

Welcome and overview of day

9:00 – 9:15AM



By the end of this session, you will have;

- 1) Gained an awareness of the sessions taking place on Tuesday 13th May.



The Cancer – Understanding Prevention in Intellectual Disabilities (CUPID) Project

Organise a training school about organisational context and implementation of equitable cancer prevention strategies including access to screening programmes.

WG2: Cancer prevention policies: audit and evaluation

WG1: The interdisciplinary co-production team

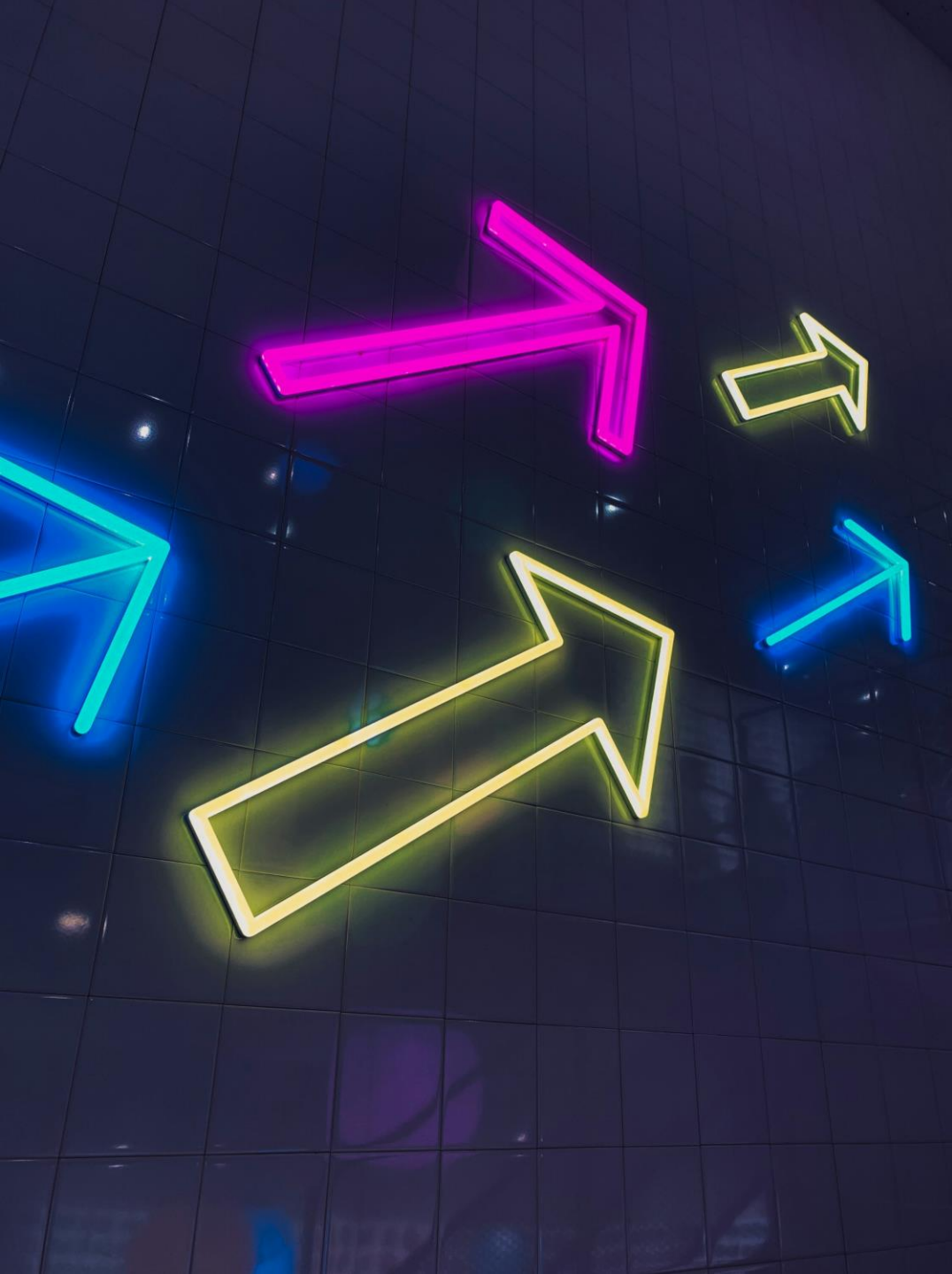
WG3: Universal EU Cancer prevention strategy methodology

Organise a training school about health system goals for targeted cancer prevention and screening programmes for people with intellectual disabilities.

WG4: Dissemination and Outreach

Timetable

Date	Information
09:00 – 09:15AM	Welcome, overview of day, importance of targeted cancer prevention and screening for people with intellectual disabilities
09:15 – 10:00AM	Overview of – Cancer risk-factor and symptom awareness for people with intellectual disabilities. (Online and in person)
10:00 – 10:45AM	Inclusive and Accessible cancer screening/prevention information. (In person only)
10:45 – 11:00AM	BREAK
11:00 – 12:00PM	Health Systems across the EU (and beyond): What does cancer screening and prevention look like? (Online and in person)
12:00 – 13:00PM	Learning from WG1 – The voice of people with ID toward cancer screening and cancer prevention systems. (Online and in person)
13:00 – 14:00PM	LUNCH
14:00 – 16:00PM	Cancer screening and cancer prevention- How do these apply to people with ID and what should health systems do? (In person only)
16:00 – 16:45PM	Closing remarks and Evaluation



Coming next...

- Cancer risk-factor and symptom awareness for people with intellectual disabilities. Natalie Gil. 9:15am – 10:00am. In-person and online.
- Inclusive and Accessible cancer screening/prevention information. Dr Kate Sykes. 10am – 10:45am. In-person only.

Are there any questions?





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of the European Union

Acknowledgement

This article/publication is based upon work from COST Action
CUPID supported by COST (European Cooperation in Science and Technology).

COST Description

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

Weblink

www.cost.eu

Cancer risk-factor and symptom awareness for people with intellectual disabilities.

Understanding primary and secondary prevention factors using systematic evidence mapping & synthesis.

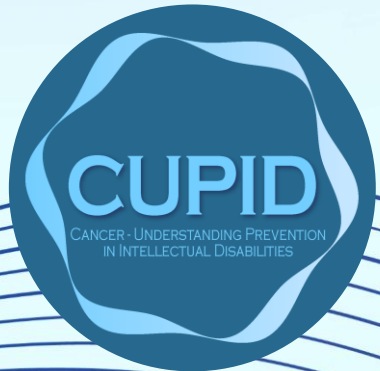
Natalie Gil BSc, MSc, GMBPsS

Postgraduate Researcher & Trainee Health Psychologist



Overview

- Background
- Primary, Secondary & Tertiary cancer prevention
- Explore risk-factor and symptom awareness among PwID
- Understand how this fits into prevention
- How to systematically synthesise knowledge in the form of a scoping review



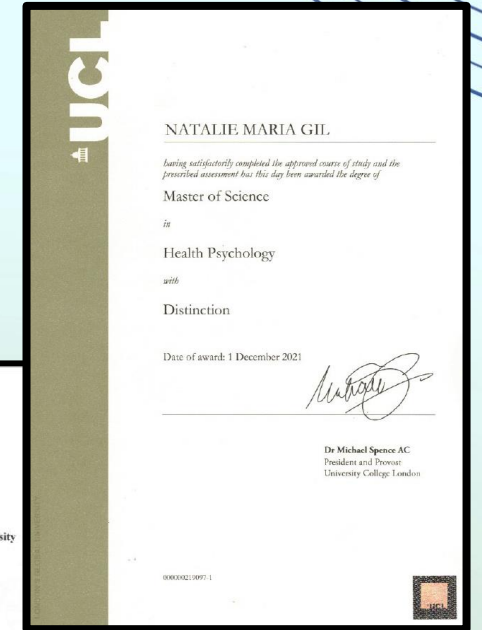
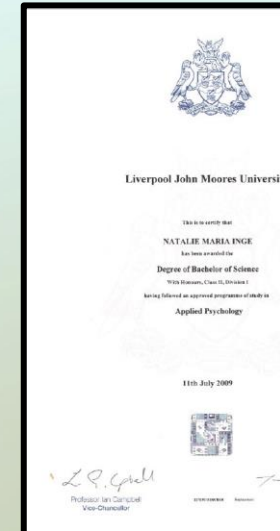


My Background

- Applied Psychology, BSc (Hons) 2009
- Health Psychology MSc 2021 (Stage 1)
- Research Assistant (Cancer & Inequalities)



- Health Sciences PhD (began 2022)
- Doctoral Qualification in Health Psychology (began 2023) (Stage 2)



“Prevention is the protection of health by personal and community-wide efforts.”

Cancer prevention and early detection
involves a multi-level approach,
including
primary, secondary, and tertiary strategies.



PRIMARY

Primary prevention focuses on taking proactive measures to prevent diseases from ever occurring.

SECONDARY

Secondary prevention emphasizes the significance of identifying diseases in their nascent stages before symptoms manifest.

TERTIARY

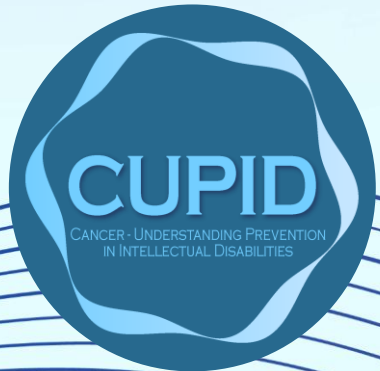
Tertiary prevention aims to enhance the quality of life for individuals living with chronic conditions while minimizing the impact of the disease.

Primary prevention reduces the likelihood that a disease or disorder will develop. The aim of primary prevention is to limit the incidence of disease by controlling specific causes and risk factors.

Avoidance/Reduction of known carcinogenic factors
(e.g. smoking cessation)

Modifying lifestyle factors that influence risk of
cancer (e.g. exercise, dietary changes)

Protective therapeutics (e.g. sun protection,
infection prevention, vaccination)



Secondary prevention focuses on early detection (even prior to presentation of symptoms) and treatment of cancer, to prevent disease progression or recurrence.

Screening (e.g. mammograms PAP smears, colonoscopies) to detect cancer or precancerous conditions

Early Detection – identifying and diagnosing cancer at its earliest stages, when treatment is most effective

Effective treatment – appropriate and timely treatment to prevent disease progression/spread



Tertiary prevention focuses on managing existing cancers to prevent complications, recurrence, to improve quality of life. Involving minimizing impact of disease and treatment on patient wellbeing.

