UiO : Institute of Health and Society
University of Oslo

Health literacy in COPD:
An intervention on information and health care for people with chronic obstructive pulmonary disease

A Norwegian Initiative

Project leaders:

Post doctor Christine R. Borge

Professor Astrid K. Wahl

Main research group:

- **Post doctor Christine R. Borge**: University of Oslo and Lovisenberg Diakonale Hospital
- **Professor Astrid K. Wahl**: University of Oslo (health literacy, quality of life, self-management)
- **Post doctor Mare H. Larsen**: University of Oslo (similar project in psoriasis patients. MI expert)

Co-research group:

- **Professor Richard Osborne**: Deakin University, Australia (Health literacy)
- **Professor Eivind Engebretsen**: University of Oslo (knowledge translation and implementation)
- **Associate professor Eline Aas**: University of Oslo (economic evaluation)
- **Professor Frode Gallefoss:** Sørlandet hospital, Norway (pulmonary physician)
- **Professor Bjørn Lau:** University of Oslo (psychologist)
- **Professor emeritus Torbjørn Moum:** University of Oslo (Expertise in statistics)
- **Professor Marit H. Andersen:** University of Oslo and Oslo University Hospital (Similar project in kidney transplantation)

Lead organizations and partners

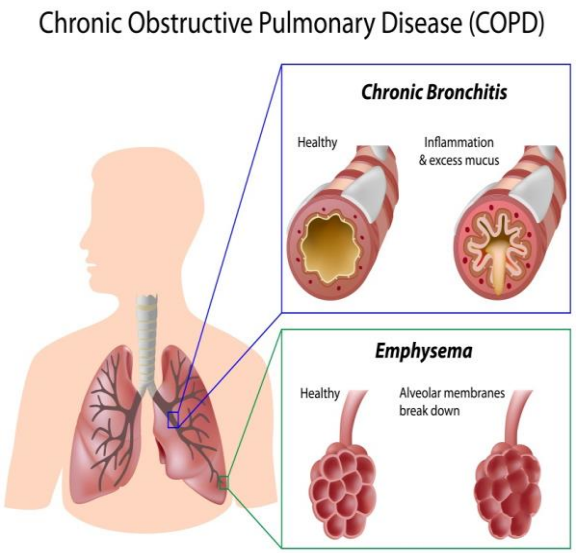
- Lovisenberg Diakonale Hospital
- University of Oslo, the Medical Faculty
- Oslo municipality (Sagene, St.Hanshaugen, Grunerløkka, Gamle Oslo)
- Users of COPD health services

Funding

- ExtraStiftelsen / LHL (Lung & Heart association)
- Lovisenberg Diaconal Hospital
- Oslo University
- Oslo municipality
- Collaboration funds from Southern and Eastern Norway Regional Health Authority
- Kirsti Rønning Fund

Chronic Obstructive Pulmonary Disease (COPD)

- 250-300 000 people live with COPD in Norway -Helsedirektoratet 2012
- There are 65 million with moderate and severe stage of COPD world wide - WHO 2015
- Prevalence increases - Waatevik m.fl. 2013
- 26 % re-admission within 30 days – Elixhauser et. Al. 2006
- Breathlessness, cough, sputum, depression, anxiety, difficulties with sleeping, fatigue and pain - GOLD 2017, Borge 2010



Study focus;

- Inspired by the Ophelia framework, the project develops and evaluates a health literacy partnership health promotion intervention (users, hospital, municipalities, university) in the context of Chronic Pulmonary Disease (COPD).
- The intervention is delivered in home context over a period of 6 months after discharge from the hospital due to COPD exacerbation.

Study phases;

- *Phase 1: Identifying health literacy needs*
  - October 2016 – August 2017
- *Phase 2: Co-designing the intervention*
  - April 2017 – June 2017
- *Phase 3: Implementing and evaluating the intervention*
  - September 2017 – December 2019

Phase 1:

Needs assessment study of health literacy

a) Focus groups with health care professionals and patients with COPD

b) Cross sectional study in patients with COPD (n=157)

Focus Groups

- *Research question: How is health literacy understood and addressed by patients and service providers?*

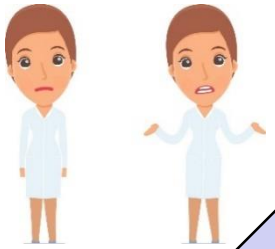
  - Four focus groups with patients
  - Two focus groups with multi disciplinary group of health care professionals
  - One focus group with physicians and pulmonary physicians

  - A “short story” on HL in COPD was presented (based on previous research).
  - An interview guide .

Results from focus groups

Nurse

?



Cooperation with the multi disciplinary team of health care professionals

?

