

The Healthy Woman's Project

Women with learning disabilities having a smear test

Merinda Levi and Bev Kimpton worked with women with learning disabilities on a project called the Healthy Woman's Project.

We did research to find out what women with learning disabilities and carers think about having a smear test. Research means finding out.



We talked and listened to what women said about having a smear test. We listened to what carers said about supporting a woman having a smear test.

This is what we found out about women with learning disabilities:

- Some women felt ok about having a smear test.
- There are things that make it hard for women with learning disabilities to have a smear test. Some women did not understand the letter from the doctor. Some women did not get told enough about the smear test. This made it difficult to decide to have the test.
- Women need to be told more about having a smear test in a way that they can understand.
- There are things that doctors and nurses can do to make having a smear test better for women with learning disabilities.



Good things about having a smear test

Women said that it is important to have time to get ready and used to the idea of having a smear test. Some women got ready for the test by talking and listening to their carer. Some women visited the doctor or nurse before having the smear test to ask questions and talk about any worries.

Most women liked a woman doctor or nurse to do their smear test. Women found having a smear test embarrassing but it was better if the doctor or nurse was a woman.

Most women said it was important to know the doctor or nurse taking the smear test. It helped women feel more relaxed. It helped when the doctor or nurse explained what they were doing down below.

Problems for women with learning disabilities having a smear test

Most women were invited for a smear test by getting a letter from their doctor. Some women said that the letter was not written clearly or plainly. Some women said that the letter was not always easy to understand if they had difficulties with reading.

Some women did not get a leaflet with their letter for a smear test. Family, friends and carers told a lot of women about having a smear test.

Some women did not know that they could ask for a woman doctor or nurse to do their smear test.

Carers and doctors decided for some women about whether they should have a smear test.



Women need good information about going for a smear test

Women said it would be good to have lots of different sorts of information on having a smear test. This included leaflets, a CD Rom, DVD or video.

Women wanted to know:

- What happens when you go for a smear test?
- Why do you need to have a smear test?
- Do you need a smear test if you've never had sex?



Carers wanted more information about having a smear test. This is because they often helped women to decide about going for a smear test.

How doctors and nurses can make having a smear test better

It is important for the doctor and nurse to take the time to listen and talk to the woman.

It is important that the doctor or nurse does not decide whether the woman has ever had sex. The doctor or nurse needs to talk and listen to the woman herself.

Having a longer appointment can help women get ready for a smear test. Sometimes it helps women to have an appointment to talk about the test before they have it.

It is important for doctors and nurses to help the woman relax. Women said that bringing in music tapes, or holding their hand during the smear test could be helpful.



What happens next?

The Healthy Woman's project is:

- Making different sorts of information on having a smear test. There will be leaflets, CD Rom and Audio CDs available.
- Making an information leaflet about helping women to decide if they want to have a smear test. This will tell you about why women need a smear test. It will tell you if you need one if you have never had sex.
- Making a plan on working out the best way for doctors and nurses to do a smear test.
- Teaching doctors and nurses about the best way to do smear tests.

About the project

Merinda Levi and Bev Kimpton work for NHS Lothian. We are working on a three year project called the Healthy Woman's project. We have written a report called **Women with learning disabilities and carers experiences and views of cervical screening**. You can download this at:

<http://www.scan.scot.nhs.uk> by following the links SCAN (in top menu) – Projects – The Healthy Woman's Project – Project documents – Research.

If you would like a copy of the report, or want to know more about the project you can contact:

Merinda Levi on:  **0131 667 2897**

You can also listen to this on the tape provided.

You can photocopy this information sheet, or pass it on to any one you know.

Illustrations: Paul Mudie @ FAiR

Thanks to Mary Siggs, Speech + Language Therapist for helping us with this information sheet.