

***Beyond Words: A Focus on Augmentative communication.***

***Augmentative and Alternative Communication  
and its critical role in cancer prevention  
and screening for people with intellectual disabilities***

***Webinar: 06 May 2026***

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# *Beyond Words*

*Augmentative and Alternative Communication  
and its critical role in cancer prevention  
and screening for people with intellectual disabilities*

**Part 1 / Dr Oliwia Kowalczyk :**  
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**Focus on AAC - Communication as a health  
equity issue**



# Cancer Mortality: A Preventable Gap

• [Cancer](#). 2021 Nov 17;128(6):1267-1274. doi: [10.1002/cncr.34930](https://doi.org/10.1002/cncr.34930)

## Cancer-related mortality among people with intellectual disabilities: A nationwide population-based cohort study

[Maarten Cuypers](#)<sup>1,2</sup>, [Bianca W M Schaik](#)<sup>1</sup>, [Anne J N Boonman](#)<sup>1</sup>, [Jenneken Naaldenberg](#)<sup>1</sup>, [Geraline L Leusink](#)<sup>1</sup>

• [Author information](#) • [Article notes](#) • [Copyright and License information](#)

PMCID: PMC9299498 PMID: [34787905](#)

➤ [Cancer Med](#). 2024 May;13(9):e7210. doi: [10.1002/cam4.7210](https://doi.org/10.1002/cam4.7210).

## Cancer risks related to intellectual disabilities: A systematic review

[Amina Banda](#)<sup>1</sup>, [Jenneken Naaldenberg](#)<sup>1</sup>, [Aura Timen](#)<sup>1</sup>, [Agnies van Eeghen](#)<sup>2,3</sup>, [Geraline Leusink](#)<sup>1</sup>, [Maarten Cuypers](#)<sup>1</sup>

Affiliations + expand

PMID: 38686623 PMCID: PMC11058689 DOI: [10.1002/cam4.7210](https://doi.org/10.1002/cam4.7210)

# 1.5×

Cancer reported as cause of death 1.5×  
more often in people with ID

Concentrated in  
screening-  
preventable cancers



# Screening Uptake: The Numbers

NHS England 2021–22 (Sykes et al., Brit J Learning Disab, 2024) · Andiwijaya et al., meta-analysis, 2022 · Chan et al., Cancer Epidemiol, 2022

## CERVICAL SCREENING

General: 67% · ID: 31%

**Gap: -36 pp**

## BREAST SCREENING

General: 62% · ID: 47%

**Gap: -15 pp**

## BOWEL SCREENING

General: 67% · ID: 50%

**Gap: -17 pp**

Primary barrier: inaccessible information  
& lack of communication support



# Augmentative & Alternative Communication (AAC)

## UNAIDED AAC

### Gesture & Body Language

Pointing, nodding, facial expression — universal and always available

### Makaton

Structured signing using symbols and signs alongside speech

### PECS-based Approaches

Picture Exchange Communication System adapted for health contexts

## AIDED AAC

### Symbol Boards & Easy Read

LOW-TECH

Low-tech: communication books, picture cards, accessible documents

### Talking Mats

LOW-TECH

Visual framework enabling preference and opinion expression in health settings

### Speech-Generating Devices

HIGH-TECH

High-tech: Proloquo2Go, Grid 3 — digital, voice-output AAC systems



# The ID Communication Profile

RECEPTIVE VS. EXPRESSIVE ASYMMETRY

Receptive Language · What is understood

**STRONGER (72%)**

↕ *The clinical gap — frequently misread as incomprehension*

Expressive Language · What can be produced

**WEAKER (40%)**

## CLINICAL IMPLICATION

Silence ≠ incomprehension.

People with ID often understand far more than they can express back. Diagnostic overshadowing begins here.

**60–90%**

of people with ID have receptive and expressive language difficulties

**up to 95%**

have reduced literacy levels

**NOT one group**

ID is not a single condition — communicative capacity spans a wide spectrum



# The Double Burden

HEALTH LITERACY = capacity to acquire · comprehend · evaluate · apply health information

## Burden 1 — Reduced baseline health literacy

Cognitive-linguistic differences: phonology, vocabulary, reading comprehension, contextual application of written information

## Burden 2 — Information environments that assume high literacy

Screening letters & consent forms written at reading age 11–14. Pre-symptomatic testing conceptually demanding without tailored explanation.

**The gap is structural — not personal. The problem is the information environment, not the person.** ·

Chinn 2016 · Vetter et al. 2022



### READING AGE GAP

Cancer screening info

**Age**  
**11–14**

Adults with mild–mod ID

**Age**  
**7–9**

Gap

**2–7**  
**years**

*Not just literacy. Screening — being tested for something you cannot feel — requires tailored explanation.*

# What the Evidence Shows

Key findings from peer-reviewed literature, 2017–2026

## Systematic Review · 29 studies

Wilson et al. JARID 2026

Most current comprehensive review. Up to 95% of people with ID have reduced literacy. Co-production and facilitation are the key differentiators.

**THE FIELD'S MOST CURRENT REVIEW**

## Meta-Narrative Review

Chinn et al. Health Expectations · 2016

Honest baseline: evidence for Easy Read effectiveness was insufficient as a standalone tool. No consistent evidence of comprehension improvement from materials alone.

