

Recommendations on cancer screening and treatment

European Disability Forum - Position Paper

February 2022

**Recommendations for a Europe’s Beating Cancer Plan inclusive of persons with disablities**

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# Introduction

### The European Disability Forum

The European Disability Forum (EDF) is an umbrella organisation of persons with disabilities that promotes the rights of over 100 million persons with disabilities in the European Union. We are a unique platform which brings together representative organisations of persons with disabilities from across Europe. We are run by persons with disabilities and their families, and as such represent a strong, united voice of persons with disabilities in Europe.

### Purpose of the position paper

This document was prepared to contribute to the consultation on the [Cancer Screening Recommendation](https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13155-Cancer-Screening-Recommendation-update_en) and to feed into the implementation of the Europe’s Beating Cancer Plan. It provides recommendations to the European Union on the development of measures on cancer screening and treatment inclusive of the rights and needs of persons with disabilities.

### Acknowledgements

This position paper was prepared thanks to the contribution of EDF Board and members.

## Executive Summary

Recent studies show that persons with disabilities are at a higher risk to develop cancer, to receive a late diagnostic and treatment, and to die from cancer, comparing to persons without disabilities.

The European Disability Forum welcomes the Europe’s Beating Cancer Plan and increased inclusion of persons with disabilities in EU health policies. Unfortunately, the mention of persons with disabilities in EU policies does not translate into concrete actions to ensure their equal access to cancer screening and care, and to address the pre-existing inequalities and factors putting them at higher risk of cancer or inadequate care.

The European Disability Forum calls on the EU to:

* **Collect disaggregated data and statistics** on cancer screening and care, including by disability, notably through the Cancer Inequalities Registry.
* **Adopt measures to promote and support disability-inclusive health services, including cancer prevention, screening and care**.
  + The new cancer screening scheme must require the development of services that are available, accessible, affordable, relevant, appropriate, and acceptable to service users with disabilities.
  + The Council Recommendation on Cancer Screening must be extended beyond breast, colorectal and cervical cancer to include additional cancers, and include provisions on accessibility of the healthcare services, in particular of screening equipment, for persons with disabilities.
  + EU fundings should support the development of disability inclusive cancer services in Member States.
  + The European Commission should consider the development of accessibility standards for screening equipment such as that used for mammograms, and treatment processes such as radiotherapy.
* **Introduce accessible public health campaigns and communication on cancer measures.** 
  + Communication on cancer prevention, screening and treatment must include persons with disabilities and be disseminated in a variety of accessible formats, including sign language, Braille and Easy to Read.
  + Information on cancer prevention and screening shall be available to all persons with disabilities, including those in institutions, in psychiatric hospitals and in prisons.
* **Promote and support the training of healthcare professionals and people working with persons with disabilities**, including people in institutions and other closed settings such as psychiatric hospitals and prisons.
* **Consult representative organisations of persons with disabilities** in the development, implementation and monitoring of cancer prevention and care policies.

# EU’s obligations to ensure the right to health of persons with disabilities

The EU and all its Member States have committed to protect and promote the rights of persons with disabilities by ratifying the United Nations Convention on the Rights of Persons with Disabilities ([CRPD](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)).

**Article 25 of the CRPD** obliges the EU and its Member States to ensure that all persons with disabilities “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. They must take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

According to the Convention, this means that they must:

* Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons
* Provide those health services needed by persons with disabilities specifically because of their disabilities
* Provide these health services as close as possible to people’s own communities, including in rural areas
* Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent
* Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner
* Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability

The right to healthcare and rights of persons with disabilities are also enshrined in **Articles 21, 26 and 35[[1]](#footnote-1) of the Charter of Fundamental Rights of the EU**.

In 2015 the UN Committee on the Rights of Persons with Disabilities adopted specific recommendations to be followed by the EU in its [**Concluding observations on the initial report of the EU**](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FEU%2FCO%2F1). In relation to the right to health, the Committee recommended that the EU “explicitly prohibit discrimination on the grounds of disability in the field of health care and take measures to ensure access to quality health care for all persons with all types of disabilities”.

