

# Experience-based co-design: Involving elderly people and their caregivers in the improvement of oncology care pathways

Experience-based co-design:  
Sharing experiences and co-  
designing new applications

Erasmus MC  
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# Project team



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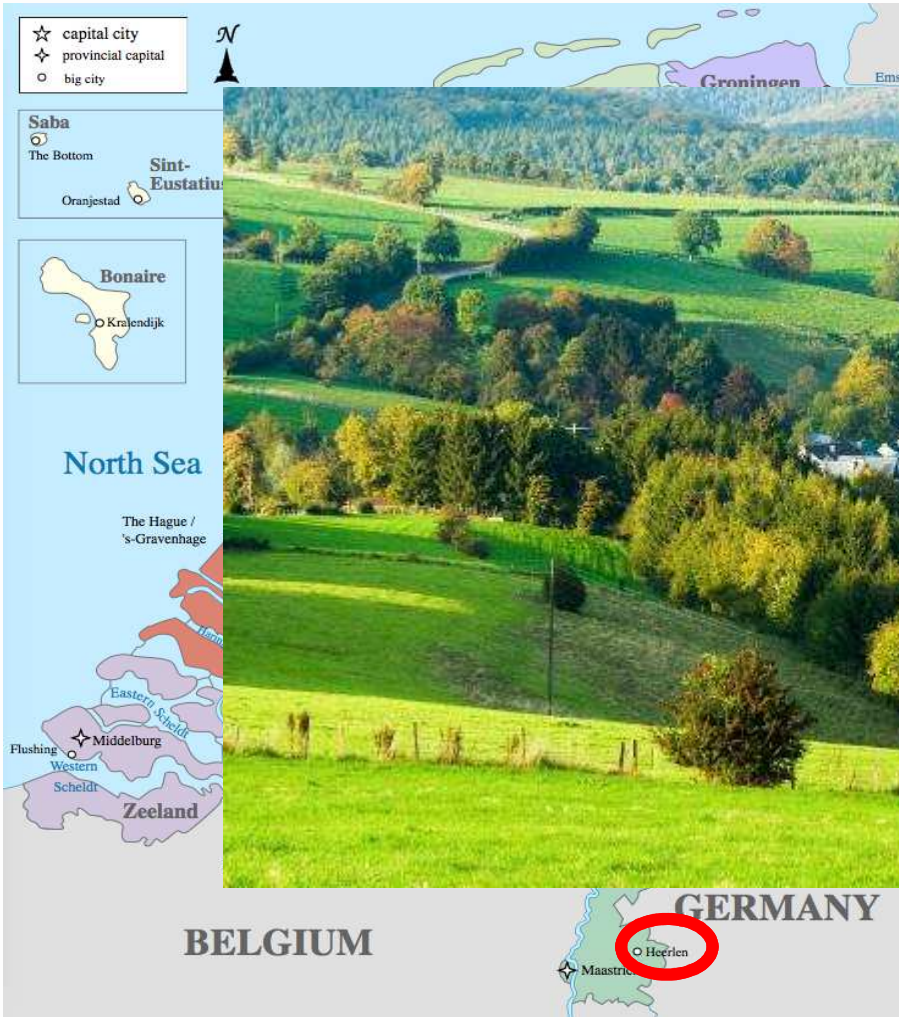
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Esther Stoffers  
Patient advocate  
Huis voor de Zorg

