

# **Colorectal Cancer Prevention in Austria: Including People with Intellectual Developmental Disabilities**

Project application for submission to the  
Österreichische Gesellschaft für Hämatologie & Medizinische Onkologie (OeGHO;  
Austrian Society for Hematology & Medical Oncology)

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## **Abstract**

### **Wider research context**

People with intellectual developmental disabilities (IDD) experience major health inequalities and face multiple barriers and obstacles regarding their health and health care. Colorectal cancer (CRC) is among the cancers with the highest prevalence, incidence, and mortality rate. It has the third highest prevalence of all cancers in Austria and is the third leading cause of cancer death worldwide. In Austria, there are recent efforts for planning and implementing a national organised CRC screening, to increase early diagnosis and lower mortality rates. Such screening programmes have been proven to be very effective. However, international data suggest, that people with IDD are far less likely to use early screening services, thus they often present with advanced cancer at diagnosis and a concurrently poor prognosis. However, to date, no research efforts have investigated specific barriers and facilitators regarding CRC screening for people with IDD. In Austria, an organised CRC screening programme is about to be developed. This provides the unique opportunity to include people with IDD in the planning and potential implementation of an important health prevention strategy, contributing to equal and inclusive health care options for people with disabilities as demanded by the *Convention on the Rights of Persons with Disabilities by the United Nations* (UN-CRPD), and following a patient & public involvement strategy.

### **Objectives**

The primary goal of the present project is to determine the needs of people with IDD to effectively participate and be included in an organised CRC screening programme and to explore facilitators and barriers to participation from the perspectives of people with IDD and their caregivers.

### **Methods**

A mixed methods approach will be applied in three steps: (1) To explore the needs, experiences, and opinions of people with IDD regarding CRC screening, we will conduct focus groups using the nominal group technique. (2) Primary caregivers will be surveyed upon their experiences and opinions on barriers and facilitators and support needs for CRC screening, as well as on their general awareness of CRC using semi-structured interviews. (3) Results will be disseminated to research, policy, and practice, including an easy-language report for people with IDD.

### **Level of originality**

International data suggest that people with IDD are not reached by organised CRC screening programmes. However, no data on potential barriers, facilitators and needs from the perspective of people with IDD and their caregivers currently exist. This project is the first to investigate factors contributing to a CRC screening programme that includes people with disabilities. Our data will provide a basis for the equal inclusion of people with IDD in an evolving cancer screening programme in Austria, thus contributing to an evidence-based improved cancer diagnosis in people with IDD and lower mortality rates in an underserved population group.

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## **1. Theoretical background and state of the art**

Colorectal cancer (CRC) is among the cancers with the highest prevalence, incidence, and mortality rate. It has the third highest prevalence of all cancers in Austria.<sup>1</sup> In 2020, CRC had the third highest incidence worldwide, and there were approximately 830,000 deaths caused by CRC, making it the third leading cause of cancer death worldwide.<sup>2</sup>

### **1.1. Colorectal cancer screening programmes**

In the European Union, organised screening programmes for cancer prevention and early diagnosis are recommended for three cancer entities: breast cancer, cervical cancer and CRC.<sup>3</sup> In Austria, there are screening programmes for breast cancer and cervical cancer, but currently there is no nationwide programme for CRC screening. Pilot projects have been established in two states, namely Burgenland and Vorarlberg, and there are efforts and recommendations to establish a nationwide CRC screening in Austria. In 2021, the National Screening Committee (NSC) for Cancer was established as an advisory body to the Federal Minister of Social Affairs, Health, Care and Consumer Protection. The NSC published recommendations for the introduction of an organised CRC programme in Austria.<sup>4</sup>

A study in 16 European countries indicated that CRC screening programmes were very effective in reducing cancer incidence in the medium and long term.<sup>5</sup> However, screening programmes have to be inclusive and accessible for all population groups to assure equal health care opportunities. In many respects, people with disabilities are an underserved population group in terms of health care and health prevention, as their respective needs are hardly taken into account when population-based programmes or policies are developed. In particular, people with intellectual developmental disabilities (IDD) are prone to health problems but are often not included in health promotion, prevention and care strategies.<sup>6</sup>

### **1.2. Intellectual developmental disabilities (IDD)**

Intellectual developmental disabilities (IDD) are 'a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills'.<sup>7(p177)</sup> IDD comprises Intellectual

Disability<sup>8</sup> and is also known as *Intellectual Developmental Disorder* in the fifth edition of the DSM-5,<sup>9</sup> and as *Disorders of Intellectual Development* in the 11<sup>th</sup> revision of the ICD-11,<sup>10</sup> with Code 6A00 (Code F7 in ICD-10). Throughout this application, the term intellectual developmental disabilities (IDD) will be used.