The **[EU Strategy on the Rights of Persons with Disabilities 2021-2030](https://ec.europa.eu/social/main.jsp?catId=1484)** recognises that people with disabilities have the right to high-quality healthcare, including health related rehabilitation and prevention. It also stated that “further action is needed as persons with disabilities report unmet needs for medical examination four times more often than persons without disabilities”. In relation to cancer, the Commission plans to “**address specific inequalities for persons with disabilities in accessing cancer prevention, early detection and care** through specific actions identified through the inequalities registry in the Europe’s beating cancer plan”.[[2]](#footnote-2)

# Cancer and persons with disabilities in the EU

## Background information

Europe comprises only one eighth of the total world population, but it has around one quarter of the global total of cancer cases, with some 3.7 million new patients per year.[[3]](#footnote-3) Cancer represents the second most important cause of death and morbidity in Europe[[4]](#footnote-4) and can also lead to disability.[[5]](#footnote-5)

While persons with disabilities face barriers and discrimination in accessing healthcare, data and statistics on cancer patients with pre-existing disabilities are not widely collected across the EU. It is even more concerning considering that some factors suggest that preexisting disability and cancer could be associated.[[6]](#footnote-6)

Persons with disabilities are not only at higher risk to develop cancer, but also to receive a late diagnostic and treatment, leading to a higher mortality rate than people without disabilities.[[7]](#footnote-7) For example, persons with disabilities in **Sweden** are twice more at risk of dying from cancer comparing to other cancer patients. Women with psychosocial disabilities who have breast cancer are in general diagnosed and treated once their reach a later stage of cancer, comparing to other women with breast cancer.[[8]](#footnote-8)

## Barriers faced by persons with disabilities in accessing cancer screening and treatment

Studies indicate that the lower participation of persons with disabilities in cancer screening and treatment is due to a number of **physical, institutional, financial, and attitudinal barriers**.[[9]](#footnote-9) Such barriers include, among other factors, inaccessible healthcare facilities and/or equipment, lack of social support, financial constraints, past negative experiences with healthcare professionals, discomfort, inadequate or inaccessible information, and lack or inaccessibility of transport.

For example, data collected in **Romania** show that women with physical impairments could not access tests for breast cancer and cervical cancer as examination tables cannot be adjusted to the correct height, and the equipment for mammography cannot be used by those who cannot stand.[[10]](#footnote-10)

The inadequate training of healthcare professional is another barrier leading to late diagnostic and inappropriate treatment. A 2020 study indicates that doctors may be reluctant to refer patients with disabilities, possibly due to diagnostic overshadowing and do not seek ways to adapt processes to make them disability-inclusive, which reflects the general lack of disability inclusiveness in the provision of healthcare services.[[11]](#footnote-11)

## EU measures on beating cancer

### 2003 Cancer Screening Recommendation

In 2003 the EU adopted guidelines on cancer screening through [Council Recommendation](https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:327:0034:0038:EN:PDF). Cancer screening is essential to ensure early detection and treatment, and reduce cancer mortality. The Recommendation focuses on implementation of screening programmes, screening data, monitoring, training and compliance.

Unfortunately, the text is vague and does not explain how Member States can ensure greater access to marginalised people and those at higher risk of cancer, including persons with disabilities. For example, there is no requirement on accessibility of the services and no definition of what “high quality cancer screening” means.

Since the document was adopted almost two decades ago, it does not take into account the obligations of the EU and its Member States under the CRPD and the rapid digitalisation of European health systems.

### Europe’s Beating Cancer Plan

In February 2021, the European Commission launched a [Europe’s Beating Cancer Plan](https://ec.europa.eu/commission/presscorner/detail/en/IP_21_342). This plan aims to address cancer related inequalities between and within Member States with actions to support, coordinate and complement Member States' efforts. It is structured under 4 keys areas (prevention, early detection, diagnosis and treatment, and improved quality of life) with 10 flagship initiatives and multiple supporting actions. Persons with disabilities and the EU Strategy on the rights of persons with disabilities are included in the [text of the Plan](https://ec.europa.eu/health/system/files/2021-02/eu_cancer-plan_en_0.pdf).[[12]](#footnote-12) However, accessibility of cancer services for persons with disabilities is not specifically mentioned.

In February 2022, the Commission launched the first stage of a [Cancer Inequalities Registry](https://cancer-inequalities.jrc.ec.europa.eu/). The registry provide data on cancer prevention and care to identify trends and inequalities between Member States and regions. Unfortunately, pre-existing disability was not included in the “inequality dimension indicators”.[[13]](#footnote-13) This is a missed opportunity to adequately evaluate and address the inequalities faced by persons with disabilities.

Under the Plan, the Commission is making a proposal to update the 2003 Council Recommendation on cancer screening to ensure it reflects the latest available scientific evidence. The Recommendation may extend the targeted cancer screening beyond breast, colorectal and cervical cancer, including additional cancers, such as prostate, lung and gastric cancer.