Preventing recurrence and development of new cancers (e.g. adjuvant chemotherapy, targeted therapies, risk-adapted surveillance)

Managing complications and side effects of cancer and treatment (e.g. addressing pain, fatigue, depression, isolation)

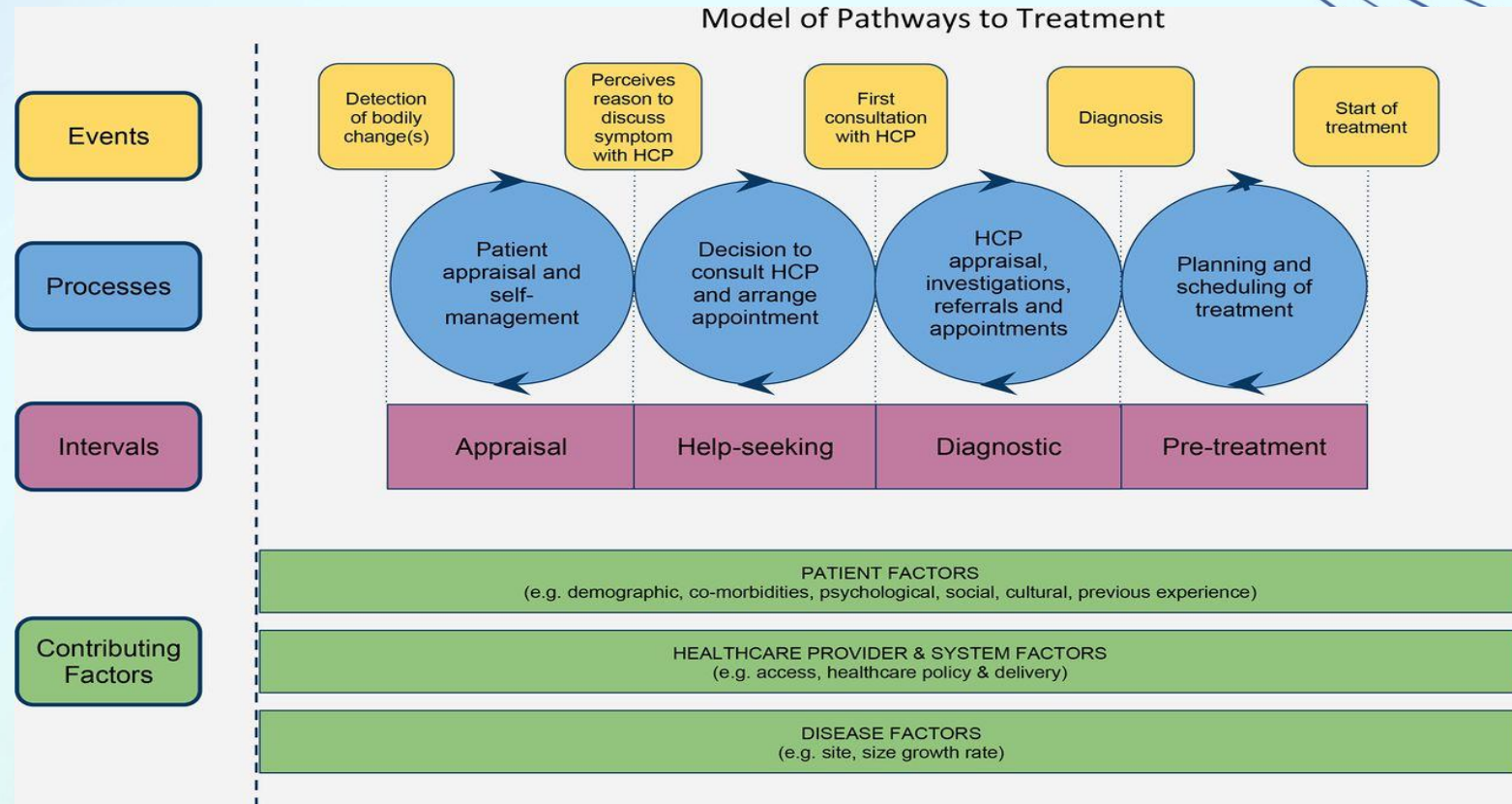
Improving quality of life and functionality (e.g. physical rehabilitation, support for navigating emotional, social, financial challenges)



My Research: Improving Early Cancer Diagnosis for PwID

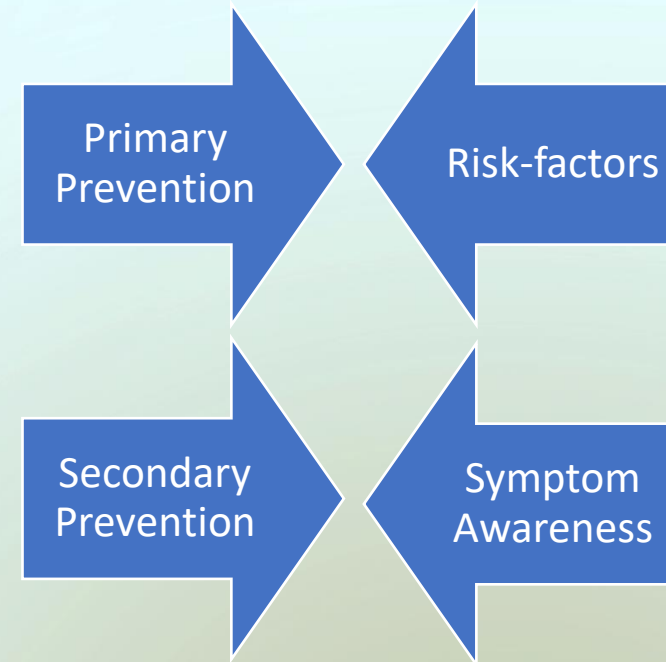
Using Model of Pathway to Treatment as a framework to understand:

- Cancer risk-factor and symptom awareness among people with lived experience of ID
- Differences in cancer diagnostic intervals for people with and without ID
- Lived experiences of cancer care for PWID



Cancer risk-factor and symptom awareness among PwID, paid-and-unpaid carers, and healthcare practitioners: a scoping review.

- Risk factor awareness is a concept most closely linked to primary prevention
- Symptom awareness is a concept most closely linked to secondary prevention



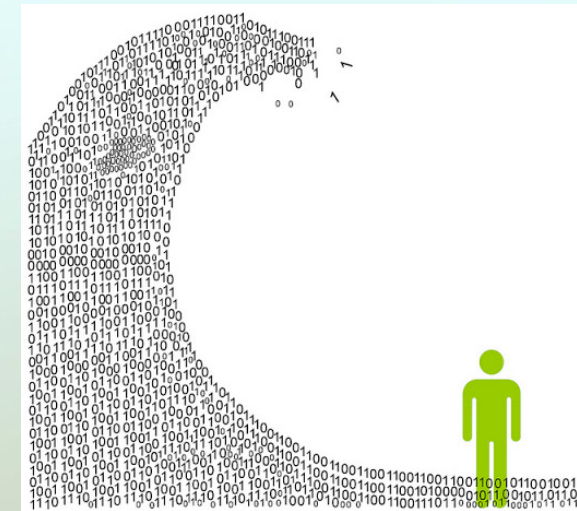
How can we best
synthesise evidence
on this topic?

What is the purpose of a review?

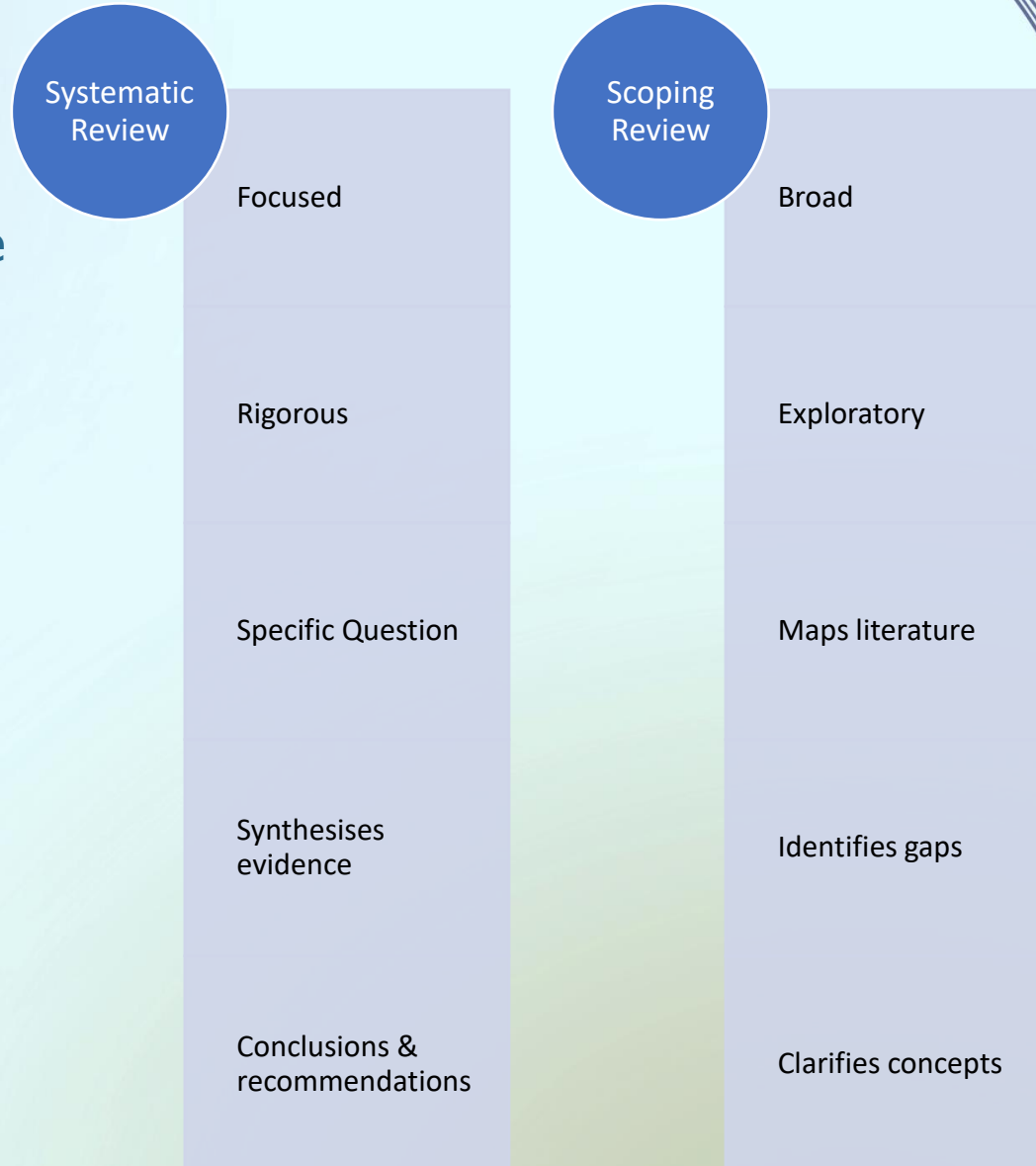
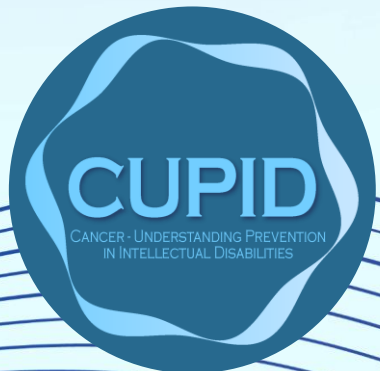
A well conducted literature review can:

- Provide the most trustworthy answer to specific review question
 - Map what evidence currently exists on a chosen topic
- Identify gaps in knowledge that require further research; and
- Demonstrate the strength of available evidence/the quality of existing studies.

