

LIFE AND WELL-BEING SCIENCE

CUPID: Improving cancer prevention in intellectually disabled population



There is currently a very poor understanding of cancer prevention among people with intellectual disabilities. Among the intellectually disabled population, many cancer diagnoses are symptomatic presentations following behavioural distress or physical changes.

Cancer deaths among this population occur up to 20 years earlier than the general population. Therefore, factors influencing unequal health status and premature death among people with intellectual disabilities warrant further investigation.

Article 25 of the United Nations Convention on the Rights of People with Disabilities acknowledges their right to healthcare. The Council of Europe Disability Strategy 2017-2023 recognises health systems' failure to engage with and include people with disabilities.

Many external and internal factors influence healthcare

engagement among this population, resulting in long-term health consequences.

External factors include diagnostic overshadowing, paternalism and cancer screening delays. Challenges with communication, cognitive ability and decision-making capacity by the individual with intellectual disability influence healthcare engagement.

This is even more particularly sensitive when it comes to gynaecological check-ups and screening for cervical cancer. While the introduction of cervical cancer screening and human papillomavirus (HPV) vaccination programmes are making a measurable impact to reduce cervical cancer prevalence and mortality in several European countries, there are still discrepancies in service provision and uptake in different countries, with women with intellectual disabilities being at greater risk of being impacted.

There are multiple obstacles to the uptake of cervical cancer screening among women in general but even more so in women with intellectual disabilities. Barriers to cervical cancer screening can be due to geographical, psychosocial or economic rea-



A CUPID Copenhagen meeting in March 2024.

sions, together with poor understanding by the caregiver/s and/or the patient herself or misconceptions from healthcare professionals.

Improved knowledge to caregivers, healthcare professionals and persons with intellectual disability will lead to better uptake of cervical cancer screening and HPV vaccination.

The implementation of enablers to overcome the obstacles faced by women, especially those with intellectual disability, is a public health priority which has the potential to lead to less morbidity and mortality related to cervical cancer. It is timely to develop collaborative links with the EU research and service provider communities to reach a consensus on addressing these challenges in cancer prevention.

The COST (European Cooperation in Science and Technology) Action initiative CUPID (Cancer Understanding Prevention in Intellectual Disabilities) comprises a multidisciplinary group hailing from over 25 countries. It is establishing active working partnerships with academics, researchers, non-governmental organisations, carers, people with intellectual disabilities and policymakers.

CUPID is striving to establish a research agenda and exchange information regarding cancer prevention in the intellectually disabled population.

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MYTH DEBUNKED

Women with intellectual disabilities do not need regular gynaecological check-ups

JEAN CALLEJA AGIUS

It is wrong to assume that a person with intellectual disability is not at risk of getting cervical cancer.

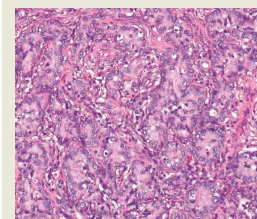
A person with intellectual disability can still be sexually active. Unfortunately, they are at increased risk of being sexually abused.

Even if a person is not sexually active, there is still the risk of getting cervical carcinoma, as HPV infection is not the only cause.

Every community needs to work on enablers in HPV vaccination coupled with cervical screening, in particular in women with intellectual disability.

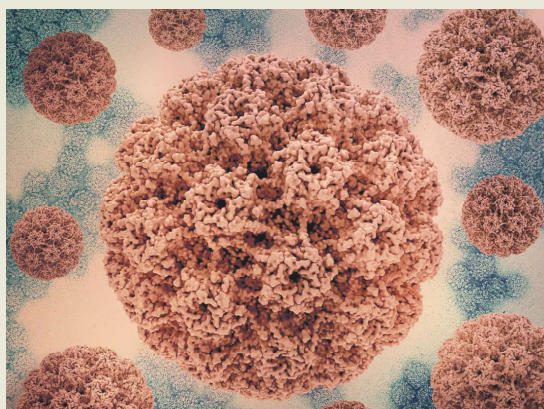
First and foremost, caregivers need to be better informed on the importance of HPV vaccination for both genders and, in the case of females, cervical cancer screening.

The accessibility to screening for women with intellectual disability needs to be facilitated by sensitising healthcare professionals. The national screening programme has to be adapted accordingly to ensure equity.



Adenocarcinoma of the cervix, hematoxylin and eosin staining, magnification x200. PHOTO: POLINA DAMYANOVA

PHOTO OF THE WEEK



Human papillomavirus (HPV) infection causes cervical cancer. Persistent infection with high-risk HPV types, such as HPV 16 and HPV 18, cause up to 80% of cervical cancers worldwide. These infections can be preventable through vaccination to all genders, ideally before the start of sexual activity.

Pap smear testing remains important, even if a person is not sexually active, because cervical cancer can still occur. By undergoing a Pap smear test, HPV infection or cervical cancer can be detected at an early stage and managed before it becomes lethal.

A Pap smear involves using a small brush to collect cells from the cervix and surrounding area gently. These cells are then examined under a microscope to detect cervical cancer or abnormal cell changes that could lead to cancer. The Pap smear test can also help identify other conditions, such as infections or inflammation. PHOTO: [HTTPS://WWW.FLICKR.COM/PHOTOS/NIAID/53511363080](https://www.flickr.com/photos/NIAID/53511363080)

DID YOU KNOW?

- More than 80% of cases of cancer of the neck of the womb (cervical cancer) are caused by a virus called human papillomavirus (HPV), and there are effective vaccines against HPV, which have been proven to reduce cervical cancer.
- Cervical cancer can occur even in persons who are not sexually active.
- Cervical cancer can be prevented through regular Pap smears.
- The proportion of women with intellectual disability who are not screened for cervical cancer is nearly twice what it is in the women without intellectual disability, even in case of prior pregnancy.

For more trivia, see: www.um.edu.mt/think.

SOUND BITES

- Cervical cancer screening programmes are effective in reducing morbidity and mortality. In Europe, significant progress has been made concerning screening strategies, namely the choice of screening test, its frequency, the age to start and stop the screening, and the introduction of HPV vaccination. However, there is variation among countries in delivering screening programmes, due to organisational, economic or cultural reasons.

[HTTPS://WWW.SCIENCEDIRECT.COM/SCIENCE/ARTICLE/ABS/PII/S0301211523006929](https://www.sciencedirect.com/science/article/abs/pii/S0301211523006929)

- A systematic review was carried out to understand better the barriers faced by people with intellectual disability with regard to cervical screening. These include fear and anxiety, misassumptions preventing screening participation, lack of education and accessible information, and challenges around patient-provider communication in obtaining informed consent. Policy and practice efforts, which are co-produced and community-led, must address these barriers.

[HTTPS://PMC.NCBI.NLM.NIH.GOV/ARTICLES/PMC11310793/PDF/FPSYT-15-1379497.PDF](https://pmc.ncbi.nlm.nih.gov/articles/PMC11310793/pdf/fpsyt-15-1379497.pdf)

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