Compared to people without IDD, people with IDD have, on average, poorer access to health services, poorer overall health, more health problems, and shorter life expectancy.<sup>11,12</sup> However, the life expectancy of people with IDD has been rising in the last decades, which also leads to a higher risk of cancer in this population.<sup>13,14</sup> People with IDD often present with advanced cancer at diagnosis and a concurrently poor prognosis, which is mostly attributable to delayed diagnosis.<sup>15–17</sup> Therefore, attending to regular cancer screening programmes would be an important preventive action to reduce cancer mortality in people with IDD and tackle health inequalities. To achieve this and provide equity in cancer prevention and cancer care, equal access to screening programmes has to be ensured.

### **1.3. Colorectal cancer and cancer screening for people with IDD**

Risk factors for CRC, such as overweight, obesity, an unhealthy diet, and lack of exercise, are generally more frequent in people with IDD than in people without IDD.<sup>6,18</sup> Additionally, the clinical presentation of CRC in people with IDD can be masked (e.g. by challenging behaviour and communication problems) and is therefore often diagnosed late in the course of the disease, making treatment difficult and less successful.<sup>18,19</sup> A study on mortality in people with IDD found CRC as one of the potentially avoidable causes of death in this population.<sup>20</sup> International data from countries where an organised CRC screening programme is implemented show that CRC screening is generally underused in people with IDD.<sup>18,21</sup> The odds for people with IDD being up-to-date with colorectal tests were found to be 46% lower than for people without IDD.<sup>21</sup> These are clear indications that screening programmes are not inclusive of people with IDD if their needs and conditions are not specifically considered in the design of the programme and access to screening. However, to date, there is no research on specific barriers and facilitators for CRC screening in people with IDD.

#### **1.4. A legal perspective: the UN-CRPD and the Austrian “NAP Behinderung”**

The current inequalities in cancer care, as well as cancer prevention activities for people with IDD stand in direct conflict with the *Convention on the Rights of Persons with Disabilities* (UN-CRPD).<sup>22</sup> Articles 25 and 26 of the UN-CRPD require state parties to ensure that people with disabilities can receive the “*highest attainable standard of health without discrimination on the basis of disability.*”<sup>22</sup> Austria ratified the UN-CRPD in 2008. For the European Union, the convention entered into force in 2011, with all member states having signed the convention. Considering the existing disparities in health care for people with IDD, the present project is directly in accordance with the requirements of the UN-CRPD.

In 2022, the Austrian government adopted the "National Disability Action Plan 2022-2030 (Nationaler Aktionsplan Behinderung 2022-2030),<sup>23</sup> to realise the demands of the UN-CRPD in Austria; included are the conception and realization of comprehensive and barrier-free health care and health prevention for people with disabilities. Furthermore, the present project is in line with one of the sustainable development goals of the UN, i.e. “to ensure healthy lives and promote wellbeing”,<sup>24</sup> and with one of the national health goals defined by the Austrian government, i.e. “to assure equal opportunities to stay healthy for all people”.<sup>25</sup>

#### **1.5. Inclusion of people with IDD in CRC screening**

Existing research activities on the inclusion of people with IDD in organised cancer screening programmes target only breast cancer and cervical cancer screening, but no previous study investigated barriers, facilitators, and support needs for the inclusion of people with IDD in CRC screening programmes.<sup>26</sup> Assessing and providing such data can form the basis for appropriate and targeted health promotion and prevention strategies aimed at equally including people with IDD. As a nationwide CRC programme in Austria is about to be developed, with recommendations from important stakeholders and an expert committee, this provides the perfect and unique opportunity to include people with IDD in the starting phase of this health prevention programme. Therefore, we target the fundamental question of how to assure equal access to a CRC screening programme for people with disabilities.

## **2. Research goal and research questions**

The present project aims to investigate necessary steps and measures to assure equal inclusion of people with IDD in a potential national CRC screening programme in Austria. We will assess barriers and facilitators for participation in CRC screening from the perspective of the people with IDD and their caregivers, thus assuring public and patient involvement in the early stages of this health prevention programme.

The individual research questions and workpackages of this project, as well as the accompanying aims and research methods, are listed in the Table on page 7.

