

Primary HPV Screening for People with Down Syndrome

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Background

People with Down syndrome (DS) are less likely to receive all preventative screenings, including cervical cancer. A retrospective cohort study of women with DS identified **only 26% had ever screened for cervical cancer**. Barriers to screening include **difficulty with speculum exams** and the **perceptions and historical context of sexual health** care for people with DS.

HPV self-swab testing was approved by the FDA in October 2025 under supervision of a healthcare provider.

Objectives

- Develop **multi-modal approach** to prepare people with DS for HPV self-swab
- Implement HPV self-swab screening pilot to **expand access** to preventative care for people with DS and increase screening rates in primary care

Methods

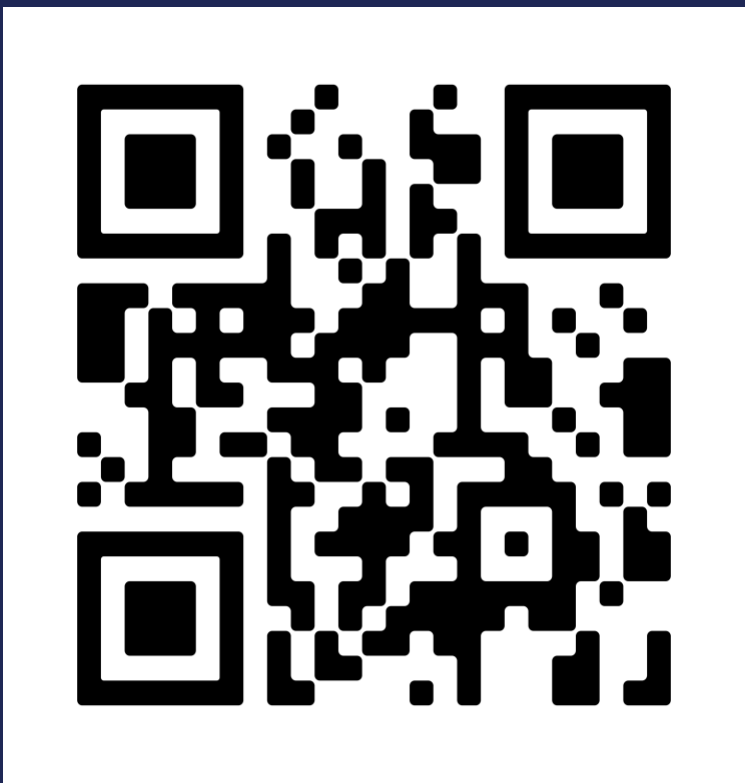
- A **social story, walkthrough video, and information sheet** were developed and included use of a **vagina model** to demonstrate anatomy and each step of the self-swab
- A number of teaching methods were utilized in clinic to support patients including **teach-back and tell-show-do** method to **ensure understanding and informed consent**



This is how I will test for HPV.	I will be with my doctor or nurse at my appointment.
If someone came with me to my appointment, I can choose if they stay or wait outside.	I will wash my hands.

I will open the HPV test kit. If I need help, my doctor or nurse can help me.	I will hold the swab at the red mark.
I will get into a comfortable position. With my doctor or nurse, we can figure out the best position for my body.	I can use one hand to spread my labia apart so my swab can go inside my vagina.

"I did it!" - Person with DS
"I'm really proud that this empowers our patients to be involved in their healthcare"
- Parent & nurse



Full Social Story

@ResearchAtJeff

Percentage of U.S. Women up to date on Cervical Cancer Screening

All U.S. Women, 75.80%

U.S. Women with DS, 23%

Results & Discussion

- In the pilot launch Jan 30 – April 30, **22 patients completed self-swab screenings** in the primary care office
 - 30% of swabs completed by people with DS
- Preparation materials have been shared with **OBGYN providers, community partners, and other researchers across the U.S.** interested in expanding gynecological care access for people with IDD
- An **educational module** was developed alongside patient-facing materials to **educate providers on implementing self-swab screening** for people with DS and other IDD in their practice

Future Directions

- Home self-swab testing approval in ongoing to **expand access outside of the provider's office** through independent or caregiver supported testing at home
- Increasing clinic-wide screening rates
- Successful self-swabs to **support confidence** on other topics in sexual health for people with DS

References



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