**THE CRITICAL BASELINE**

## Randomised Controlled Trial

Buell et al. · JARID · 2019

Simplified language + skilled mediation significantly outperformed all other conditions. Language alone: insufficient. Mediation alone: insufficient. Combined: effective.

**HIGHEST-QUALITY EXPERIMENTAL EVIDENCE**

## Observational · Conversation Analysis

Chinn · JARID · 2019

Easy Read used in only 22% of primary care consultations where available. The implementation gap — not the evidence gap — is the primary barrier.

**32 CONSULTATIONS · VIDEO ANALYSIS**

## Systematic Review

Hewitt et al. · JARID · 2023

Co-researchers with ID contribute meaningfully to health research quality. Inclusive design improves material performance. Evidence finding, not just ethics.

**CO-PRODUCTION AS EVIDENCE-BASED STANDARD**

## Scoping Review

Gibson et al. · JMIR · 2021

AAC technologies in clinical consultations improve information exchange for adults with ID. Multimodal, partner-supported approaches outperform single-mode interventions.

**AAC IN CLINICAL CONSULTATION SETTINGS**



# From Evidence to Implementation

## ✗ Easy Read leaflet alone

*distributed, not facilitated*

Insufficient evidence for comprehension improvement. Used in only 22% of consultations. Often left unread.

## ~ Mediation alone

*verbal explanation, no accessible material*

Modest effect. Depends entirely on individual clinician. Not reproducible or scalable.

## ✓ Easy Read + skilled facilitation

*co-produced, mediated delivery*

Significantly better outcomes (Iacono et al. RCT, 2020). The workshop model is the evidence-supported standard.

## ✓✓ Co-produced multimodal AAC

*developed with people with ID*

Best outcomes. Co-production as process standard. People with ID as active contributors — not passive recipients.

## The Co-Production Principle

Materials designed without the involvement of people with ID consistently underperform those developed with them.

**This is an evidence finding —  
and an ethical requirement  
under the UN CRPD.**





# **Theory meets a room.**

## ***Evidence meets people.***

Last month in Slovakia, an Easy Read workshop on cancer and cancer screening was delivered for people with intellectual disabilities.

This is what translation from evidence to implementation looks like.



# ***Beyond Words***

*Augmentative and Alternative Communication  
and its critical role in cancer prevention  
and screening for people with intellectual disabilities*

**Part 2 / Dr Margaret Denny:**

*denny.margaret@gmail.com*

**Easy Read/AAC workshop on cancer and  
cancer screening and education**



# KOŠICE- SLOVAKIA









# Ways of talking about cancer and cancer screening

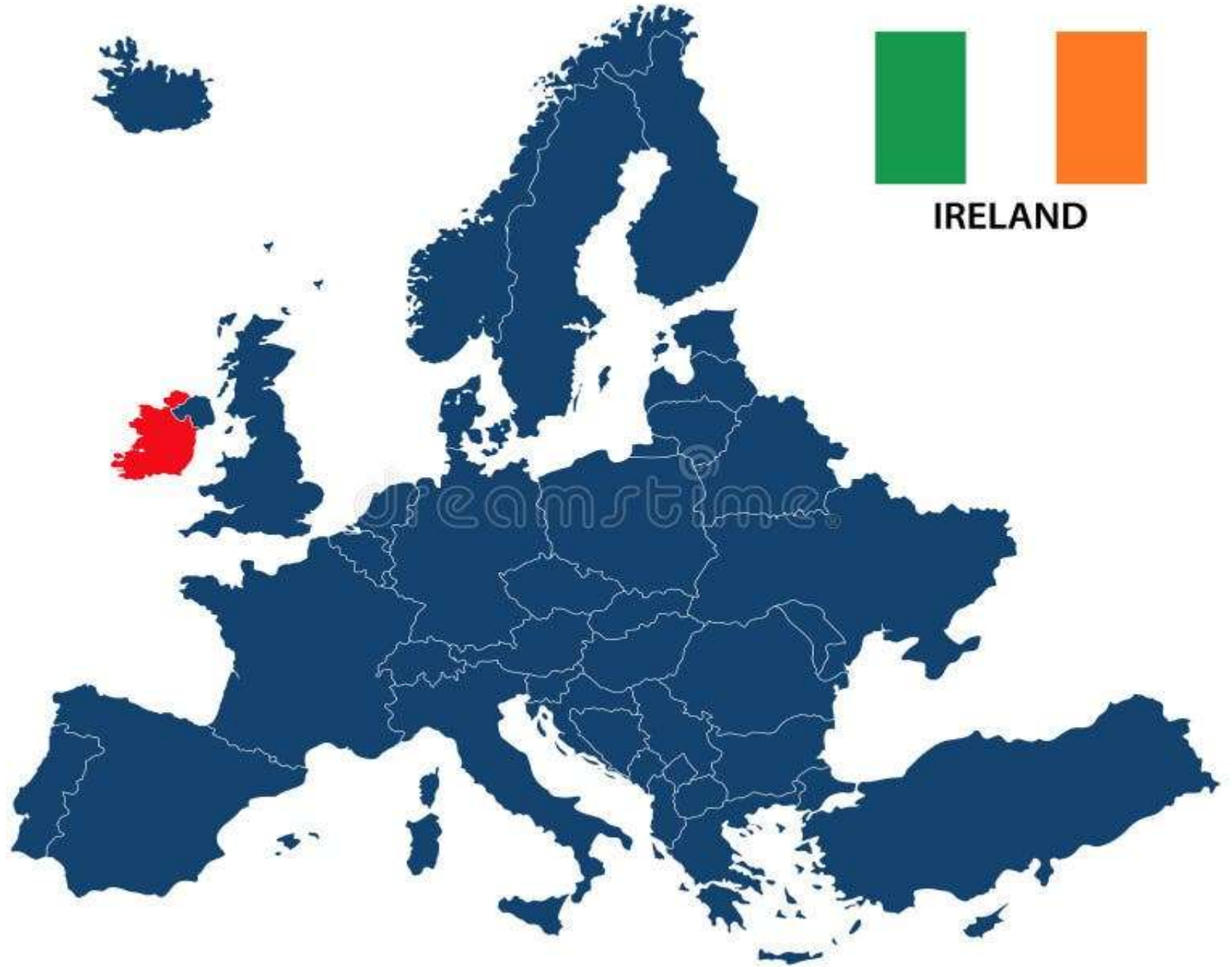
[Dr Margaret Denny](#)