## **3. Originality**

Currently, there is a lack of data, both in Austria and internationally, on how to include people with IDD in organised CRC screening programmes. Such data are of utmost importance to tackle health care inequalities and provide a basis to reach underserved target groups, such as people with IDD, and assure equal access to health prevention activities. The present project is the first to address the needs as well as barriers and facilitators to participation in CRC screening from the perspective of people with IDD and their caregivers. Thus, we can provide evidence-based recommendation on how to include people with IDD in an Austrian CRC screening programme. To realize this project at the current planning phase and future starting point of a CRC screening programme provides the unique opportunity to effectively include people with disabilities in an important health prevention activity and minding a public & patient involvement strategy.

Furthermore, we attach great importance to the usability of our study results and will provide them in a German-language report to relevant stakeholders and in an easy language version to people with IDD. This itself represents an intervention to raise awareness for CRC screening in people with IDD.

Table: research questions and study design

Workpackages (WP)	Aim	Research question (RQ)	Method
WP 1: Needs of people with IDD	To gather opinions of people with IDD regarding facilitators, barriers, and support needs related to CRC screening.	RQ 1: In the opinion of people with IDD, what barriers and what facilitators are there to participate in CRC screening; and what support needs should be addressed?	Focus groups with people with IDD
WP 2: The support system	To examine CRC awareness in caregivers of people with IDD. To gather opinions and views of caregivers on facilitators, barriers, and support needs related to CRC screening.	RQ 2: How is the extent of awareness of CRC in caregivers of people with IDD? RQ 3: In the opinion of caregivers, what barriers and what facilitators are there for participation of people with IDD in CRC screening; and what support needs should be addressed?	Semi-structured Interviews with caregivers of people with IDD
WP 3: Dissemination	Disseminating the findings of this study to (1) policy-makers and stakeholders to raise awareness for including people with IDD in cancer screening, to (2) people with IDD and their caregivers to raise awareness for CRC screening, and to (3) the scientific community.	RQ 4: What is the impact of the study results?	Dissemination activities; short report in German-language and easy language, scientific paper and presentation

Note: CRC, colorectal cancer



## **4. Methods**

The project will follow a mixed methods approach, applying qualitative and quantitative methods. In WP 1, the views of people with IDD will be captured by a qualitative study using focus groups. In WP 2, the opinions of caregivers will be assessed via semi-structured interviews. In WP 3 study results will be disseminated.

### **4.1. WP 1: Needs of people with IDD**

To explore the opinions and needs of people with IDD regarding CRC screening, we will conduct focus groups using the nominal group technique (NGT). The NGT is a highly structured method, is inclusive of different communication styles, and has proven to be useful in gathering opinions from people with IDD<sup>27,28</sup>. We will use cancer information in easy language<sup>29,30</sup> and the well-established METACOM symbols<sup>31</sup> to support communication in the focus groups.

Following recommendations regarding number of nominal groups and total number of participants<sup>32</sup>, we will conduct two to four nominal groups, with five to seven participants each, resulting in a total number of 10 - 28 participants with IDD in this stage of the project.

For analysing data we will apply thematic analysis<sup>33</sup>. Two persons will code the data blinded to each other's primary decisions but will undergo frequent meetings and discussion throughout the whole process. One coder will be the applicant of this project; the other coder will be a qualified psychologist or pedagogue with expertise in IDD and qualitative methods. We will adhere to the 15-point checklist of criteria for good thematic analysis by Braun and Clarke<sup>33</sup> and apply the trustworthiness criteria of dependability, credibility, confirmability and transferability<sup>34</sup>. To aid the analysis, MAXQDA, a software for qualitative data will be used.

### **4.2. WP 2: The support system**

Primary caregivers of people with IDD will be surveyed upon perceived barriers and facilitators to participate in a CRC screening programme, and about their general awareness of CRC using an internationally validated questionnaire, the Bowel Cancer Awareness Measure (CAM) by Cancer Research UK.<sup>35</sup> The primary caregiver is often a close confidant of the person with IDD, and is responsible for making health care decisions for and with the person with IDD, scheduling medical appointments, and minding the general health of the person with IDD.

Therefore, we assess the opinions and views of the caregivers regarding barriers, facilitators and support needs for CRC, as well as their general awareness of CRC. The latter – as part of general health literacy – is an important mediator for screening uptake, and needs to be addressed when examining screening participation. A certain level of CRC awareness must be present among caregivers to support screening activities among the people with IDD they care for.

As data collection method, semi-structured interviews will be applied. This method allows for the preparation of key questions, but every respondent is free to talk and elaborate on the topics she/he deems important. Thus, this method is especially suitable to explore and collect novel aspects and views on a topic.<sup>36</sup> The interview will assess quantitative and qualitative aspects, including (1) sociodemographic characteristics of the caregiver and the person with IDD they care for, (2) Bowel Cancer Awareness Measure (CAM) by Cancer Research UK,<sup>35</sup> (3) barriers, facilitators, and needs to participate in a CRC screening programme.

