus. People said things like:

“I said to him ‘What is it?’ and he just said it’s injection, a tick and he didn’t know what the other thing was.” (said a carer)

A person with a learning disability said:

“It’s about some people who are...I they’re just in...it’s during lockdown and they’ve seen an advertisement of the vaccine and then they go to FaceTime with their friends or their family or a group member and then they decided to take the vaccine.”

Some people wanted Makaton or some easy read words on the pages too. But eight people did not want the book changed at all.

We know that a book can’t suit everyone. People understand things in different ways. It is clear that we can make some changes to the book to make it easier to understand.

Survey

55 people answered the internet survey. These people were:

- 2 people with a learning disability
- 42 health professionals
- 8 carers of people with a learning disability
- 3 ‘others’

Only half of the people had come across the booklet previously, and three quarters of the people had not used it before. People said it was helpful but there were things that could be improved in the pictures and the storyline. It was helpful for having conversations about the vaccine.

Vaccine data and planning

We looked at how many people have had the vaccine in the East of England and around Hertfordshire. By the end of December 2021:

- 67.1%, 20485 people had a booster (third injection) in East of England but around Hertfordshire it was higher: 72.34%, 4,519.

This is more than the national average of 66.1% of all adults in the UK had received all three vaccinations. Hertfordshire and local areas had one of the best vaccination rates in the UK.

We also talked to people (seven health professionals) who helped make sure the vaccine was given out to people with learning disabilities in Hertfordshire. They also talked to us about why some people had the vaccine and some didn't. They said it was important to talk to people lots, and help people make the right decisions for them. They also said it helped for hospitals, community groups, GPs (local doctors), and learning disability teams to all work together.

What is happening now?

We are telling different groups of people about the study and what we have found out. We have spoken to people who work at 'Books Beyond Words'. We told them what people would like changed in the booklet to make it easier to understand. They are now making those changes. We have written an internet 'blog'. This tells health professionals and researchers about how the Purple All Stars group helped develop the study. We are also writing an academic paper (like a science magazine) for researchers and people who work with learning disabilities. This will tell them how using resources like this one can help people with a learning disability talk about their health.

Thank you for your interest in the study. If you have any questions please contact Helena Wythe, researcher at h.f.wythe@herts.ac.uk or Natalie Pattison at n.pattison@herts.ac.uk.