(Booth et al., 2016)



- Systematic review attempts to collate empirical evidence from a relatively **smaller number of studies pertaining to a focused research question**
- Scoping review seeks to present an **overview of a potentially large and diverse body of literature pertaining to a broad topic.**



“...despite researching less defined research question/s, a scoping review should be no less systematic in its approach to searching, extracting, and reporting data, with the process transparent, well-documented and replicable, thus increasing the reliability and validity of the findings.”²



²Gil N, Cox A, Whitaker KL, Kerrison RS., J Intellect Disabil Res. 2024 Mar;68(3):193-211.

Why be 'systematic'?



A systematic approach is essential for the clarity, validity and auditability of a review:

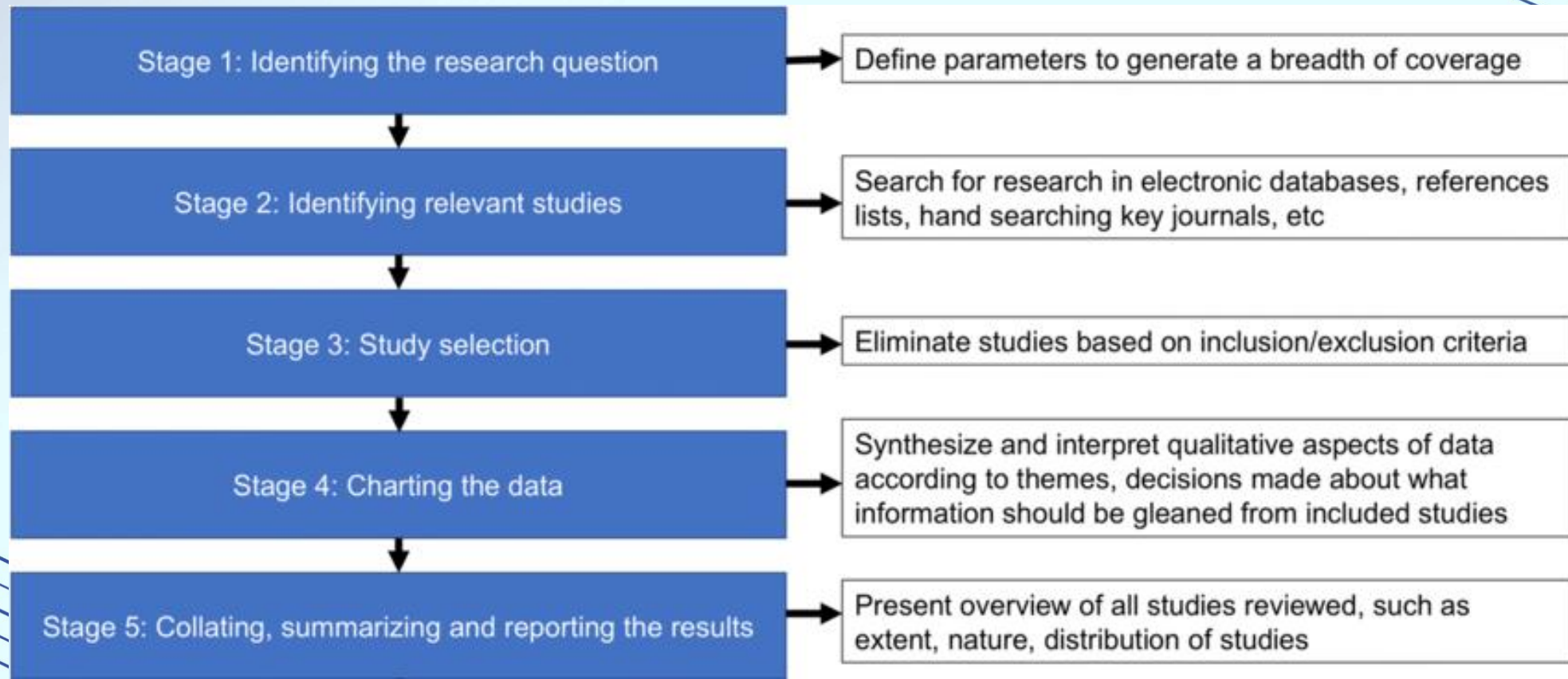
Clarity – A systematic structure makes a review easier to read and understand, tables and flow charts are commonly used to 'reveal rather than conceal'.

Validity – setting clear research terms and inclusion/exclusion criteria means literature is included based on relevance rather than outcome.

Auditability - if the process is transparent and each step is documented and justified then others would be able to repeat the review and get the same results.

Methodology

- Arksey & O'Malley Framework for Scoping Review (2005)
- 5 Incremental Stages



Stage 1: Identifying the research question

Using a framework: Population Concept Context

Population

- People with mild, moderate, or profound and multiple intellectual disabilities
- Specialist or non-specialist healthcare practitioners (hcps)
- Paid or family carers of people with intellectual disabilities

Concept

- Literature relating to cancer awareness, knowledge, understanding, risk-factor awareness or symptom awareness among people with intellectual disabilities and their paid-or-unpaid carers or hcps.

Context

- Worldwide
- Any setting
- Original research articles (any methodology); systematic, narrative, scoping or literature review articles; editorial and commentary pieces; published in peer-reviewed journals



Working title: What is currently known about cancer risk factor and symptom awareness among PwID, paid-and-unpaid carers, and HCPs?

Research Subquestions

1. What is known about risk-factor awareness among people with an intellectual disability?
2. What is known about symptom awareness among people with an intellectual disability?
3. Which cancers are being studied?
4. Which populations being studied e.g. mild/moderate/profound and multiple disability?
5. Which perspectives are considered e.g. people with intellectual disabilities, paid-and-unpaid carers, GP, intellectual disability nurses?
6. What types of studies are being conducted e.g. qualitative/quantitative
7. What types of articles are being published e.g. original research, reviews, editorials?
8. Where are studies being conducted, e.g., country/location?



Stage 2: Identifying relevant studies

Indexing Medical Subject Headings (MeSH) terms

	Medical Subject Headings (MeSH)
Intellectual Disabilities	Learning Disabilit* Developmental Disabilit* Learning Disabilities/nursing* Intellectual Disabilit* Intellectual Development Disabilities Mental Retardation Special Needs Caregivers/*psychology Persons with Mental Disabilities* Persons with Mental Disabilities/psychology
Cancer	Neoplasms/psychology* Neoplasms*/prevention & control Early Detection of Cancer Early Detection of Cancer/psychology* Early Diagnosis Cancer Symptoms Self-Examination*
Awareness	Awareness Risk-factors Help-seeking Communication* Attitude to Health* Health Knowledge, Attitudes, Practice* Health Education Patient Education as Topic/methods* Preventive Health Services Health Beliefs

Stage 2 Continued... Building a Search String

(MH) Learning Disabilit* OR (MH) Intellectual Disabilit* OR (MH) Developmental Disabilit* OR (MH) Learning Disorder OR (learning disability* OR Intellectual Disabilit* OR Developmental Disabilit*) TI/AB

AND

(MH) Cancer OR (MH) Neoplasms/psychology* OR (MH) Neoplasms*/prevention & control OR (MH)

Early Detection of Cancer OR (MH) Early Detection of Cancer/psychology* OR (MH) Early Diagnosis Cancer OR (MH) Self-Examination* OR Cancer TI/AB

AND

(MH) Communication* OR (MH) Attitude to Health* OR (MH) Health Knowledge, Attitudes, Practice* OR (MH) Health Education OR (MH) Preventive Health Services OR (MH) Health Beliefs OR (Awareness OR Knowledge OR Understanding OR Risk-factors OR Help-seeking) TI/AB

Limiters

Adult Human English Language 1997-



Stage 3: Study Selection

Inclusion / Exclusion Criteria

Inclusion	Exclusion
Reports cancer awareness, symptom awareness, risk-factor awareness,	Not Learning Disability focused
Empirical (qualitative, quantitative, mixed methods) article	Do not report empirical research (e.g. Editorials)
Indexed in Medline, CINAHL, PsycINFO, or EMBASE	Grey literature (book chapter, theses, conference proceedings)
Published on or after 1 st January 1997	Published before 1 st January 1997
Published in English	Published in languages other than English due to limited resources for translation.
No restriction on country	



Stage 4: Charting the Data

Author	Date	Journal	Title	Country	Type	Design	Cancer	Population	Sample	Methods	Analysis
Collins K; McClimens A; Mekonnen S; Wyld L	2014	Psycho- oncology	Breast cancer information and support needs for women with intellectual disabilities: a scoping study.	England	Qualitative	Scoping study	Breast	Adults with ID; Carers; ID advocates	26 participants; 3 women with ID; 23 carers / advocates	Semi-structured interviews	Thematic analysis
Cowie M; Fletcher J	1998	British journal of nursing	Breast awareness project for women with a learning disability.	England	N/A	Report	Breast	Adults with learning disabilities; Carers	N/A	Intervention	N/A
Kirby S; Hegarty J	2010	European Journal of Oncology Nursing	Breast awareness within an intellectual disability setting.	Canada	Quantitative	Descriptive	Breast	HCP's	105 nurses	Questionnaire (Modified Toronto Breast Self-Examination Inventory)	Statistical analysis

Stage 5: Collating, Summarising and Reporting Results

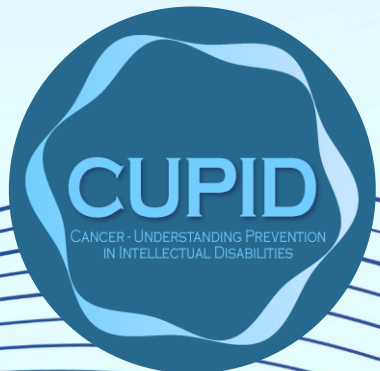
Reporting using Narrative Synthesis

Textual Analysis – analyses extracted data using narrative method to identify themes, & patterns

Narrative Synthesis – Integrates findings from included studies in a coherent narrative, exploring similarities, differences, and gaps in the literature

Presentation of Findings – Presents synthesis findings in clear concise manner, often using tables, figures to illustrate patterns and relationships

Assessment of evidence – Evaluates quality & strength of the evidence presented, considering factors such as design, sample size, data collection methods.



Stage 5 Continued... PRISMA-Scr Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-Scr) Checklist

SECTION	ITEM	PRISMA-Scr CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-5
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	5
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	-
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	6,7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	5,6
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	7
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	8
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	8
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	8,9
Synthesis of	13	Describe the methods of handling and summarizing	8

SECTION	ITEM	PRISMA-Scr CHECKLIST ITEM	REPORTED ON PAGE #
results		the data that were charted.	
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	9
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	10-12
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	9,10
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	9-25
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	19-26
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	27
Limitations	20	Discuss the limitations of the scoping review process.	29
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	30
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	30

JB1 = Joanna Briggs Institute; PRISMA-Scr = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

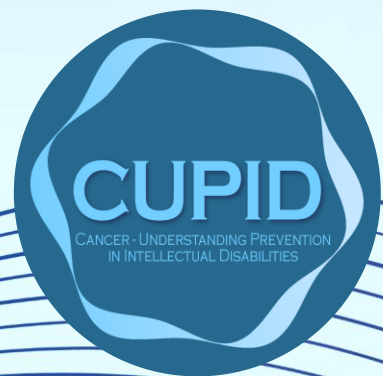
* Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-Scr): Checklist and Explanation. *Ann Intern Med*. 2018;169:467-473. doi: 10.7326/M18-0850.