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# Spôsoby, ako hovoriť o rakovine a skríningu rakoviny



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Consent to take photographs  
and put on our project site.



Súhlas s fotografovaním a zverejnením  
na našom projekte.



# Today

We will talk about cancer



# Dnes

Budeme hovoriť o rakovine





We will talk about the project

Cancer – understanding prevention in  
intellectual disabilities (**CUPID**)





Budeme hovoriť o projekte  
Rakovina – pochopenie prevencie  
mentálneho postihnutia (CUPID)





We will think about the  
different ways we talk to one  
another in healthcare





Budeme premýšľať o rôznych  
spôsoch, akými spolu v  
zdravotnej starostlivosti  
komunikujeme

At the end of this chat...



I am going to ask you  
to answer a few  
questions

# Na konci tohto rozhovoru...



Požiadam vás, aby  
ste odpovedali na  
niekoľko otázok

## Cancer Prevention and Services for People with Intellectual disability



**Why am I being asked these questions?**



A group of people are writing some instructions.



The instructions will help services support people with intellectual disabilities.



The guide will focus on health.

# Požiadam vás, aby ste odpovedali na niekoľko otázok ohľadom tohto Easy Read článku

## Cancer Prevention and Services for People with Intellectual disability



**Why am I being asked these questions?**



A group of people are writing some instructions.



The instructions will help services support people with intellectual disabilities.



The guide will focus on health.



# CUPID plan

The CUPID plan helps people with intellectual disabilities to know about cancer, cancer screening, and cancer education.

# CUPID

**Cancer- Understanding Prevention  
in Intellectual Disabilities**



Program CUPID pomáha ľuďom s mentálnym postihnutím dozvedieť sa o rakovine, skríningu rakoviny a vzdelávaní o rakovine.

# CUPID

**Cancer- Understanding Prevention  
in Intellectual Disabilities**



# CUPID What we do...

We talk about cancer.

We work with people with intellectual disabilities.

Many countries join us.

Screening finds cancer early.

We work together.



[This Photo](#) by Unknown Author is licensed under [CC BY](#)





[This Photo](#) by Unknown Author is licensed under [CC BY](#)

# CUPID Čo robíme...

Rozprávame sa o rakovine.

Pracujeme s ľuďmi s mentálnym postihnutím.

Pridáva sa k nám mnoho krajín.

Skríning odhalí rakovinu včas.

Pracujeme spolu.



# Cancer

**Cancer** is an illness.



# Rakovina

Rakovina je choroba.



## Cells



Your body is made of tiny parts called **cells**.

Cancer happens when cells in the body grow too fast.

# Bunky



Vaše telo je zložené z drobných častí nazývaných bunky.

Rakovina vzniká, keď bunky v tele rastú príliš rýchlo.

# Cause of cancer

Cells usually grow carefully.

Sometimes cells grow too fast.

They can form lumps.

These lumps stop the body  
working properly.

This is called cancer sometimes.





# Príčina rakoviny

Bunky zvyčajne rastú opatrne.

Niekedy bunky rastú príliš rýchlo.

Môžu tvoriť hrčky.

Tieto hrčky bránia telu správne fungovať.

Niekedy sa tomu hovorí rakovina.

# People with intellectual disabilities



Fewer people go for  
cancer screening.

Cancer may be found late.



# Ľudia s mentálnym postihnutím



Menej ľudí ide na skríning  
rakoviny.

Rakovina môže byť  
odhalená neskoro.



# Cancer Screening



Cancer screening is a health check.

It finds cancer early.

You may feel well.

Finding cancer early helps treatment start sooner.





# Skríning rakoviny

Skríning rakoviny je zdravotná prehliadka.

Rakovinu odhalí včas.

Môžete sa cítiť dobre.

Včasné odhalenie rakoviny pomáha začať liečbu skôr.



# Finding cancer early



Doctors can help sooner when cancer is found early.

Treatment can work better.

Sometimes cancer is found too late.

Early checks are important.



# Skoré odhalenie rakoviny



Lekári môžu pomôcť skôr, keď je rakovina odhalená včas.