Quantitative data will be analysed using SPSS in its current version. Answers to open questions will be coded by two persons blinded to each other's decision using the approach of thematic analysis<sup>33</sup> as described in chapter 4.1..

### **4.3. WP 3: Dissemination**

Disseminating and transferring research-based knowledge to policy and practice is an internationally evolving demand in the healthcare field<sup>37</sup>. This demand will be addressed in this project by disseminating the results not only to the scientific community via publications and presentations, but also to policy and practice. In WP 3, the results of this study will be disseminated to stakeholders in the health- and social policy sector via a German-language report. Additionally an easy language report will be designed for people with IDD. This will raise awareness of CRC and cancer screening in an underserved, marginalised population group.

### **4.4. Sampling and Recruitment**

In WP1, we will include people with IDD aged 35 years or older. The current recommendations for an organised CRC screening programme target people 45 – 75 years.<sup>4</sup> In People with IDD an accelerated ageing process is often observed, with age-related diseases occurring earlier in the person's life. Therefore, also younger people will be included in the focus

groups. To achieve a diverse sampling, we will aim to include (a) people with IDD receiving services or support from different organisations and (b) people with IDD living alone or with family, (c) different age groups of people with IDD within the specified range. However, due to access to the sample and voluntary participation, sample characteristics cannot be predicted. In WP2, we will include caregivers who are currently the primary (closest) caregiver of a person with IDD aged 35+. The caregiver must be at least 18 years old.

As mentioned in chapter 1, there are already pilot projects in Austria implementing organised CRC screening in specific states, e.g. Burgenland. We aim to include people from a state that already has a pilot CRC screening project as well as from a state that does not. By doing this, we expect to have richer and more diverse data and to be able to explore whether and how people with IDD are currently involved in the CRC screening pilot.

To reach our target samples, we will contact organisations providing services and support for people with IDD. The applicant of this project is well connected with service providers for people with IDD including Lebenshilfe Österreich, the CARITAS, and HABIT, and with further local organizations in Austria.

## **5. Ethical considerations**

Considering the intellectual limitations of people with IDD, it is important to ensure that all provided information is understood, and that participants know about their rights (e.g. dropping out of the study at any time without any consequences) throughout the whole study. It is unlikely that this study will cause harm to participants with IDD. However, to protect participants and to provide a maximum of support during and after participation, we will take measures described in chapter 5.3. Costs incurred by people with IDD and their caregivers as a result of participation, e.g. travel costs, will be covered. Ethical approval for this study will be obtained from the Ethics Committee of the Medical University of Vienna.

### **5.1. Informed consent and incentives**

All participants in this research project will receive information on the study and handling of data. People with IDD participating in the project will be informed in face-to-face settings with an easy language version of the study information. They can choose whether they want to have a

person they trust (relative, caregiver, guardian) present. A leaflet with the study information in easy language will be handed out to all participants with IDD. Informed consent will be in written form, signed by the person with IDD. If the person with IDD has a legal guardian, this guardian will also receive an information sheet and has to sign the informed consent form. To thank people with IDD for their participation and their time, we will offer an incentive of 20 EURO for each participant in the focus groups.

## **5.2. Anonymity**

Data gathered in interviews and focus groups will include personal information of study participants. To store this data securely, data will be pseudonymised with a code for each participant. We will create a key file in which the pseudonymised data are linked to the personal data. This key file will be keyword-protected and stored on the server of the Medical University of Vienna without access from external parties. Raw data (audio files and transcripts) of focus groups will also be saved separately from the other data in a secured way (password protected on server/data-storage of the University). Data analysis and interpretation will be conducted with pseudonymized data, only.

## **5.3. Support for participants with IDD**

Talking about cancer can be challenging or trigger anxiety. Although we aim to enable a positive experience for our participants, we want to make sure that they are not left alone with any concerns that may arise. People with IDD (and caregivers) can contact the project team with questions or concerns they may have via telephone or e-mail. The project applicant is a clinical psychologist with experience in working with people with IDD and can provide crisis intervention if needed. If further mental health support is needed, a strong network to existing mental health services for people with IDD in Austria is in place.

## **5.4. Impact of the COVID-19 pandemic**

People with IDD have been greatly affected by COVID-19. We will place the utmost importance on assuring a positive experience to all participants with IDD in this project. If COVID-19 restrictions at the time of study conduction interfere with the planned steps of the project, we will use virtual methods for data collection. If focus groups with people with IDD cannot be conducted,

we will carry out one-to-one virtual interviews. Although we hope to physically meet and interact with our study participants, the projects aims can also be reached via a virtual study. The safety and health of participants will always have the highest priority throughout this project.

