



# Exploration of experiences of cancer treatment around individuals with intellectual disabilities

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# Cancer care for people with ID

- Patients with intellectual disabilities (ID) receive less cancer care than the general population
- Indications tailored cancer care is needed, but how?
- **Aim:**  
To explore first hand experiences of accessing and undergoing cancer treatment, combining three perspectives

# Methods



Prospective qualitative interview study, patient-centered approach



Who: Patients with a recent cancer diagnosis and ID, their ID caregiver/relative and oncological care provider

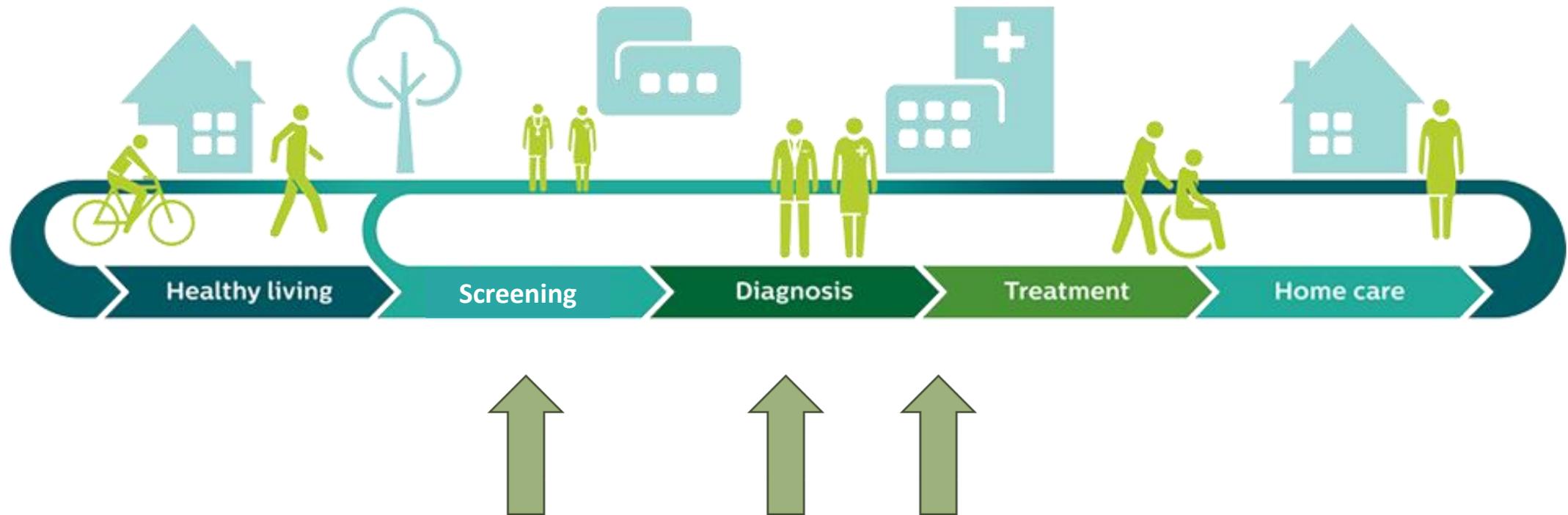


How: semi-structured interviews focusing on experiences during the initial phase of cancer care.

# Participants

- 9 participants with ID
  - 3 men, 6 women
  - aged 42-73
- Various types of cancer  
breast (n=3), skin (n=2), bladder, prostate, ovarian, and lymphatic
- Varying severity of ID
  - 2 mild ID – independent interview
  - 7 moderate ID – interview together with family/daily caregiver

# Categorizing results according to stages



# Screening or detection of cancer

- Observation by others
  - Screening program or routine check-ups
  - Changes in appearance
  - Changes in behavior
- Physical complaints in person with ID
  - striking: prominent symptoms often lack
  - when present cause remains unclear