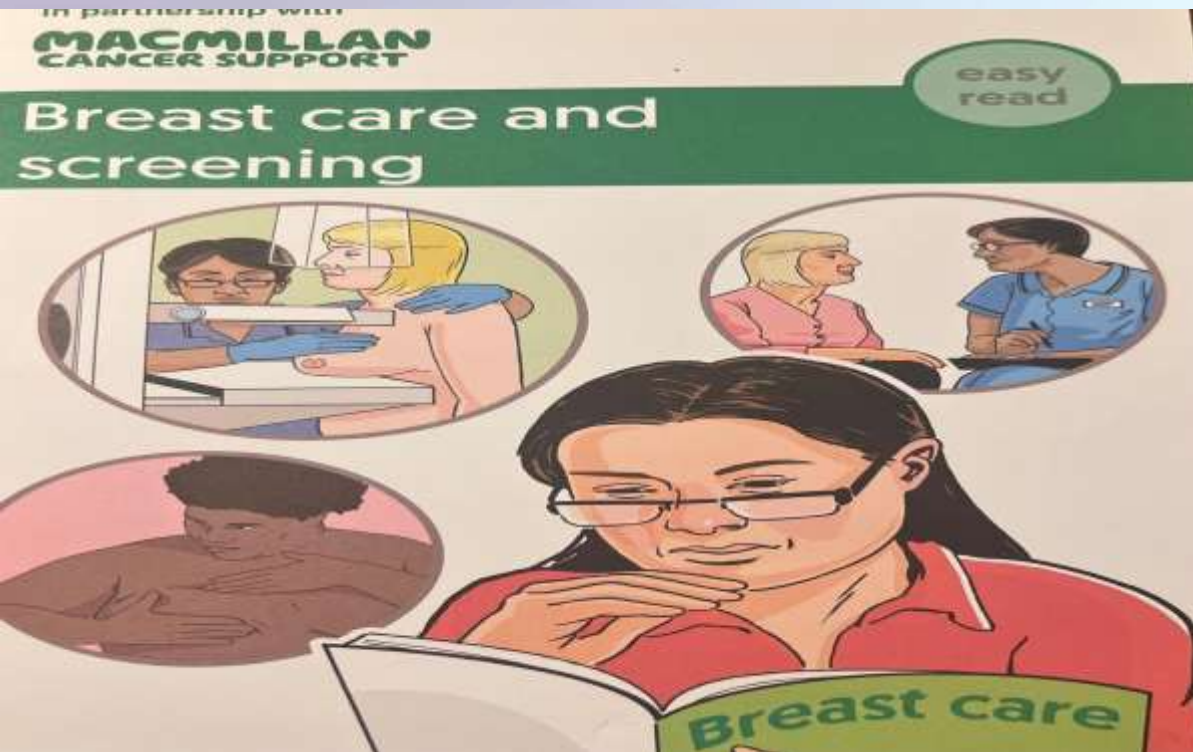
Liečba môže fungovať lepšie.

Niekedy sa rakovina objaví príliš neskoro.

Skoré kontroly sú dôležité.

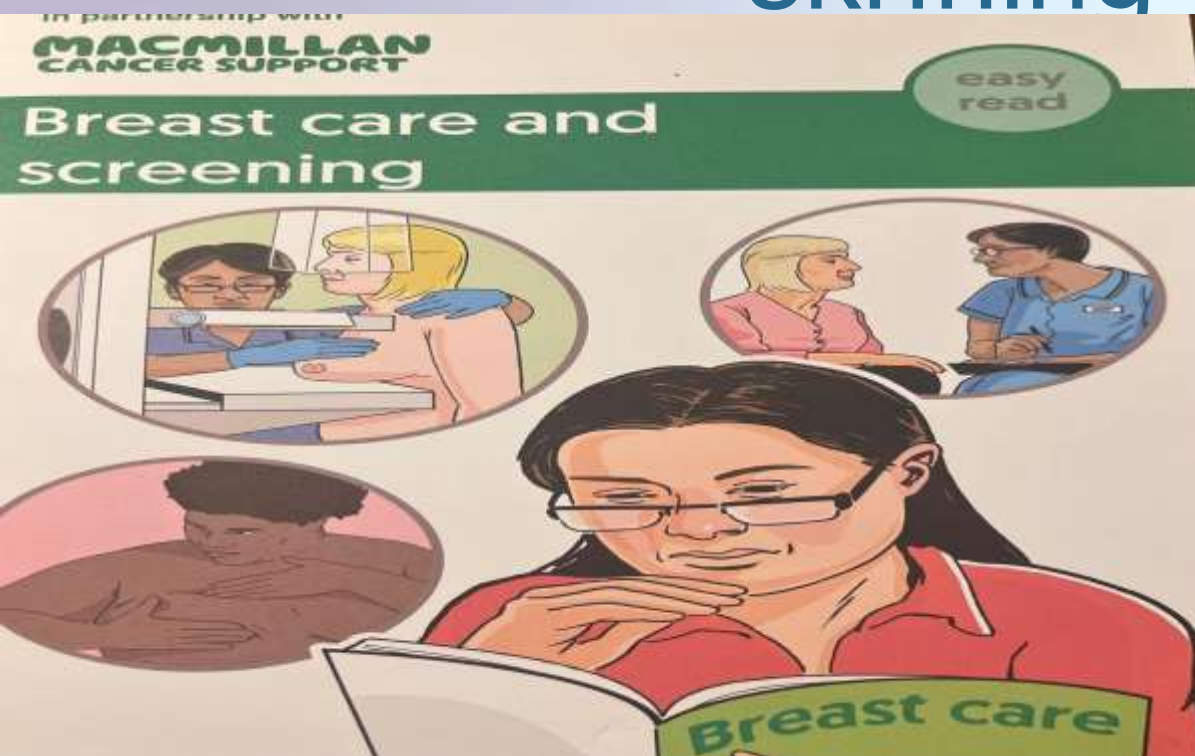


# Breast care and screening



I will now show you a book on breast care and screening.