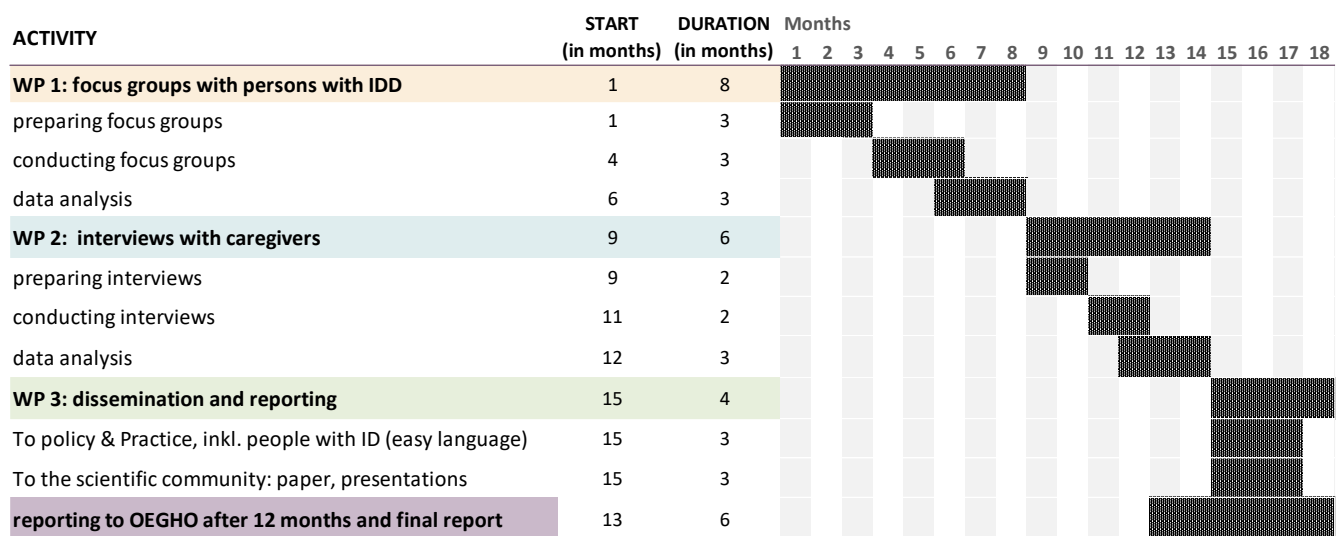
## 6. Gender aspects

We aim for a balanced gender distribution in both samples, people with IDD and caregivers. However, in the latter we expect a higher proportion of women in our final sample, since more women work as caregivers. Aspects of CRC screening can be experienced as shameful or distressing. Therefore, we will provide participants in focus group the option to choose an only-female or only-male group, if preferred.

## 7. Work plan and timeline

The detailed time schedule is depicted in the Figure.

Figure: time plan



## 8. Financial aspects

The requested funds for this project amount to **EUR 49 644,-** and consist of the following costs:

### **Personal costs (EUR 47 448,- for 18 months) including:**

[personal costs are calculated based on the FWF Standard Personnel Costs and Salaries]

- The principal investigator Mag.<sup>a</sup> Dr.<sup>in</sup> Elisabeth Zeilinger, post-doc, is covered by the research site.
- EUR 32 688,-: postgraduate (psychologist or pedagogue) for 16h/week for 18 months: with expertise in easy language and communication with people with IDD, and with background in qualitative research for coding qualitative data (parallel blind with the principal investigator).
- EUR 14 760,-: Student assistant 10h/week for 18 months for supporting the organisation of the project, for scheduling interviews and focus groups, for being an observer and recording data during focus groups, and for administrative support.

### **Travel costs (EUR 740,-) including:**

- EUR 280,-: Travel costs for participants with disability of the focus groups and their support persons (5,-/person): max. 28 people for focus groups (plus 28 support persons): 56x5: 280,-
- EUR 460,-: OEGHO conference: travel and hotel costs (2 nights) for one person.

### **Material and other costs (EUR 1 856,-) including:**

- EUR 716,-: 2x Software licences for two years for MAXQDA (qualitative analysis, data management)
- EUR 180,-: Communication material and signposts for focus groups with people with IDD
- EUR 560,-: Incentives for participants (20,- for each participation) including: max. 28 people in focus groups: 28x20 = 560,-

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