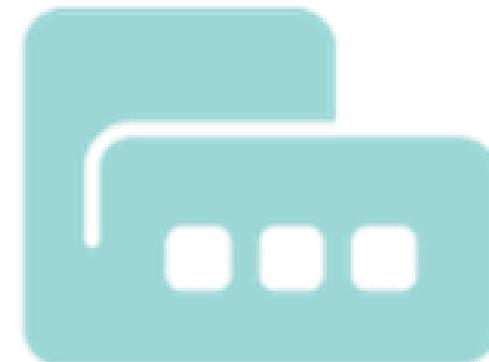
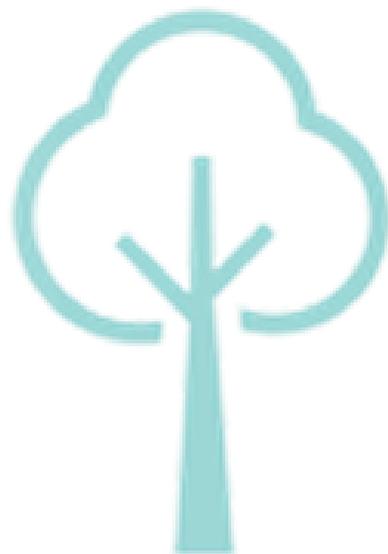
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→ Daily caregivers have an essential role in detection

→ Pay close attention to changes

**‘My brother noticed that something was wrong. Everything was red, eh, my pee was completely red. Not good. Then I had to go to the hospital.’**



Healthy living

Screening

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# Diagnostic process: additional assessments

## 1. Emotions patient and network

- Worries and anxiety
- Uncertainty about procedures and results

→ Emotional support from caregiver's presence

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→ Tailored communication  
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## 3. Logistic challenges

- Presence of a caregiver or family
- Visits to different or distant hospitals
- Transportation issues

→ Clear expectations of visit  
→ Coordination in hospital

**'I got pricked all over. But for other appointments, I didn't have to stay, I could just go back and forth every day, back and forth. [...]**

**I go by car from here. Someone always goes with me. Sometimes my daily caregiver, then this person, then that person. Whoever can, really.'**



Living

Screening

Diagnosis

# Towards treatment – decision making

- Different stakeholders and roles:
  - **Treating oncologist**: leading role in informing and proposing treatment
  - **Caregivers**: advocate patient's well being and assist in information transfer
  - **Patient**: centered, but unable to make autonomous decisions
- Distinction between diagnosis and treatment phase is unclear

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  - **Patient**: centered, but unable to make autonomous decisions
- Distinction between diagnosis and treatment phase is unclear
  - Active involvement of patients' network
  - Clear communication and information for all involved
  - Interdisciplinary collaboration among all stakeholders

'So her mentor, mother and my ID-colleagues are involved and we immediately said, 'we are not going to do that'. She's not coming. Because such a doctor says operation and other very scary words. And when patient hears that, she immediately thinks that she will die tomorrow. So if we're going to talk about those things, we don't take her with us because that will just make her panic.'



Treatment

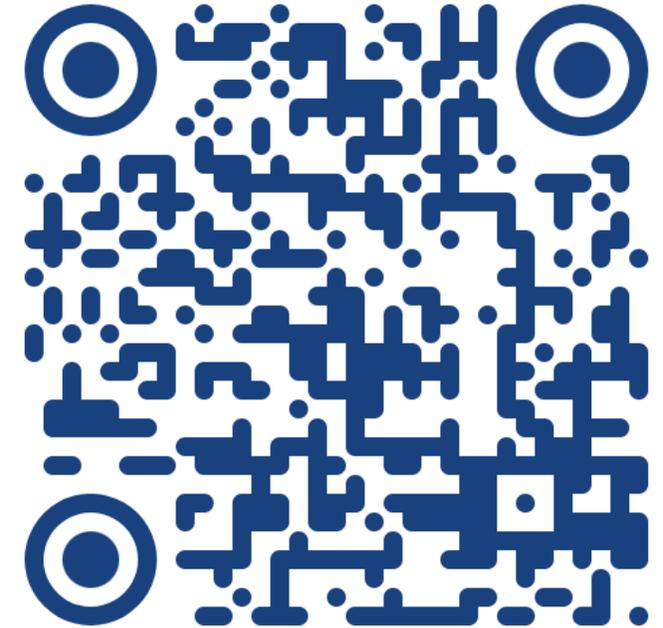
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# And now?

- Analysing all perspectives
  - Prospective interviewing
- Recommendations for tailored cancer care

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