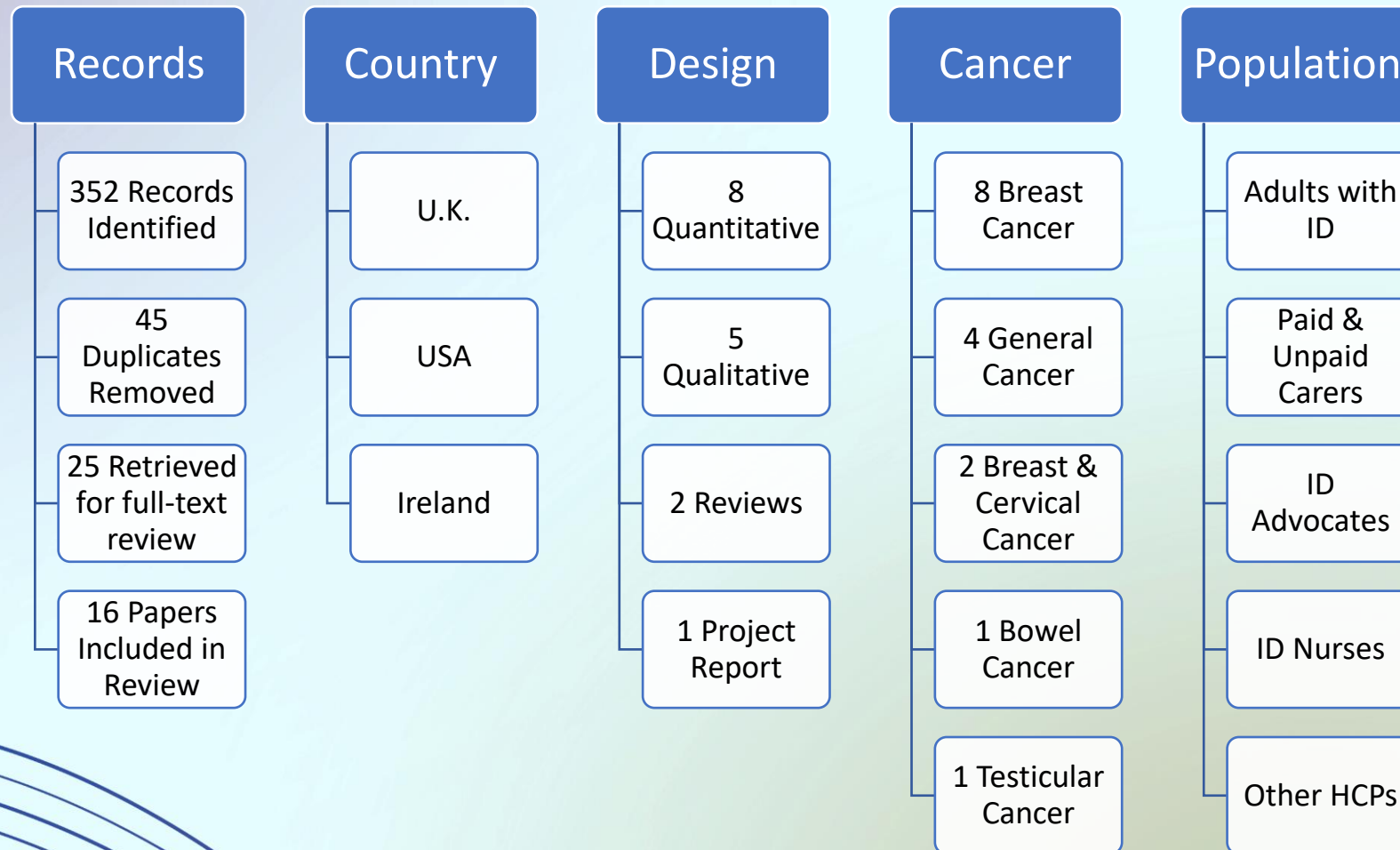


Optional Step: Critical Appraisal – example form



QUALITY APPRAISAL			
Research design			
Was the aim clearly presented?	Yes	No	Unclear
Was the rationale clearly presented?	Yes	No	Unclear
Was a methodology appropriate?	Yes	No	Unclear
Was the method/design apparent, and consistent with research intent?	Yes	No	Unclear
Was the data collection strategy apparent and appropriate to enable cancer patients to express their experience of a telehealth intervention?	Yes	No	Unclear
Sampling strategy			
Was the sample and sampling method sufficient?	Yes	No	Unclear
Study aim: narrow or broad? (a narrow aim would require a smaller sample)	Narrow	Broad	Unclear
Sample specificity: dense or sparse? (specificity = participants who belong to the specified target group) (If dense, it would require smaller sample size)	Dense	Sparse	Unclear
Analysis			
Was the analytic approach appropriate?	Yes	No	Unclear
Were deviant case/contradictory findings discussed?	Yes	No	Unclear
What were they?			
Was there evidence of member checking and/or independent analysis of data by more than one researcher?	Yes	No	Unclear
Presentation and interpretation of findings			
Was the context described and taken account of in interpretation?	Yes	No	Unclear
Were appropriate quotes used in the presentation of findings and discussion of findings?	Yes	No	Unclear
Was the interpretation of findings justified by the data that are presented?			
Reflexivity			
Was researcher reflexivity demonstrated?	Yes	No	Unclear
Ethical considerations			
Was consideration of ethical sensitivity demonstrated? (e.g in relation to participants)	Yes	No	Unclear
Relevance and transferability			
Is relevance and transferability evident generally about the study?	Yes	No	Unclear

Stage 5: Collating, Summarising and Reporting Results



Narrative Synthesis



Risk Factor & Symptom Awareness

- *Breast cancer awareness among HCPs and paid-and-unpaid carers*
- *Breast cancer awareness among PWID*
- *Awareness of other cancers*

Interventions to improve cancer awareness

- *Breast cancer interventions*
- *Interventions for other cancers*

Findings

JIDR Journal of Intellectual Disability Research
Published on behalf of mentap and in association with IASSID

Journal of Intellectual Disability Research

doi: 10.1111/jir.13110

VOLUME 68 PART 3 pp 193–211 March 2024

Systematic Review

Cancer risk-factor and symptom awareness among adults with intellectual disabilities, paid and unpaid carers, and healthcare practitioners: a scoping review

N. Gil, A. Cox, K. L. Whitaker & R. S. Kerrison

School of Health Sciences, University of Surrey, Guildford, UK

Abstract

Background The physical health of people with intellectual disabilities (ID) has been identified as an area of ongoing concern and priority. Research has increasingly focused on cancer, with studies indicating that people with ID are at an increased risk of cancer and of mortality, compared with the general population. This review aims to systematically identify and synthesise the published academic literature exploring cancer risk-factor and symptom awareness among people with IDs, carers and healthcare professionals.

Methods In line with Arksey and O'Malley's (2005) framework for scoping reviews, five incremental stages were followed: (1) identifying research question, (2) identifying relevant studies, (3) study selection, (4) extracting and charting data, and (5) collating, summarising and reporting results. Findings were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping reviews (PRISMA-ScR).

Results The search strategy identified 352 records, 16 records met all eligibility criteria and were included for review. The studies address a range of areas

including knowledge and awareness of cancer risk-factors and symptoms and interventions to promote awareness of cancer.

Conclusions Cancer risk-factor and symptom awareness is low among adults with ID, paid and unpaid carers and healthcare practitioners (HCPs). Theoretically underpinned, co-designed tools and interventions to improve awareness are lacking. There is uncertainty surrounding how to best support people with ID in raising cancer awareness, even within the professional healthcare environment. There is a predominance of research on breast cancer awareness. Future studies focusing on other cancers are needed to build a complete picture of awareness among adults with IDs, paid and unpaid carers, and HCPs.

Keywords Cancer, Cancer awareness, Early diagnosis, Intellectual disability, Learning disability, Symptom awareness

Introduction

The physical health of people with intellectual disabilities (ID) has been identified as an area of ongoing concern and priority (Elliott et al. 2003; Norway and Dix 2019; Wigham et al. 2022). An intellectual disability is defined as a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing

Cancer risk-factor and symptom awareness is low, across groups.

Adults with ID display fatalistic view of cancer

Carers have no greater cancer knowledge than general population

Lack of risk-factor and symptom awareness training

Breast cancer research predominates

Unclear if measures used are truly accessible for PWID

Theoretically underpinned & co-designed tools / interventions lacking.

Correspondence: Mr Natalie Gil, School of Health Sciences, University of Surrey, Van Goyenk Building, Priory Road, Surrey Research Park, Guildford GU1 7YU, UK (e-mail: n.gil@surrey.ac.uk).

Conclusion



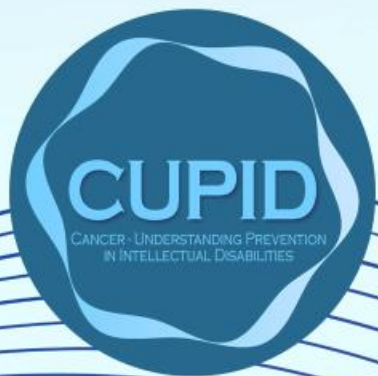
UNCERTAINTY HOW TO
SUPPORT PWID IN RAISING
CANCER AWARENESS



CONSENSUS MUST BE REACHED
ON HOW TO FACILITATE &
EMPOWER PWID



FURTHER RESEARCH NEEDED
TO BUILD COMPLETE PICTURE
OF AWARENESS



Key Takeaways.....

Defined Primary, Secondary, and Tertiary Prevention

Discussed Pathway to Treatment Model

Outlined differences between Systematic & Scoping Reviews

Detailed the steps of a Scoping Review

Presented findings on cancer risk-factor and symptom awareness for PwID & their support network



Thank you for listening.....



Acknowledgements

Academic Supervisors

Dr Robert Kerrison

Dr Anna Cox

Professor Katriina Whitaker

Clinical Supervisor

Dr Emily McBride

Inclusive and Accessible cancer screening/prevention information

10:00 – 10:45AM

Dr Kate Sykes

Kate.sykes@northumbria.ac.uk



By the end of this session, you will have;

- 1) Gained an awareness of what accessible information is.
- 2) Gained an awareness of the main principles of easy-to-read.
- 3) Applied the principles to cancer prevention and cancer screening information.
- 4) Discussed and listed of considerations to make cancer screening and prevention more accessible.