# Starostlivosť o prsníky a skríning



Teraz vám ukážem knihu o starostlivosti o prsníky a skríningu.

# Chat

**How does talking help people look after their health and go for cancer screening?**



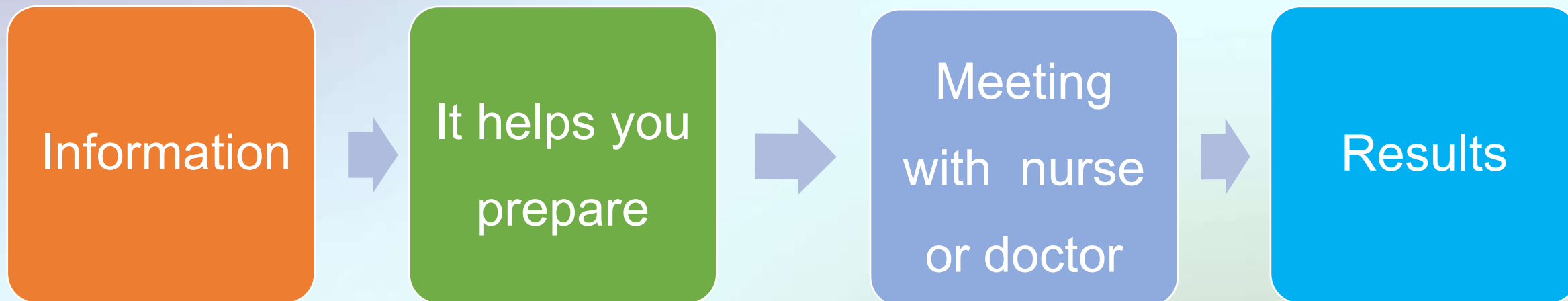


# Chat

**Ako rozprávanie  
pomáha ľuďom  
starat' sa o svoje  
zdravie a podstúpiť  
skríning rakoviny?**



# Cancer screening helps you understand



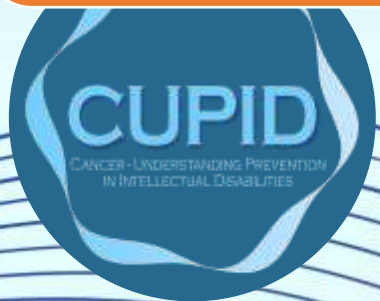
# Skríning rakoviny vám pomôže lepšie pochopiť

Informácie

Pomáha ti  
to pripraviť  
sa

Stretnutie  
so sestrou  
alebo  
lekárom

Výsledky



# Talking with healthcare staff can be hard



# Rozhovor so zdravotníckym personálom môže byť náročný



# Talking in different ways

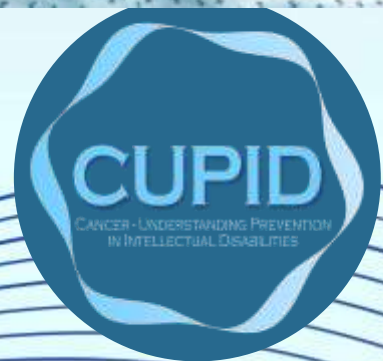


Helps with screening.

We can use gestures, symbols, and devices.

Helps people who find talking hard.

Helps with healthcare.



# Rozprávajú sa rôznymi spôsobmi

Pomáha to pri skríningu.

Môžeme používať gestá, symboly a zariadenia.

Pomáha ľuďom, ktorým je rozprávanie ťažké.

Pomáha to so zdravotnou starostlivosťou.





Eye movements  
& eye gaze



Vocalisations  
(i.e. non-speech  
sounds)



Gestures  
(e.g. pointing)

# UNAIDED AAC

(Augmentative and alternative  
communication)



Body & head  
movement



Facial  
Expressions



Sign Language

# Low-Tech Talking Systems (Simple physical supports)

<https://www.autismadventures.com/category/communication/augmentative-and-alternative-communication-aac/>



# Nízkotechnologické hovoriace systémy (jednoduché fyzické podpory)

<https://www.autismadventures.com/category/communication/augmentative-and-alternative-communication-aac/>



# High-Tech ways of Talking (Electronic devices)



# Moderné spôsoby rozprávania (elektronické zariadenia)



# Talking



These ways of talking help at screening.

They help you understand.

They reduce worry.

Doctors can find cancer early.





# Rozprávanie

Tieto spôsoby rozprávania  
pomáhajú pri skríningu.

Pomáhajú vám pochopiť.

Znižujú obavy.

Lekári môžu rakovinu odhaliť  
včas.

# Appointment letter



You may get a letter about screening.

Someone can explain it simply.

You can ask questions anytime.

This helps you get ready.



# Menovací list



Môžete dostať list o skríningu.

Niektu to vie jednoducho vysvetliť.

Otázky sa môžete pýtať kedykoľvek.

To vám pomôže pripraviť sa.



# Talking to your doctor



Talking to your doctor is important.

You can use pictures or symbols to say how you feel.

You can ask questions about your health.