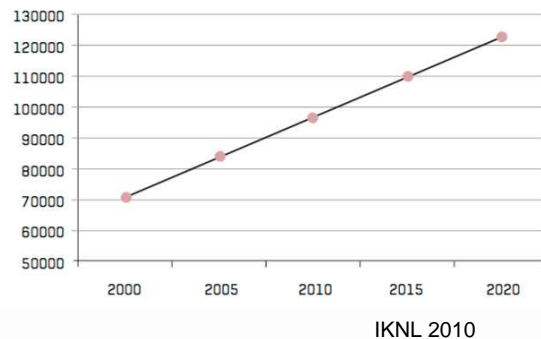


Marja Veenstra  
Patient advocate  
Huis voor de Zorg



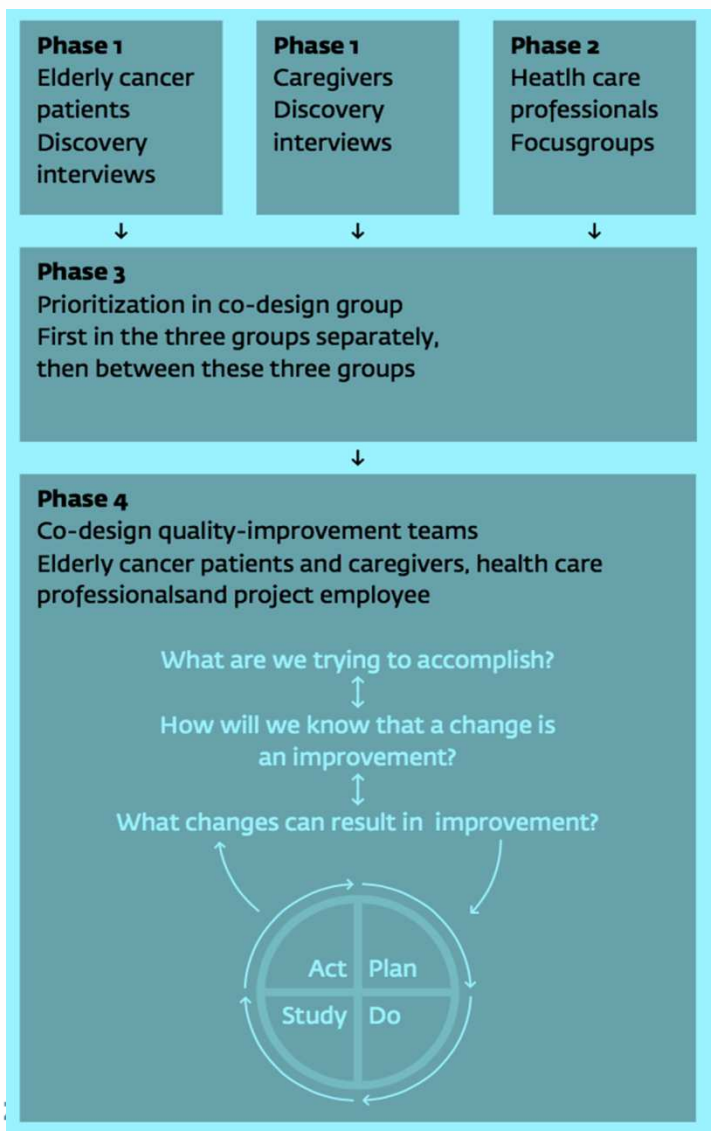
8  
 poor  
 65 years  
 hospitals,  
 nursing homes, hospices, mental  
 health care, home health care

# Elderly cancer patients



- > 30 % of Dutch elderly people will have cancer
- Of these > 60% aged 65 and older
  - Several health and social problems
  - Multi-morbidity
- Demographic development
- Cancer care pathways: organization of work processes and less patient experiences

# EBCD methodology



48 Discovery Interviews  
24 patients (72,9 years; 64-88)  
24 family caregivers: partners, friends and child

5 Focusgroup discussions  
39 professional

2 Shared experience maps  
2 Emotional maps  
8 Co-priorization meetings

Colon cancer

1. Primary contact person throughout pathway
2. Collaboration among medical specialists
3. Communication and conduct
4. Hand-over family physician

