

CUPID Working Group 2 FINAL DELIVERABLE

Towards Inclusive Cancer Prevention and Screening in Europe: Policy Landscape, Good Practices, and Recommendations for Individuals with Intellectual Disabilities

Executive Summary

1. Background and Introduction

1.1 People with Intellectual Disabilities

1.2 Overview of cancer epidemiology in People with Intellectual Disabilities

1.2. Cancer prevalence and incidence in People with Intellectual Disabilities

1.2.1. Cancer mortality in People with Intellectual Disabilities

1.2.2. Overview of cancer epidemiology in People with Intellectual Disabilities

1.3 Importance of Cancer prevention and screening

1.4 Issues and difficulties People with Intellectual Disabilities face when accessing Cancer prevention and screening

1.5 Definition and relevance of Cancer policies in People with Intellectual Disabilities

1.6 Necessity of adjustments in policy and practice statements to meet the needs of People with Intellectual Disabilities

1.7 Describe the rationale for this review in the context of existing knowledge

Aim and Objectives

2. Methods

2.1 Data sources (databases) and search strategy (keywords and queries used)

2.2 Eligibility Criteria

2.3 Study selection process (PRISMA) and data items extraction

2.4 Quality Assessment: AACODS checklist - evaluation and critical appraisal of grey literature.

2.5 Synthesis Methods (how studies were grouped for the syntheses)

2.6 Use of an AI tool during the process

2.7 Protocol registration

2.8 Overview of Cancer Services Across the EU

2.9 Overview of Selected Countries

3. Results

3.1 Study Selection (description of the PRISMA flowchart) Figure 1 - description of Figure 1. The PRISMA search flow diagram of databases and registers.

3.2 Study Characteristics - Description of the findings from Table 1 - Table 1. Characteristics of the cancer policy and recommendations documents by country

3.3. Study Characteristics - description of the findings from Figure 2. Country distribution of the included cancer screening or prevention documents.

3.4 Study Characteristics - description of the findings from Figure 3. Distribution of cancer prevention policy documents by cancer site and cancer control focus.

3.5 Results of Syntheses – description of the findings from Supplementary Table 1. Objectives and People with Intellectual Disabilities -specific adjustments and recommendations of the included documents, stratified by cancer site and cancer control focus.

3.6 Results of Syntheses – description of the findings from Table 2. Grouped People with Intellectual Disabilities -Specific Adjustments & Recommendations listed in the included documents, according to the cancer site

3.6.1 Screening-Related Adjustments and Recommendations

3.6.2 Prevention-Related Recommendations

3.6.3 Clinical Monitoring and Surveillance

3.7 Quality of Evidence

3.8 Study Characteristics - description of the findings from Figure 4. Distribution of the included cancer prevention and screening documents by national health expenditure

4. Discussion

4.1 Summary of our main findings

4.2 Interpretation of the findings from Table 1

4.4 Interpretation of the findings from Figure 3.

4.5 Interpretation of the findings from the Supplementary Table 1.

4.6 Interpretation of the findings from Table 2.

4.7 Interpretation of the findings from Figure 4.

4.8 Strengths and Limitations

4.9 Organizational Consensus and Regional Variations in Inclusive Cancer Prevention and Screening in Europe

NOTE: A comprehensive report is currently under review and, once finalized, will be made available to disseminate its key findings and outcomes to relevant stakeholders. Additional information is available upon request to the WG2 leader Prof. Dr. **Martin McMahon** martin.mcmahon@tcd.ie.