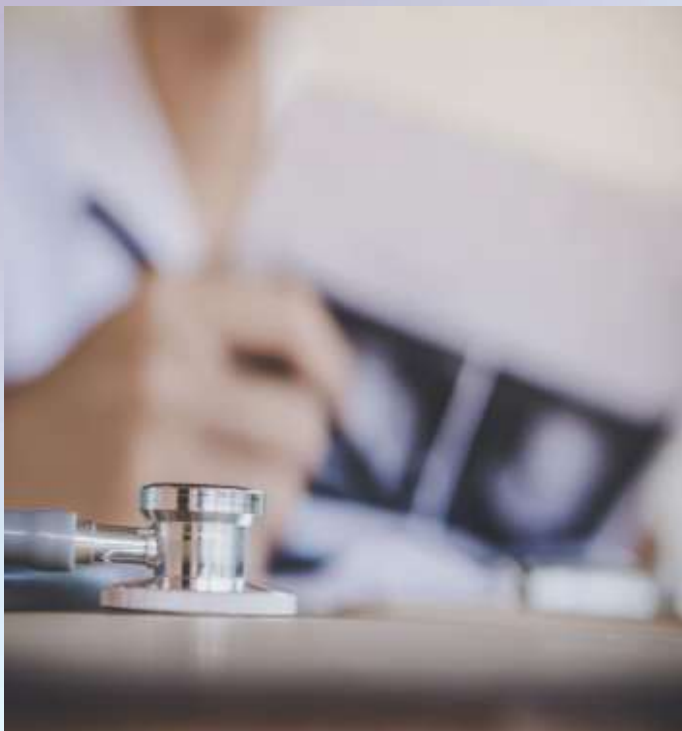


# Rozprávam sa s lekárom

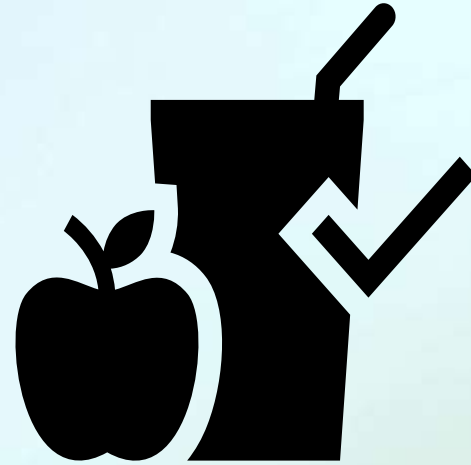
Rozhovor s lekárom je dôležitý.

Môžete použiť obrázky alebo symboly, aby ste vyjadrili, ako sa cítite.

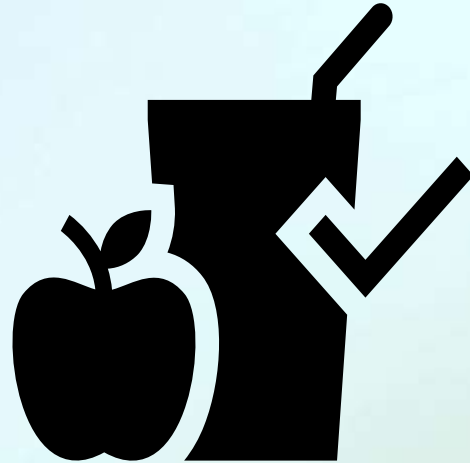
Môžete sa pýtať na svoje zdravie.



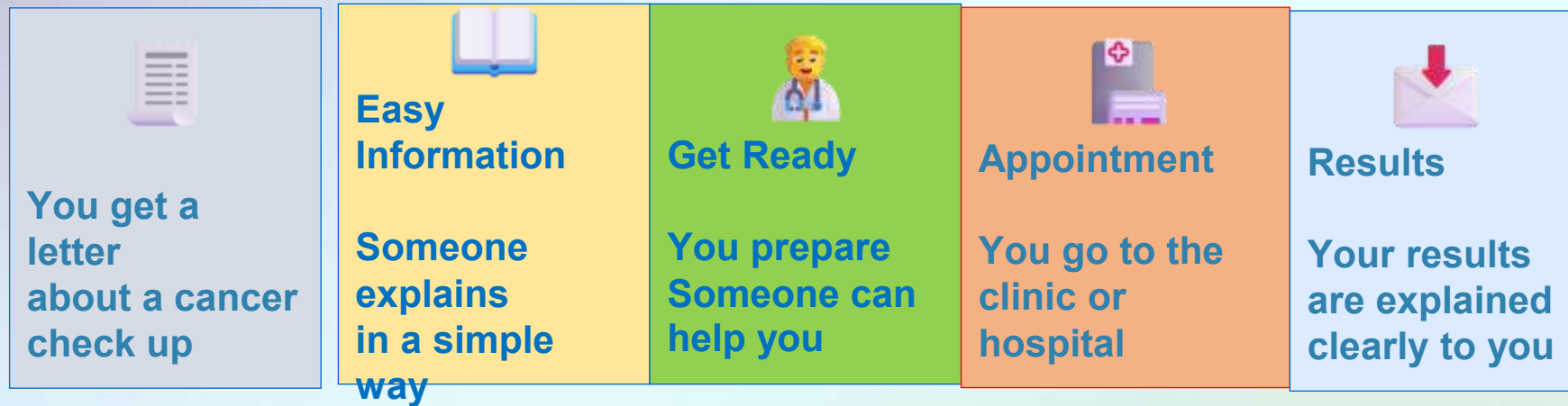
# Getting ready for a medical appointment