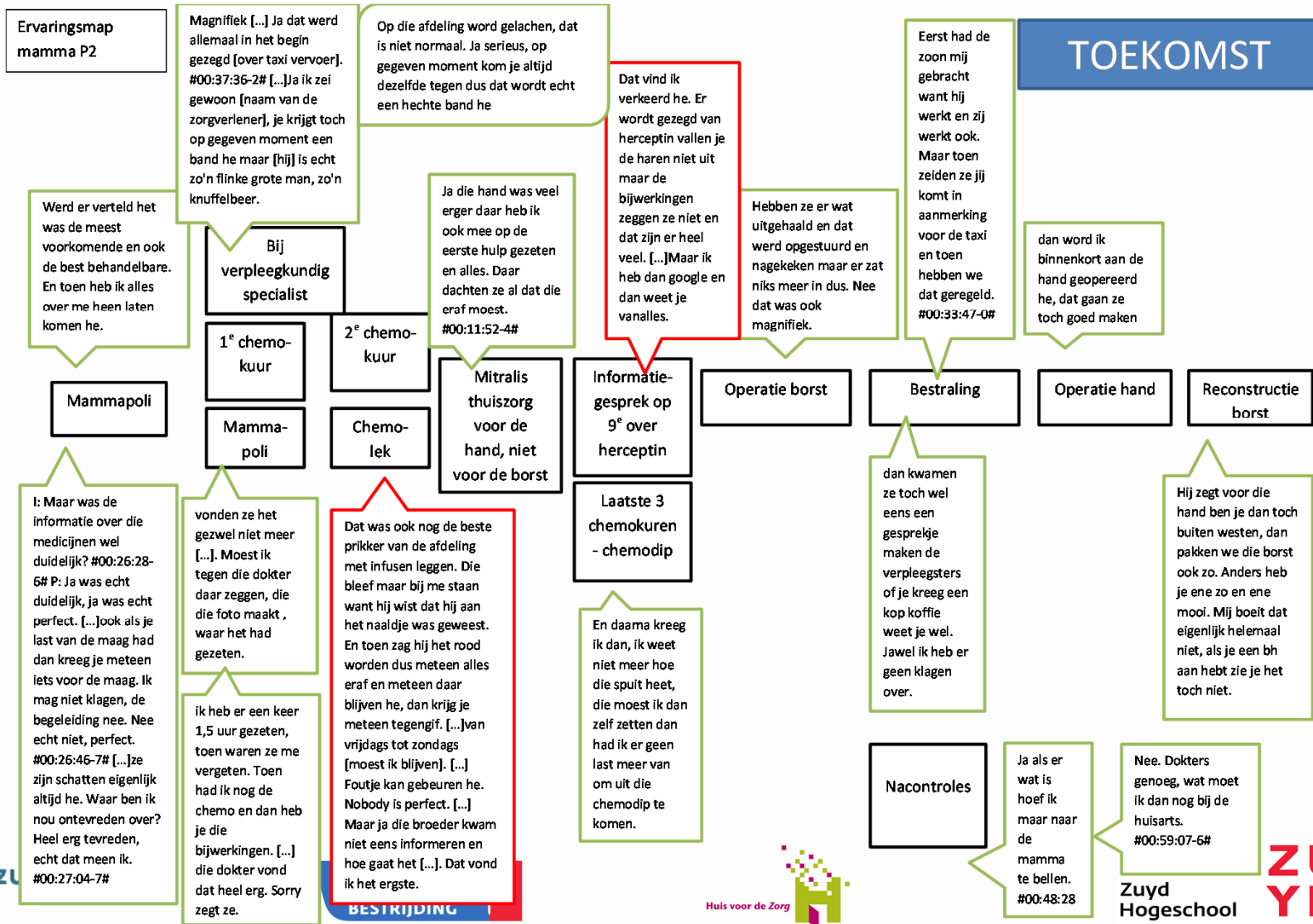
Breast cancer

1. Provision of information
2. Flexible schedules and walk-through
3. (Patient-professional relationship)

6 co-design quality improvement teams  
23 meetings over 5 months



# Experience map and touchpoints of a breast cancer patient



# Meaningful participation































Patients have an active role in activities or decision which have meaningful consequences for individual patients and the patient community.