**Please complete part 1 on the below link.
Part 2 will be completed later in the
session.**

Go to

www.menti.com

Enter the code

6620 7255



Or use QR code



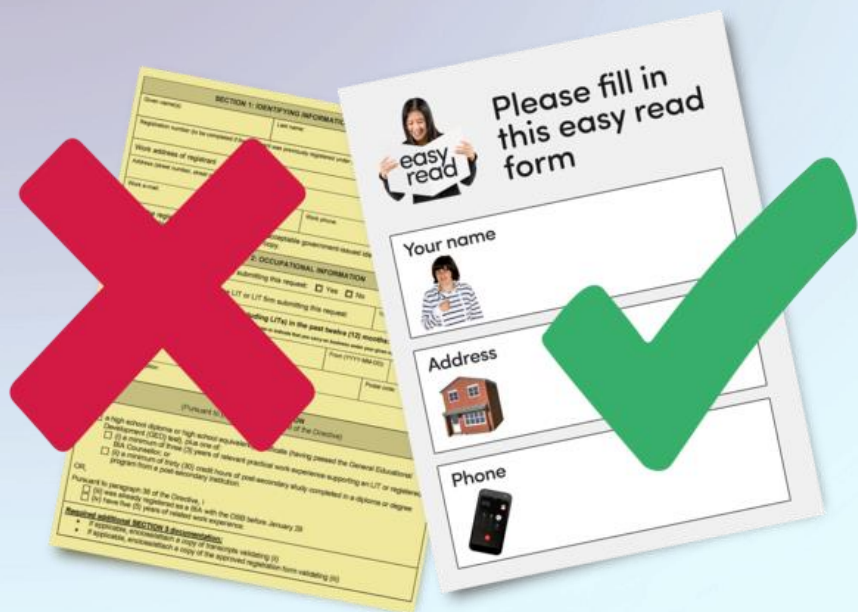
Accessible information

“By improving people’s access to understandable and trustworthy health information and their capacity to use it effectively, health literacy is critical to both empowering people to make decisions about personal health, and in enabling their engagement in collective health promotion action to address the determinants of health.”

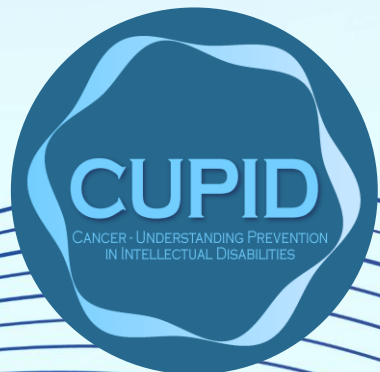
(World Health Organisation 2025)



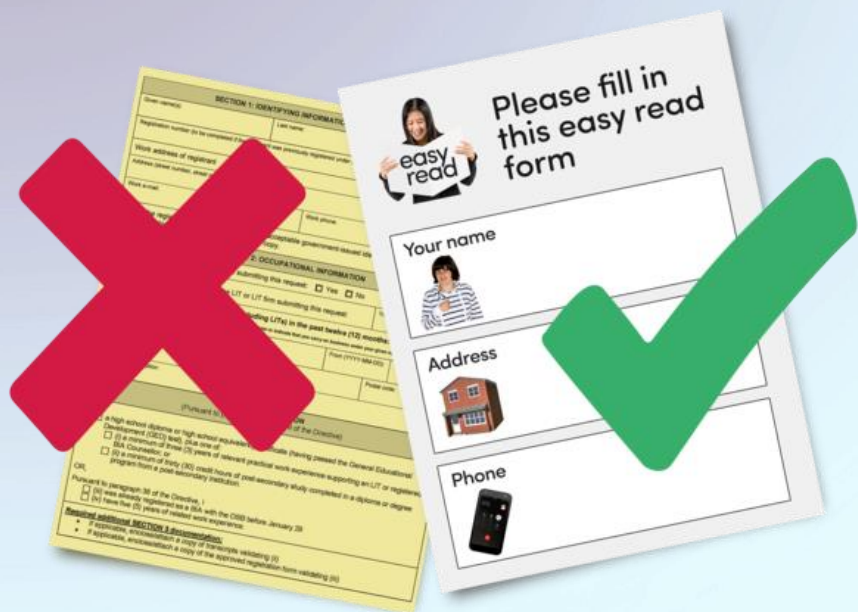
What is accessible information?



- A combination of the right resource and the right support (Jarrett et al 2015)
- If the means are not provided, the person cannot interpret the information independently and therefore depends on a 'communication partner' to access it (Mander 2016).



Why is it important?



- Reading age of adults is between 9 and 11 years old.
- 42% of working age adults are unable to understand and make use of everyday health information.
- Health literacy is essential for taking medications correctly, knowing which health services to use, and managing long-term conditions.

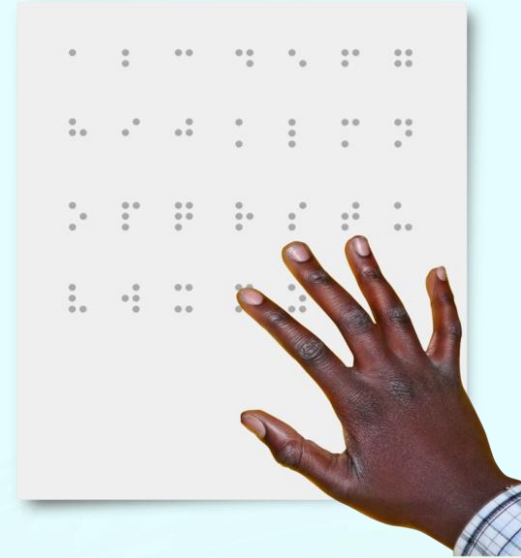
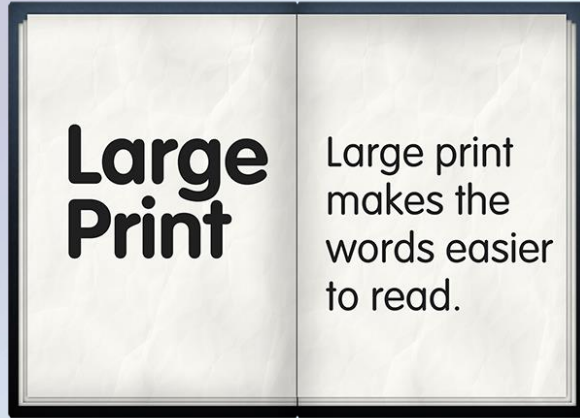


Accessible Information Standard



- In the England, we have the Accessible Information Standard.
- This is law. It tells Health and Social Care Organisations how to make sure people who have a disability or sensory loss get information in a way they can access and understand.
- Do other countries have something similar? Put your hand up if you do.





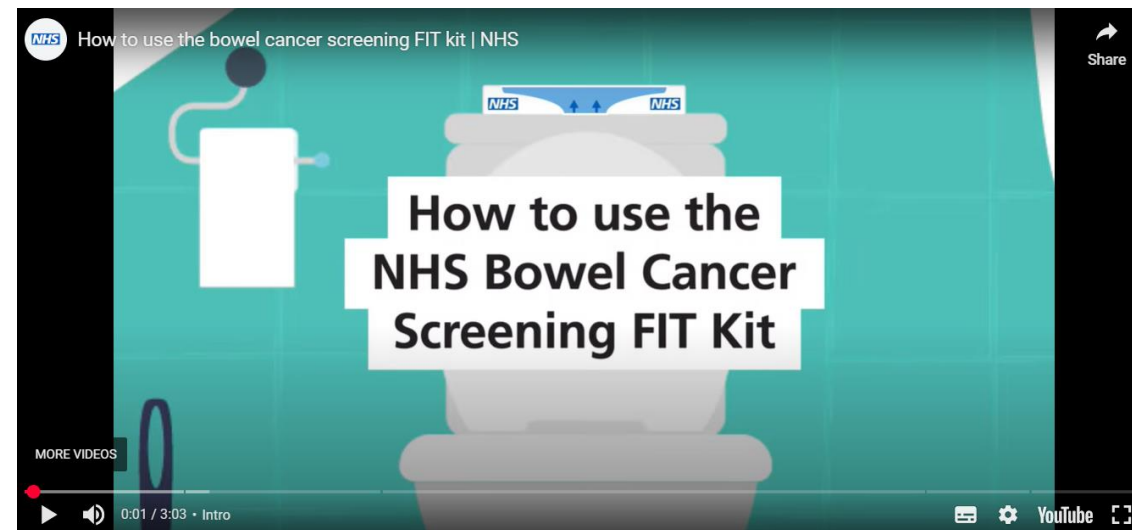
1. Invitation letter template – BSL signed version

How to watch this YouTube video

There's a YouTube video on this page. You can't access it because of your cookie settings.

You can [change your cookie settings](#) or watch the video on YouTube instead:

[BSL signed version of invitation letter template](#)



Bowel cancer screening

An easy read guide



An easy read about the NHS bowel cancer screening test



You can call the freephone helpline for advice on 0800 707 60 60

Screening saves lives

Help us help you



[Bowel cancer screening easy read invitation letter content](#)

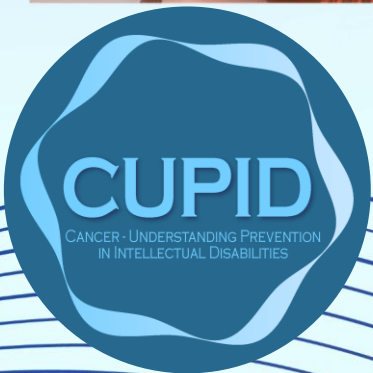
ODT, 338 KB

This file is in an [OpenDocument](#) format

This file may not be suitable for users of assistive technology.

▼ Request an accessible format.

If you use assistive technology (such as a screen reader) and need a version of this document in a more accessible format, please email publications@phe.gov.uk. Please tell us what format you need. It will help us if you say what assistive technology you use.



People request information in different formats.

Why should people have to request?

What if health systems become more equitable?

Can we implement easy read/accessible standards into everyday life?

IMPORTANT Co-production is key!



The target audience are the experts!

They know what works for them and what does not.



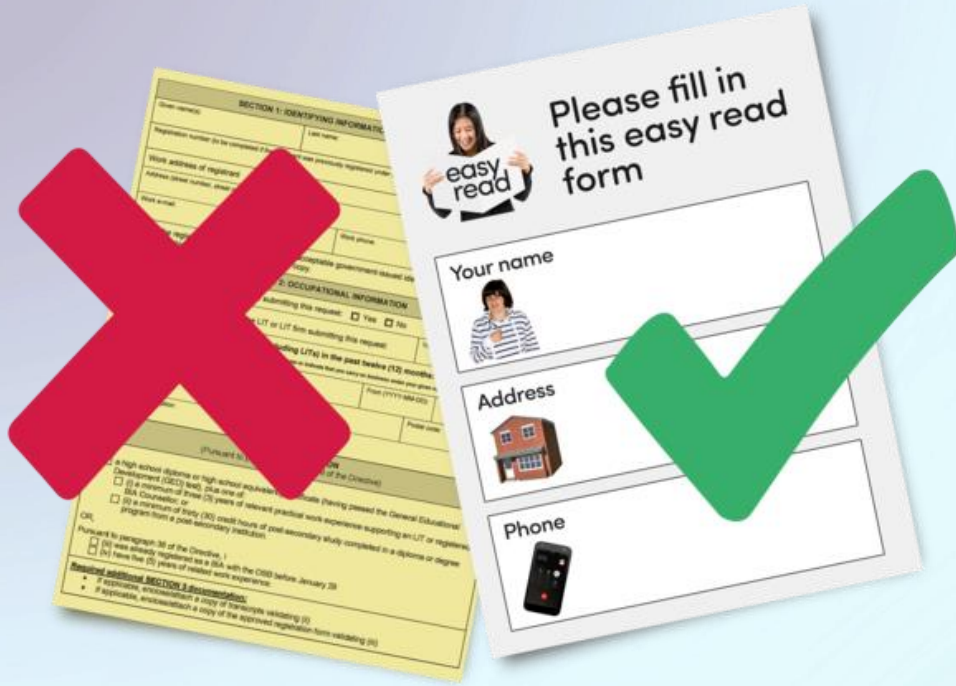
Can gain a strong insight into the audience experience.