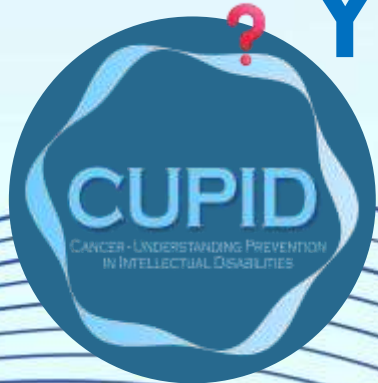
# Príprava na lekárske vyšetrenie



# What happens at a cancer check up



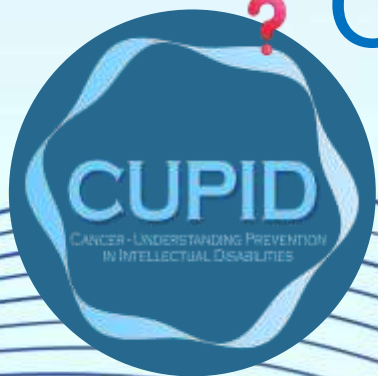
**You can ask questions at any time.**



# Čo sa deje na prehliadke na rakovinu



 Otázky sa môžete pýtať kedykoľvek.



# Cancer check up



**Doctors look for signs of cancer**



**The test helps find problems early**



**Finding cancer early can help with treatment**



# Kontrola rakoviny



**Lekári hľadajú  
Príznaky  
rakoviny**



**Test pomáha  
Nájsť problémy  
včas**



**Skoré odhalenie  
rakoviny  
môže pomôcť pri  
liečbe**



# Talking to your doctor



You can use  
pictures or symbols



You can say  
how you feel



You can ask  
questions



# Rozprávam sa s lekárom



**Môžeš použiť  
Obrázky alebo  
symboly**



**Môžeš povedať  
Ako sa cítiš**



**Môžeš sa opýtať  
Otázky**

# Tell the doctor how you feel



**Pain**



**Feeling sick**



**Scared**



# Povedz lekárovi, ako sa cítiš



**Bolest'**



**Cítim sa zle**



**Bojím sa**



# Words you can use at health check up



# Slová, ktoré môžete použiť na zdravotnej prehliadke



# Support



Talking supports help everyone.

Easy-read invitations make  
information clear.

This helps you understand.

You may feel less worried.



Talking Support pomáha  
každému.

Ľahko čitateľné pozvánky vyjasnia  
informácie.

To vám pomôže pochopiť.

Možno sa budete cítiť menej  
znepokojení.



# Change



Today we talked about making healthcare easier.

We talked about changes that are needed.

These changes will help people with intellectual disabilities.



# Zmena

Dnes sme hovorili o tom, ako uľahčiť zdravotnú starostlivosť. Hovorili sme o potrebných zmenách.

Tieto zmeny pomôžu ľuďom s mentálnym postihnutím.



Together we can

Improve cancer education.

Change how cancer screening is  
delivered.



# Spolu to dokážeme

Zlepšiť vzdelávanie o rakovine.

Zmeňte spôsob, akým sa vykonáva  
skríning rakoviny.



# What we need to do



Stop and think about our health.

Know about cancer.

Have a cancer health check.



# Čo musíme urobiť



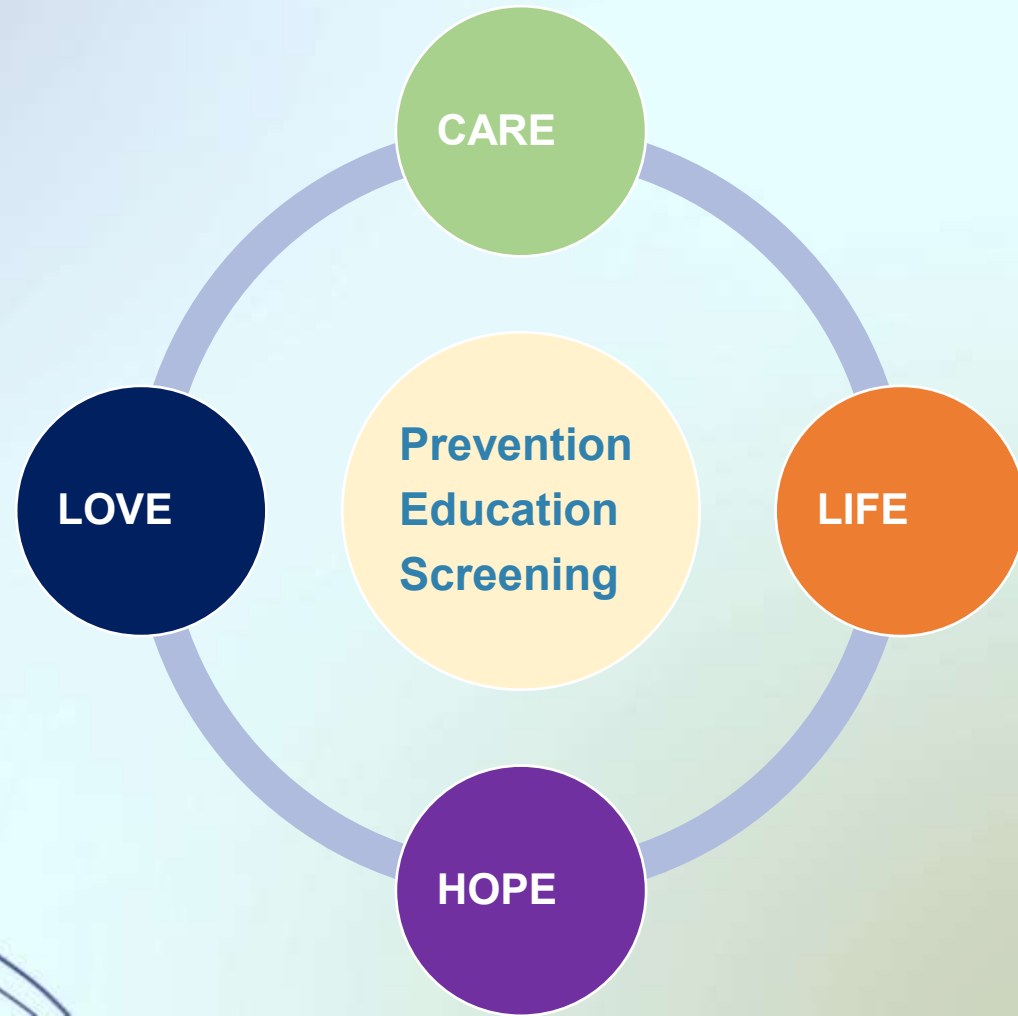
Zastavte sa a zamyslite sa nad  
naším zdravím.