# Conclusions and recommendations

The European Disability Forum welcomes the Europe’s Beating Cancer Plan and increased inclusion of persons with disabilities in EU health policies. Unfortunately, the mention of persons with disabilities in EU policies does not translate into concrete actions to ensure their equal access to cancer screening and care, and to address the pre-existing inequalities and factors putting them at higher risk of cancer and inadequate care.

The European Disability Forum calls on the EU to:

* **Collect disaggregated data and statistics** on cancer screening and care, including by disability, notably through the Cancer Inequalities Registry.
* **Adopt measures to promote and support disability-inclusive health services, including cancer screening and care**.
  + The new cancer screening scheme must require the development of services that are available, accessible, affordable, relevant, appropriate, and acceptable to service users with disabilities.
  + The Council Recommendation on Cancer Screening must be extended beyond breast, colorectal and cervical cancer to include additional cancers, and include provisions on accessibility of the healthcare services, in particular of screening equipment, for persons with disabilities.
  + EU fundings should support the development of disability inclusive cancer services in Member States.
  + The European Commission should consider the development of accessibility standards for screening equipment such as that used for mammograms, and treatment processes such as radiotherapy.[[14]](#footnote-14)
* **Introduce accessible public health campaigns and communication on cancer measures.** 
  + Communication on cancer prevention, screening and treatment must include persons with disabilities and be disseminated in a variety of accessible formats, including sign language, Braille and Easy to Read.
  + Information on cancer prevention and screening shall be available to all persons with disabilities, including those in institutions, in psychiatric hospitals and in prisons.
* **Promote and support the training of healthcare professionals and people working with persons with disabilities**, including people in institutions and other closed settings such as psychiatric hospitals and prisons.
* **Consult representative organisations of persons with disabilities** in the development, implementation and monitoring of cancer prevention and care policies.

# Document credits

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1. Article 35 of the Charter: “Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all the Union's policies and activities.” [↑](#footnote-ref-1)
2. [EU Strategy on the Rights of Persons with Disabilities 2021-2030](https://ec.europa.eu/social/main.jsp?catId=1484), page 22. [↑](#footnote-ref-2)
3. WHO Europe, [webpage on cancer data and statistics](https://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/data-and-statistics#:~:text=Europe%20comprises%20only%20one%20eighth,million%20new%20patients%20per%20year) (accessed in February 2022) [↑](#footnote-ref-3)
4. Ibid. [↑](#footnote-ref-4)
5. Cancer is classified as a disability in many countries. For example, [in Belgium the Brussels Labour Tribunal recognised cancer as a disability in 2018](https://www.unia.be/en/articles/court-describes-effects-of-cancer-as-disability-for-the-first-time). [↑](#footnote-ref-5)
6. [Cross-Sectional Analysis of the Associations Between Four Common Cancers and Disability](https://jnccn.org/view/journals/jnccn/18/8/article-p1031.xml) (2020) [↑](#footnote-ref-6)
7. Ibid. [↑](#footnote-ref-7)
8. Report from the Swedish National Board of Health and Welfare “[Arbetssätt för jämlik vård: Redovisning av metodutvecklingsprojekt på Socialstyrelsen](https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-2-6636.pdf?fbclid=IwAR1uJnFYH_OSjdoX-RBFCKx4JsSYM9cmEVwUng-ehS-cnf7WET-qlJVc4Io)” (2020) [↑](#footnote-ref-8)
9. [Cancer Disparities for People With Disabilities: Bridging the Gap](https://jnccn.org/view/journals/jnccn/18/8/article-p1144.xml) (2020) [↑](#footnote-ref-9)
10. ANED, [Country report on accessibility of healthcare - Romania](https://www.disability-europe.net/downloads/230-aned-2014-task-4-ro-final) (2014) [↑](#footnote-ref-10)
11. [Cancer Disparities for People With Disabilities: Bridging the Gap](https://jnccn.org/view/journals/jnccn/18/8/article-p1144.xml) (2020) [↑](#footnote-ref-11)
12. The flagship on reducing cancer inequalities across the EU is particularly important for persons with disabilities. [↑](#footnote-ref-12)
13. The indicators are “inequalities between countries”, “inequalities by sex”, “education inequalities”, “income inequalities” and “urbanisation inequalities”. [↑](#footnote-ref-13)
14. The U.S. Access Board issued standards for Accessible Medical Diagnostic Equipment in 2007. These standards provide design criteria for examination tables and chairs (including those used for dental or optical exams and procedures), weight scales, radiological equipment, mammography equipment, and other equipment used for diagnostic purposes by health professionals. More information: <https://acl.gov/ada/accessibility-standards-medical-diagnostic-equipment> [↑](#footnote-ref-14)