([www.eu-patient.eu](http://www.eu-patient.eu))

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# Patient participation

	Preparation phase			Research phase					Translational phase			
	Agenda setting	Writing research proposal	Project management	Recruitment	Data collection	Analysis	Prioritising within groups	Prioritising between groups	Dissemination	Implementation	Evaluation	
Control												
Partnership											 	 
Advising												
Consulting					 							
Informing												

 = Patient advocate,  
*Huis voor de Zorg*  


 = Elderly cancer patient

 = Family caregiver



# Barriers and facilitators



- **Patients and caregivers**
  - Difficulty with abstract thinking
  - Paternalism as preferred interaction model
  - + Engaging caregivers as support for the patients
- **Professionals**
  - Time pressure and over-busy work schedules
  - Unfamiliarity with qualitative research and EBCD design
- **Co-design quality improvement team**
  - + Equality and respect between cancer patients, family caregivers and professionals
  - Discontinuity of participants, changes in composition
- **Organisational level**
  - No experience with patient participation in the long run
  - + Support from management

# Impact



- Colon cancer pathway: nurses as case-managers: advanced role
- Breast cancer pathway: more tailored information provision
- Hospital: implementation of the 'three good questions' in 11 outpatient clinics



# Mw. van Goethem-Hochstenbach award



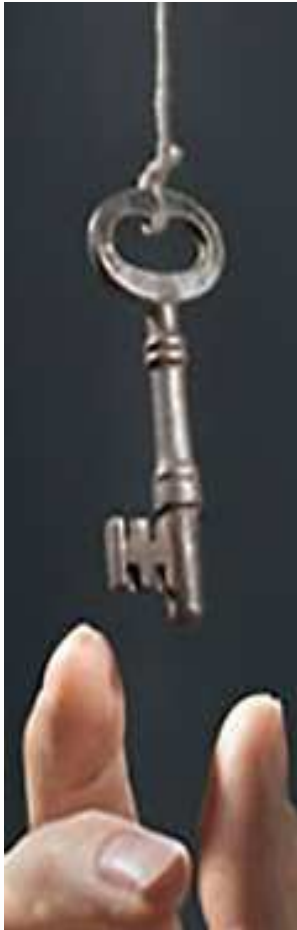
[Video EBCD ENG ZUYDERDLAND definitief 06112016.mp4](#)

# 3 EBCD sources



Deze handleiding is mogelijk gemaakt met financiële steun van KWF

# What we learned



- Power of images: videotapes - experience as perceived
- Simplified emotional map
- Co-design:
  - Interactive methods (principle of design thinking)
  - 'Space brokers'
  - Language matters! Professional vs people's language
  - Completing Plan-Do-Study-Act circle
- Funding: labour-intensive
- Project team:
  - Never-ending enthusiasm
  - Non-medical background is empowering ( discovery interviews)
  - Insider-knowledge of power-patterns and local authority (quality improvement)
  - 'Authentic' patients

# Using experiences from patients and caregivers in an Experience-Based Co-Design (EBCD) to improve the current healthcare of Cancer Associated Thrombosis (CAT)

Improving the existing treatment of thrombosis among cancer patients from the patients', caregivers' and professionals' perspective

## Background

Cancer associated thrombosis (CAT) is a common and important problem for cancer patients. CAT is associated with high morbidity and mortality rates and high costs. The care for patients with CAT is currently organised within the oncological care pathways belonging to their underlying type of cancer. These pathways have mainly been designed from the perspective of the health care professionals and the hospital organisation. However, the actual patient experiences with CAT have rarely been

used to improve the healthcare. Potential areas of improvement could possibly be found in the provision of information, diagnosis, treatment or aftercare.

## Goal

To improve the daily healthcare for patients with CAT by involving patients, caregivers and healthcare professionals as equal partners in a quality-improvement trajectory. To make the provided healthcare for patients with CAT more patient-centred and efficient.

## The research group Integrative Patient Centred Health Care in Oncology

The mission of the research group (founded by Zuyderland MC) is to improve the quality of life and physical and emotional care associated with cancer and cancer treatment. This goal can be reached by optimizing integrated healthcare (care and care) from diagnosis, to treatment and aftercare for people with an oncological disorder. The goal of the research group is consistent with the priorities of Zuyderland MC to deliver health care tailored to the wishes of individuals.



# Project team



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