Poznajte rakovinu.

Nechajte si vyšetrenie na  
rakovinu.



Together, we will find answers.



# Spoločne nájdeme odpovede.



# Remember how we can prevent cancer World Health Organisation (WHO)



- ## Five Factors of Cancer Prevention
1. Do not use tobacco
  2. Healthy diet
  3. Physical activity
  4. Reduce alcohol
  5. Cancer screening and early detection

# Pamätajte, ako môžeme rakovine predchádzať

## Svetová zdravotnícka organizácia (WHO)

Päť faktorov prevencie rakoviny

1. Nepoužívajte tabak
2. Zdravá strava
3. Fyzická aktivita
4. Obmedzte alkohol
5. Skríning rakoviny a včasné odhalenie



Thank you for listening.

We talked about CUPID

We talked about cancer

and screening.

We talked about different ways of

talking.



Ďakujem  
Ďakujem, že ste počúvali.

Rozprávali sme sa o CUPID

Rozprávali sme sa o rakovine a  
skríningu.

Hovorili sme o rôznych spôsoboch  
rozprávania.

Pokračujme v spolupráci.



# Evaluation protocol

Handout



# Evaluation protocol for services QR code

**Services /organisations Link and QR code.**

[Online Survey: Feedback on the CUPID Evaluation Protocol for  
Services/ Organisations](#)



Online CUPID Survey: Feedback on  
the Evaluation Protocol -  
Services/Organisations



# Hodnotiaci protokol pre služby QR kód

[Online Survey: Feedback on the CUPID Evaluation Protocol for  
Services/ Organisations](#)



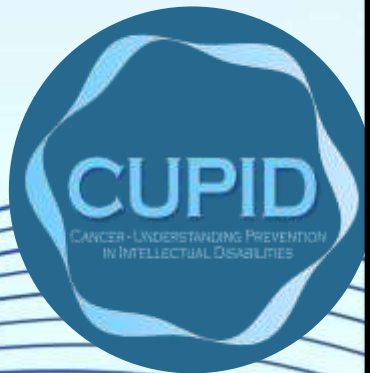
Online CUPID Survey: Feedback on  
the Evaluation Protocol -  
Services/Organisations



Thank you all



# Conclusion- Making the Connections!



# The Ecological Model

(Bronfenbrenner, 1979)



# **Socioecological Model for Equitable Cancer Prevention Education and Screening Access**

## **MACROSYSTEM**

**for PwID**

**Policy and legislation**  
**Leadership, representation and diversity**  
**Population-based screening programmes**  
**Governance and ringfenced funding**  
**Workforce capacity**  
**Societal attitudes**  
**System-level reasonable adjustments**

## **MICROSYSTEM**

**for PwID**

**Health literacy and cancer knowledge**  
**Communication and support needs**  
**PwID and reasonable adjustments**

## **MESOSYSTEM**

**for PwID**

**Family as supporters**  
**Primary care support**  
**Service pathways and interfaces**  
**Service-level reasonable adjustments**

**Outcome: Equitable access to population-based screening**  
**Equivalent participation with peers without intellectual disabilities**

# Multi-Level Framework for Change

The workshop findings can be interpreted using a multi-level ecological approach:

It highlighted that change cannot occur at one level alone.



# The Levels

**Microsystem:** Immediate environments of direct interaction, family, peers, teachers.

**Mesosystem:** Linkages among microsystems, such as home, school relationships.

**Exosystem:** Indirect settings like a parent's workplace or local policies that affect the person via others.

**Macrosystem:** Overarching cultural, legal, and economic frameworks shaping values, barriers and opportunities.



# Concluding Comments

Listen to recording.....



## References

**Bronfenbrenner, U. (1979).**

*The Ecology of Human Development: Experiments by Nature and Design.* Cambridge, MA: Harvard University Press.

[https://easyreadstandard.org/easy\\_read\\_check.html](https://easyreadstandard.org/easy_read_check.html)



# Thank you all