Find out what information people want.

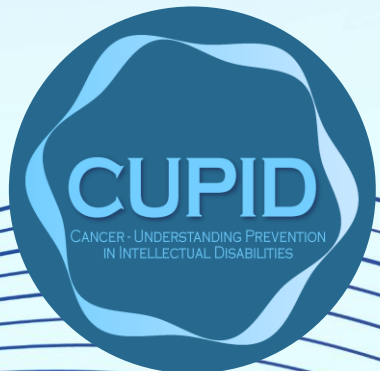
For Example - Word Checking



- I asked women with learning disabilities to check the easy read documents.
- They did not know what the following words meant:
 - Cervical → Lady Bits
 - Researcher Supervisor → Teacher
 - Conference → Big meeting



Making an Easy read

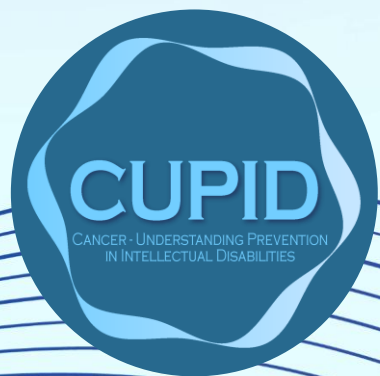


Layout

- Presented on A4 pages.
- Text aligned on the right hand side.
- Images aligned on the left hand side.
- Simple sentences.



Size and style of font



Arial	Tahoma
Verdana	Myriad
Helvetica	Calibri
Candara	Corbel
Segoe	Gill Sans

cat

font without serifs



cat

font with serifs



verbigerative
mendacious
quotient
brokerage
serpiginous



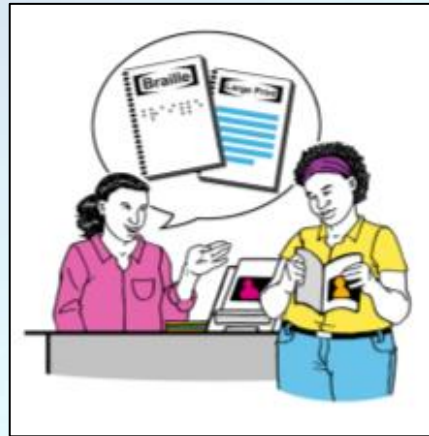
Language

- Language should be simple.
- Any **necessary** complicated words/terms should be explained.

Pictures



OR



- Just by putting a picture alongside information does not make it 'Easy Read'
- Images should be selected to represent each sentence of text where possible.

Other writing tips

- **Bold** key words/phrases.
- Use numbers, instead of words
- Use 'do not', 'can not'
- Use bullet points and sub-headings
- Keep each sentence as short as possible
- Avoid using commas



Using the home test kit

To do the screening test, you need to collect a small amount of your poo using the kit. Please use a clean disposable container to collect your sample. You then send this sample in the post for testing. The kit includes prepaid packaging and full instructions.

Once we've checked your sample, we record the result and destroy the test kit and contents.

If you have any questions, please call our free helpline on **0800 707 60 60**. This includes if you:

- need help to do the test
- are unsure if you should use it, for example, if you've had surgery
- have a stoma bag (colostomy or ileostomy) and need advice.

It's best to collect your sample when you're not having a period. Avoid the 2 days before or after you bleed.



This is an image of the home test kit. Instructions for using the kit are inside the packaging.

OR

Doing the screening test

6



The test looks for tiny amounts of blood in your poo.

You can do the test on your own or you can ask someone to help you.

To do the screening test, you need to collect a small amount of your poo.



To catch your poo you can use:

- toilet paper



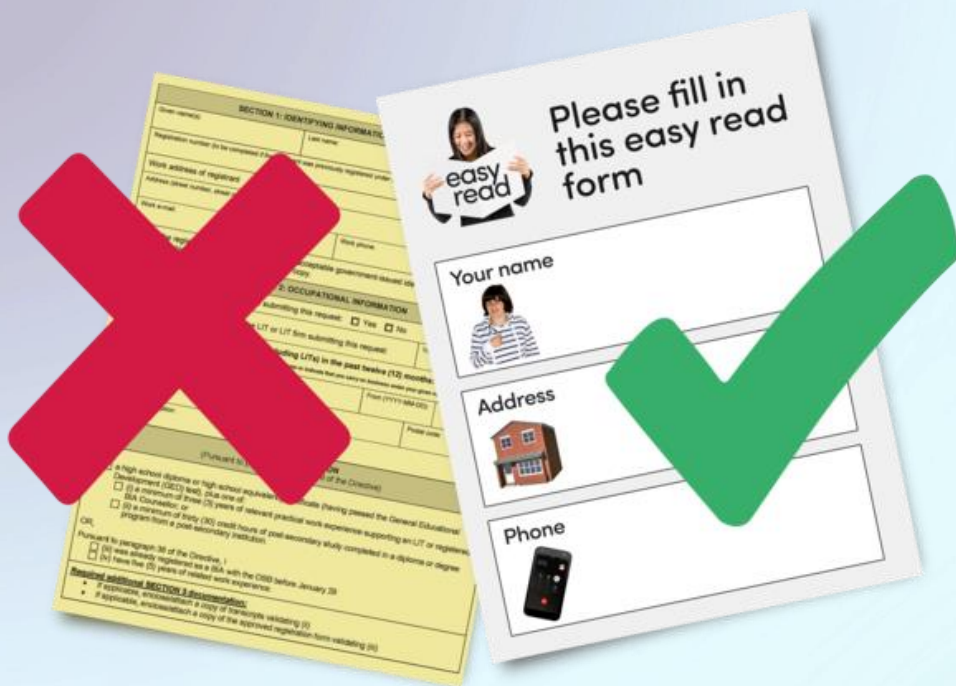
- a clean empty container

[Instructions on how to use the home test kit](#) are available in English and 30 other languages. There is also a [short animation explaining how to use the kit](#) with subtitled versions in English, British Sign Language and other languages.

Resources for people with a learning disability and people with low levels of literacy include:

- an [easy guide](#)
- an [audio podcast](#) version of the 'Your guide to NHS bowel screening' leaflet
- simple animations showing screening tests offered to men and women throughout their lives, including bowel cancer screening:
 - in an [English language version](#)
 - in the [10 other most requested languages](#)

Translations of the leaflet are available.



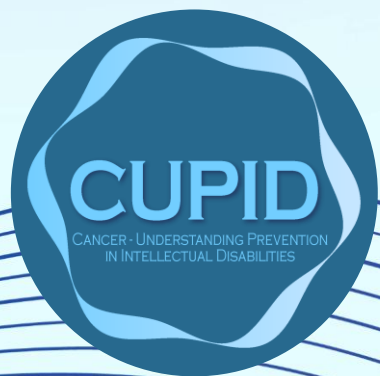
Have a go...



On your tables there are vignettes relating to cancer screening/cancer prevention.

Using the principles, have a go at changing them into a more “Easy Read” friendly statement.

The below are taken from Cancer Research UK.



What picture could you put in this column?	Below have a go at writing simple sentences based of the vignettes provided.

Vignette 1 – Sun safety

No sunscreen, no matter how high the Sun Protection Factor (SPF), can provide 100% protection from the sun. So it should be used together with shade and clothing to give your skin the best protection.

We recommend using sunscreens with:

- SPF 30 or higher (UVB protection)
- A high star rating of 4 or 5 stars (UVA protection)

UVA protection can also be shown by the letters 'UVA' in a circle. So, if you can't find the star rating on the bottle, make sure the product you use has this symbol instead. The UVA circle symbol means it meets the EU minimum standard for UVA protection.

Apply sunscreen 30 mins before going out, and again just before you head outside. By applying twice, you are less likely to miss areas and more likely to get a thick-enough layer of sunscreen.

Vignette 2 - Obesity

Obesity is a cause of 13 different types of cancer. Having a healthy diet helps you keep a healthy weight, or lose weight, which can reduce the risk of cancer.

There are some foods that can increase the risk of cancer, but eating these doesn't mean you'll definitely get cancer.

For a healthy balanced diet, cut down on:

- Processed and red meat = Eating a lot of processed meat or red meat can increase the risk of bowel cancer.
- Alcohol = Alcohol causes 7 types of cancer. So, whatever your drinking habits, cutting down reduces the risk.
- High-calorie foods and sugary drinks = Foods high in fat, sugar or calories can make it harder to keep a healthy weight.

Vignette 3 - Smoking

Smoking causes at least 16 different types of cancer and is the biggest cause of lung cancer in the UK.

Smoking causes other diseases too, such as heart disease and various lung diseases.

If you smoke, stopping completely is the best thing you can do for your health.

Both the amount you smoke, and the length of time you've been smoking for, affect your cancer risk.

The more cigarettes you smoke a day, the higher your risk of cancer. So reducing the number of cigarettes you smoke a day is a good first step.

But the number of years you smoke for affects your cancer risk the most. So it's important to make a plan to stop smoking completely.

Vignette 4 - Alcohol

There are many ways that alcohol can cause cancer.

Some of the main ways are:

- Damage to cells. When we drink alcohol, our bodies turn it into a chemical, called acetaldehyde. Acetaldehyde can damage our cells and can also stop cells from repairing this damage.
- Changes to hormones. Alcohol can increase the levels of some hormones in our bodies such as oestrogen and insulin. Hormones are chemical messengers, and higher levels of oestrogen and insulin can make cells divide more often. This increases the chance that cancer will develop.
- Changes to cells in the mouth and throat. Alcohol can make it easier for cells in the mouth and throat to absorb harmful chemicals that cause damage.



6. Stay safe in the sun

The sun is the main cause of skin cancer.



It is important to stay safe in the sun.
How not to get sunburn:



- stay in the shade, especially in the middle of the day



- wear a hat, T-shirt and sunglasses



3. Watch your weight

Being overweight can cause many types of cancer, including breast and bowel cancer.



To be healthier and help you lose weight you need to:

- eat healthier foods



- eat less unhealthy food



- move about more.



1. Stop smoking

Smoking causes most lung cancers.

It also makes you more likely to get many other types of cancer.



Stopping smoking completely is the best way to try to not get cancer. And it is never too late to stop



It is not always easy, but you can get lots of free help.

Talk to a doctor, nurse or pharmacist.



You are more likely to stop if you get support from free stop smoking services.



2. Drink less alcohol

Drinking beer, wine or spirits can make you more likely to get cancer.



Drink less alcohol to be healthier.

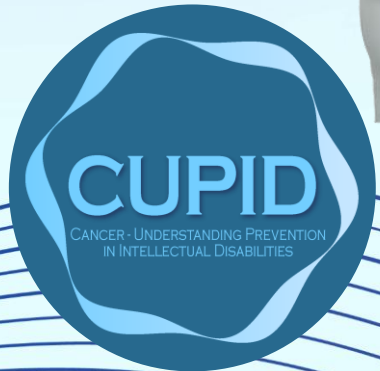


It is a good idea to keep a note of how much you drink.



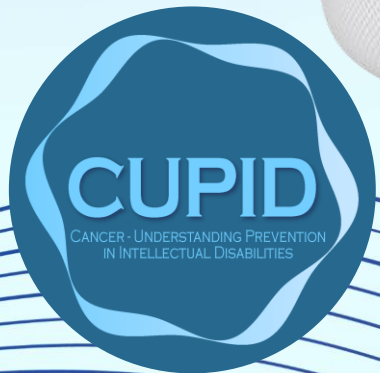
You can find out more about how to drink less alcohol at:
www.cruk.org/alcohol

How did you find that exercise?



**Remind
Me ...**

**What's the
reminder for?**



Let us recap

- 1) We know what accessible information is.
- 2) We know what accessible formats are used in other countries.
- 3) We have had a go at putting information into an easy to read format.

Part 2 – Consideration how health systems to make cancer screening and prevention more accessible

Go to

www.menti.com

Enter the code

6620 7255

10

Minutes



Or use QR code

Take away training messages:



There are 12 key principles of easy-to-read information



Applied principles to cancer prevention and cancer screening information



Discussed and listed of considerations to make cancer screening and prevention more accessible





Thank you for listening and taking part.



Does anyone have any questions?



Health Systems across the EU (and beyond): What does cancer screening and prevention look like?

11am – 12pm

Dr Kate Sykes and Aysenur Dogan

Kate.sykes@northumbria.ac.uk



By the end of this session, you will;

- Have explored and understand the different health systems relating to cancer screening and prevention (Part 1)
- Explored how the health system design can positively and negatively impact people with ID (Part 2)



Part 1: Health systems, cancer screening and prevention

Go to

www.menti.com

Enter the code

4680 5309



Or use QR code



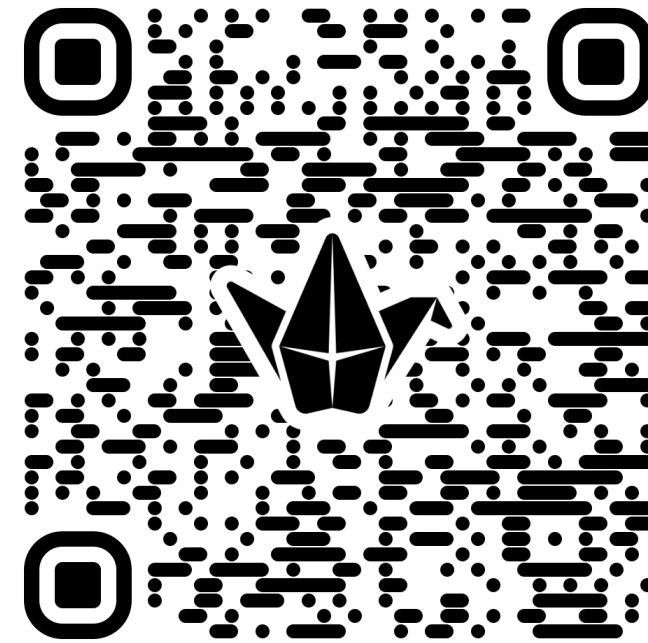


Let us review the results

Part 2: What are your reflections about how health system across Europe positively or negatively impact people with intellectual disabilities?

Go to

tinyurl.com/5n769se2



Or use QR code

COST Action CA21123

Cancer- Understanding Prevention in Intellectual Disabilities (CUPID)



Let us review the results

Take away training messages

- A summary of what health systems look like across different countries
- A summary of what prevention initiatives look like across different countries
- A summary of what cancer screening initiatives look like across different countries
 - Considered how these impact people with intellectual disabilities
 - These interactive sessions will be provided this afternoon for you to take away.



T₁ H₄ A₁ N₁ K₅
Y₄ O₁ U₁

COST Action CA21123 CANCER- UNDERSTANDING PREVENTION IN INTELLECTUAL DISABILITIES (CUPID)

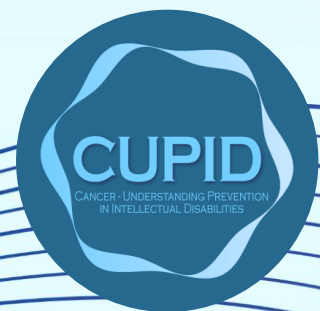
Learning from CUPID WG1:

Voices of People with Intellectual Disabilities on Cancer

Screening and Prevention

13th April, 2025

**Dr Margaret Denny, Dr Suzanne Denieffe,
Dr Oliwia Kowalczyk, and Dr Laura Widger**



Presenters



Dr Margaret Denny
CUPID WG1 Co-Lead
University of Maribor, Slovenia



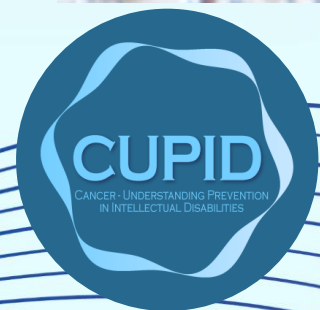
Dr Suzanne Denieffe
CUPID Chair
South East Technological University,
Ireland



Dr Oliwia Kowalczyk CUPID
WG1 Co-Lead
Nicolaus Copernicus University
Collegium Medicum, Poland



Dr Laura Widger
South East Technological University,
Ireland

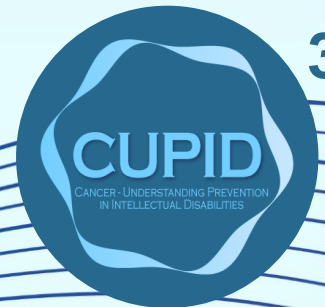


Acknowledgement



Session Outcomes

1. **Introduction to Working Group 1**, which focuses on advancing knowledge and strategies related to cancer prevention
2. A detailed examination of a relevant **case study** to identify and analyse the multifaceted barriers that hinder effective cancer prevention measures and timely diagnosis.
3. **Impact on education, policy/practice and research.**



Part 1: Introduction to WG1

WG1 Objectives:

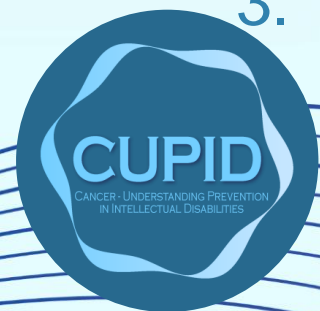
- Co-produce knowledge on cancer prevention strategies for persons with IDD across the EU.
- Use peer learning to exchange information between persons with IDD, carers, support persons, and healthcare professionals.



Part 1: Introduction to WG1

WG1 Tasks:

1. Create an international interdisciplinary team including persons with IDD from COST countries.
2. Exchange co-produced knowledge through online focus groups and questionnaires, supported by advocacy groups and based on Patient Public Involvement (INVOLVE, 2020).
3. Recommend research and training needed to improve cancer prevention strategies and policy for persons with IDD.



Part 1: Introduction to WG1

WG1 Evidence and Findings:

Data from WG1 and Training School

- Emphasis on participatory/co-production/co-engagement methods
- Importance of co-production: inclusion boosts relevance and accessibility
- Policy Experimentation



Part 2 (Training Focus): Case Study

Walk in Raymond's Shoes: Barriers/Challenges/Solutions

Discovering Raymond's Roadblocks

Challenges Raymond Faced!



Poor Communication 🗣️

Lack of Training in IDD 🧠

Neglect of Preventive Care 🛡️

Emotional and Psychological Challenges 💔

Systemic Barriers 🏥

Strengths Overlooked 🎵

Late or Missed Diagnosis 🩺

CUPID

CANCER · UNDERSTANDING PREVENTION
IN INTELLECTUAL DISABILITIES

Part 2 (Training Focus): Challenges

- Disparities in cancer screening and prevention for persons with IDD
- Limited accessible resources
- Education
- Communication
- Underrepresentation in public health strategies
- Lack of policies



Learning from Raymond's Story:

Voices of Persons with IDD on Cancer Screening and Prevention

Impact on:

1. Education
2. Policy/Practice
3. Research

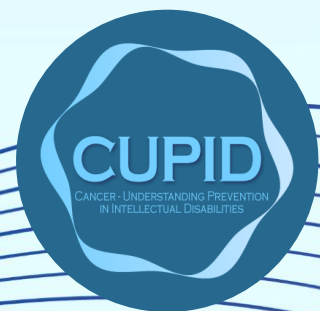


1. Education

Professional Training Gaps: Emphasises the need for medical, nursing, and allied health training on IDD

Interdisciplinary Curriculum Development: Advocates for modules on early detection, communication strategies, and health rights of people with IDD.

Empathy Building: Encourages education that highlights the underestimated depth of understanding among individuals with IDD.



2. Policy and Practice

Inclusive Screening Policies: Screening and prevention programmes must be accessible to persons with IDD.

Standardised Communication Protocols: Healthcare professionals must directly communicate with persons with IDD and use accessible materials (Easy-Read etc).

Mandatory Training: Ongoing staff training on IDD-specific health needs should be policy-driven.

Focus on Early Diagnosis: Encourage proactive testing when symptoms are reported, even if communication is limited.



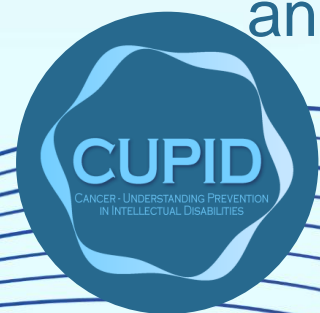
3. Research

Diagnostic Delays: Investigate causes of delayed diagnosis in IDD populations.

Effective Communication Tools: Study methods for assessing pain and symptoms in non-verbal persons.

Health Outcome Studies: Research cancer outcomes in persons with IDD to inform care guidelines/policy.

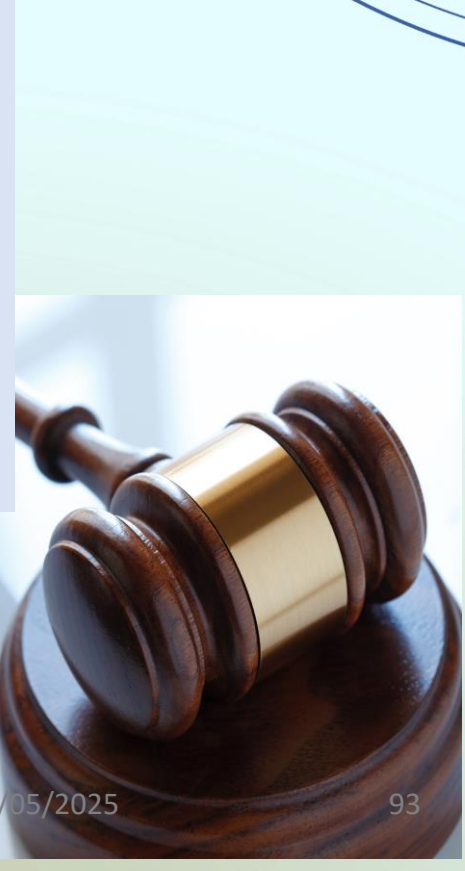
Family Involvement: Explore the critical role of families in healthcare navigation and decision-making.



Key Takeaway

Raymond's journey teaches us that cancer prevention, early diagnosis, empathetic communication, and proactive healthcare are essential.

His resilience reminds us never to underestimate the capacities/capabilities of persons with IDD.

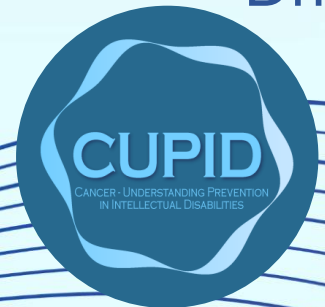


Raymond's Legacy: A Call to Action

Empower healthcare providers through education, co-production.

Reform policies to promote inclusive cancer prevention
healthcare.

Drive research that centres the voices of persons with IDD.

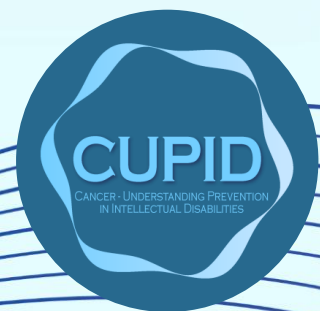


Link To Book on the TS in Prague

Title: Advancing Equity in Cancer Prevention: Highlights from Year 2 CUPID Training School Working Group 1

17-19 September 2024,
Prague, Czech Republic

<https://read.bookcreator.com/KIbzV5JSoAOpDDDtdGvXM4gnC5z1/56xJxBtmSAKGvrhrAO5pIA>



References:

Lower Participation in Screening Programmes:

Golubović, Š., Simin, D., Vuković, V., Demirović, S., & Milutinović, D. (2024). Exploring Cancer Prevention Challenges for People with Intellectual Disabilities: Perspectives from Family Caregiver. *Healthcare*, 12(23), 2463. <https://doi.org/10.3390/healthcare12232463>

Caregiver Perspectives and Challenges:

Klara S, Elmadani M, Éva H, Lívia T, Mbaabu G, Hamad OF, Mesmar A, Andrade D, Mate O.(2023). Cancer Prevention in Adults with Intellectual Disabilities: A Systematic Literature Review of Caregiver Perspectives in Institutional and Home Care Settings. *Int J Environ Res Public Health*. 2024 Oct 23;21(11):1402. doi: 10.3390/ijerph21111402. PMID: 39595669; PMCID: PMC11593732.

Need for Tailored Educational Interventions:

Elmadani,M. Klara, S., Kiptulon, E.K., Andrade,D., Orsolya,M. (2024).A systematic review of educational interventions to enhance cancer awareness and screening in individuals with intellectual disabilities: A mixed-methods approach. *Research in Developmental Disabilities*,,Volume 155,104867, ISSN 0891-4222, <https://doi.org/10.1016/j.ridd.2024.104867>.

Challenges:

Golubović, Š., Simin, D., Vuković, V., Demirović, S., & Milutinović, D. (2024). Exploring Cancer Prevention Challenges for People with Intellectual Disabilities: Perspectives from Family Caregiver. *Healthcare*, 12(23), 2463. <https://doi.org/10.3390/healthcare12232463>

Diagnosis

McMahon, M. (2023). *People with ID often diagnosed late when cancer is well advanced*. Trinity College Dublin

Policy and Systemic Recommendations: <https://cupidproject.eu/publications/>

Evaluation

<https://www.menti.com/aled1ogdjhm5>



Cancer screening and cancer prevention- How do these apply to people with ID and what should health systems do?

A world café approach

2pm – 4pm

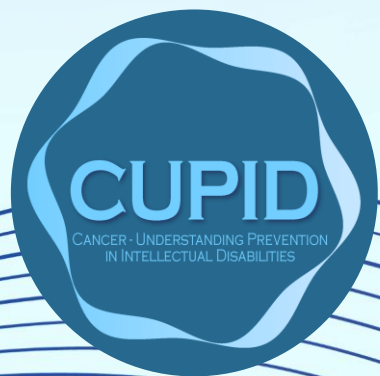


Table 1a

1. Soner Dogan (Host)
2. Agnieszka Żyta
3. Kevin O'Hagan
4. Gabriela Štefková
5. Kathy Sheridan
6. Spela Golubovic
- 7.

Table 2a

1. Peter Knapp (Host)
2. Eda Sahin
3. Chloe Delaney
4. Trine Toft Sørensen
5. Gunilla Kulla
6. Margaret Denny
- 7.

Table 1b

1. Martin McMahon (Host)
2. Vera Dimitrievska
3. Trine Allerslev Horsbøl
4. Dragana Milutinović
5. Shauna Walsh
6. Mairead O Connor
- 7.

Table 2b

1. Bilge Tuna (Host)
2. Burcu Akciğer
3. Sanela Ciric
4. Kálya Yasmine Lima
5. Francoise Hickey
6. Laura Widger
- 7.

Table 4a

1. Kate Sykes (Host)
2. Sinead Foran
3. Eleonora Passeri
4. Aysegul ILGAZ
5. Cara Martin
- 6.
- 7.

Table 3a

1. Aysenur Dogan (Host)
2. Kristina Daniunaite
3. Gemma Smyth
4. Verma Abigail Lucas
5. Lau Caspar Thygesen
- 6.
- 7.

Table 4b

1. Vladimir Vukovic (Host)
2. Dušanka Tadić
3. Monika Chełchowska
4. Natalie Gil
5. Dalia Ibrahim
- 6.
- 7.

Table 3b

1. Maarten Cuypers (Host)
2. Katarzyna Ćwirynkało
3. Genevieve Breau
4. Amina Banda
5. Suzanne Denieffe
- 6.
- 7.

By the end of this session, you will;

- Have engaged in round table discussions relating to cancer prevention and screening topics and considered them in relation to people with ID.
- Have identified what health systems need to consider for these topics in relation to people with ID.
 - Coproduced research questions.



What is a world café approach?

- Structured way of exploring issues, through discussions in small groups.
- Informal “café-style” environments with tables and tablecloths, drinks, snacks and coloured pens, and inviting staff to come along to explore issues.



- Thinking and reflecting about all the information covered in this training school...

“What do health systems need to do in terms of cancer screening and cancer prevention to make them more accessible and inclusive for people with intellectual disabilities?”



What can health systems do to make cancer **screening and vaccination programmes more inclusive and equitable** for people with intellectual disabilities?

How can health systems better support people with intellectual disabilities in understanding and **managing inherited or age-related cancer risks**?

What can health systems do to **make healthy lifestyle choices more accessible and appealing** for people with intellectual disabilities?

How can we improve education and awareness about **environmental cancer risks, like UV exposure and pollution**, in ways that are meaningful and accessible for people with intellectual disabilities?

Duration	Activity
5 minutes	Welcome, what the world café approach is, groupings
18 minutes	Round 1
18 minutes	Round 2
7 minutes	Break
18 minutes	Round 3
18 minutes	Round 4
7 minutes	Break
25 minutes	Harvest/feedback

There will be 2 tables running at once.
After each 18-minute round move to next table.
1a goes to 2a, 2a goes to 3a ect.



18:00

07:00



25:00

Harvest

- 25 minutes.
- Summary of table discussions.
- Key messages that could become research questions.

Next steps

- Review the summary from each table
- Generate research questions from the key topics identified
- Identify which topics has/has not been researched previously
 - These could be used to develop specific research studies
 - Write this world café session up for publication



Training school closing remarks and Evaluation

4pm – 4:45pm



Equitable Cancer Prevention & Screening: Advancing Inclusion for People with Intellectual Disabilities

Organise a training school about organisational context and implementation of equitable cancer prevention strategies including access to screening programmes.

WG2: Cancer prevention policies: audit and evaluation

WG1: The interdisciplinary co-production team

WG3: Universal EU Cancer prevention strategy methodology

Organise a training school about health system goals for targeted cancer prevention and screening programmes for people with intellectual disabilities.

WG4: Dissemination and Outreach

Recap of training school objectives

1. To bring people together from different working groups within the CUPID COST action, to gain practical skills, and awareness of methods, and frameworks that they can use or apply in their work.
2. Equip participants with knowledge on the organisational context and strategies for implementing equitable cancer prevention and screening programmes.
3. Examine how different health systems approach cancer prevention and screening, including policy that can impact on access and equity for people with Intellectual Disabilities.
4. Develop recommendation from discussions to improve accessibility and participation in cancer screening programmes and cancer prevention initiatives for individuals with Intellectual Disabilities.



What have we covered over the past two days?

- 1) Cancer screening = methods, inequity, effectiveness and uptake
- 2) Cancer prevention = methods, policy
- 3) Cancer screening and prevention accessible information
- 4) Health systems in different countries and what they need to change
- 5) The voice of people with intellectual disabilities



Closing remarks from Dr Suzanne Denieffe

Action Chair



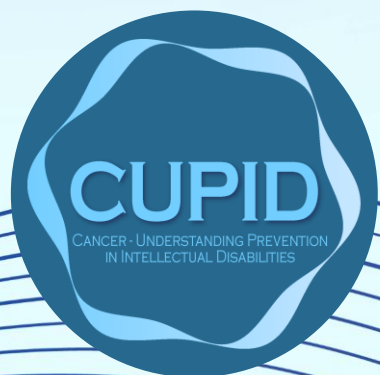
Thank you!

- Everyone who joined us on the training school.
- Organising committee for developing.
- All our presenters for developing and presenting their sessions.
- Martin, Gavin and Keiva, and all the staff at Trinity for hosting.
- COST EU for funding this project, enabling us all to meet.



Link to evaluation of day 2 and overall
training school -

<https://forms.cloud.microsoft/e/F2qc8f225q>





Social events tonight

- 5pm - Trinity Trails Guided Tour and Book of Kells Experience – Meet at Main Square, Trinity College Dublin
- For those who booked – 8pm - Celtic Nights at The Arlington Hotel

Conference tomorrow

Breaking Barriers: Enhancing Cancer Care for Individuals with Intellectual Disabilities

This conference, the first of its kind in Ireland and internationally, focuses on the critical and under-researched issue of cancer in individuals with intellectual disability. Studies show this population is more susceptible to developing specific cancers, often diagnosed at later stages, resulting in poorer outcomes and higher mortality rates.

The conference will explore key topics, including: **The epidemiology of cancer in people with an Intellectual Disability, Screening, Health Surveillance, and Detection, Ethics, Advocacy, and Patient and Public Involvement (PPI), and Policy, Practice, and Reasonable Adjustments in Cancer Settings.**

Bringing together people with intellectual disabilities, their families, carers, and national and international experts across health and social care disciplines, public organisations, NGOs, and advocacy organisations, this event seeks to raise awareness, share knowledge, and promote collaboration to improve cancer care and outcomes for this marginalised, hard to reach group.



School of Nursing and Midwifery, 24 D'Olier Street
Wednesday, 14th May, 2025, 08.30–16.30hrs

Expert Speakers:

Dr Maarten Cuypers: Epidemiologist at Radboud University Medical Centre in Nijmegen, The Netherlands.

Dr Alyson Mahar: Cancer Epidemiologist at Sinclair Cancer Research Institute, Queen's University, Ontario, Canada.

Professor Maeve Lowery: Oncologist and clinical lead for Trinity St James Cancer Institute

Dr Triona McCarthy: Consultant in Public Health Medicine at the HSE National Cancer Control Programme (NCCP)

Concurrent Presentations from:

Health Service Executive, Trinity St James Cancer Institute, Irish Cancer Society, Decision Support Service, National Screening Service, CUPID COST Action



THANK YOU



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COST Description

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