Increase security

Increase dignity

Increase:
- knowledge
- follow-up
- maintain information flow

Increase:
- motivation for endurance
- self management

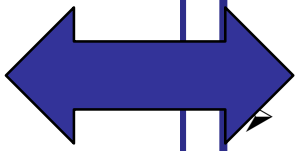
Patients with COPD

Cross-sectional study (n=157)

Research question: What are the health literacy profiles of the population and which factors are associated with health literacy in people with COPD?

- **Questionnaire Health literacy questionnaire:** 44 questions and 9 sub scores:

1. Feeling understood and supported by health providers
2. Having sufficient information to manage my health
3. Actively managing my health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating in the healthcare system
8. Ability to find good health information
9. Understand health information good enough to know what to do



- **COPD Assessment Test (CAT**): 8 questions about COPD
- **EQ 5D:** health related quality of life
- **WHO-5 wellbeing index**: 5 questions about positive well-being
- **Generalized self-efficacy scale (GSES)**
- Pulmonary lung function
- Hospitalization and health care use

Socio- demographic and clinical characteristics

	%
Male Female	46.7 53.3
Living alone	70
Not working	84.4
Smoking	37.8
Primary school Vocational training school Upper secondary school University< 4 years University> 4 years	13.3 21.1 38.9 16.7 10

		Min-max	Mean	SD
Age		42-91	64.4	9.7
Pulmonary lung function FEV1%		17-100	57.4	18.9
BMI		16-57	26.8	7.3
Number of diseases		1-13	5.3	2.3

Internet / data, use of medication, pulmonary rehabilitation / self-management program: characteristics of the sample

	%
Access to internet and data at home No access to internet and data at home	73.3 26.7
No use of internet and data at work, at home or other situations	60
Use inhalation medication wrong	53.3
Not participated in pulmonary rehabilitation or self-management course for COPD	60

Questionnaires

		Min-max	Mean	SD
Feeling understood and supported by health providers		1-4	2.7	0,8
Having sufficient information to manage my health		1-4	2,6	0,7
Actively managing my health		1-4	2,7	0,6
Social su				0,8
Appraisa				0,7
Ability to				0,9
Navigatir				0,9
Ability to				0,9
Understa what to d				0,9
Ability to				0,8
Well-being		0-100	53,6	23,8
Self-efficacy scale		1,2-4	3	0,4
COPD assessment test (CAT)		9-48	27,5	9,2

- **Health Literacy scores lower than studies performed in diabetes and general population studies in Australia.**
- **The ability to use technical health information systems is limited.**
- **Well-being score is on the verge of depression.**
- **COPD assessment test is high and provides information on several limitations in daily life.**

Persons with COPD:

- Live alone
- Low BMI
- Low well-being
- More COPD problems
- Smokes
- Low self-efficacy
- More diseases
- Used their medication wrong
- Low education
- No use of e-health
- No internet and data
- More re-admissions

Lower score on the HLQ domains

Phase 2;

In phase 2, results from phase 1 were discussed and a health literacy intervention was co-designed through:

- **Five group meetings**
  - community health care service
  - specialist health care service
  - users with COPD
  - Researchers
- **Two steering committee meetings**
  - Leaders from community health care service and specialist health care service and University of Oslo

Example: increase knowledge, follow-up and maintain information flow

The group decide on:

- Problem
- Goal
- Measures
- How to do it

The basis for discussions in group meetings:

a) Summary of the focus groups with regard to this domain:

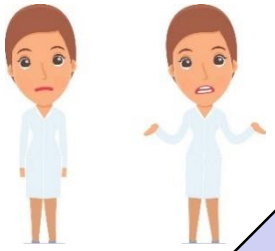
e.g: People with COPD and HPCs find that information and follow-up with regard to the disease is provided. But time, resources and knowledge of health personnel are a bottleneck. The patients express the need for more information and follow-up while not knowing what they need.

b) Statements from the focus groups.

c) Results from the cross-sectional survey.

The intervention

Nurses



Cooperation with the multi disciplinary team
h care
ionals

Questionnaire booklet and interviews will identify:

- Health literacy needs
- COPD related symptoms
- Issues of self-management problems
- Symptoms of depression and anxiety

All in the intervention group will receive:

- Motivating interviews (MI)
- Self-management information about COPD (disease, medication, equipment related to COPD and medication action plan)

Increase security

information flow

Increase dignity

Inc
- motivation for endurance
- self management

Tailored follow ups:

- Health literacy needs
- Disease related problems

Patients with COPD

Individual tasks/actions that the individual patients can choose among
Welfare technology
Smoking cessation
COPD self-management course in groups at the hospital
Nutritional advice
Physical training groups
Healthy life center
Visitation service
The office of applications in the home care service: - Nursing service - Physiotherapist - Occupational therapist - Psychiatric nursing service - Nutritional assistance - Everyday rehabilitation Home cleaning - Shopping - Day center
Information on how to navigate the health care service
Information booklets on COPD

Phase 3;

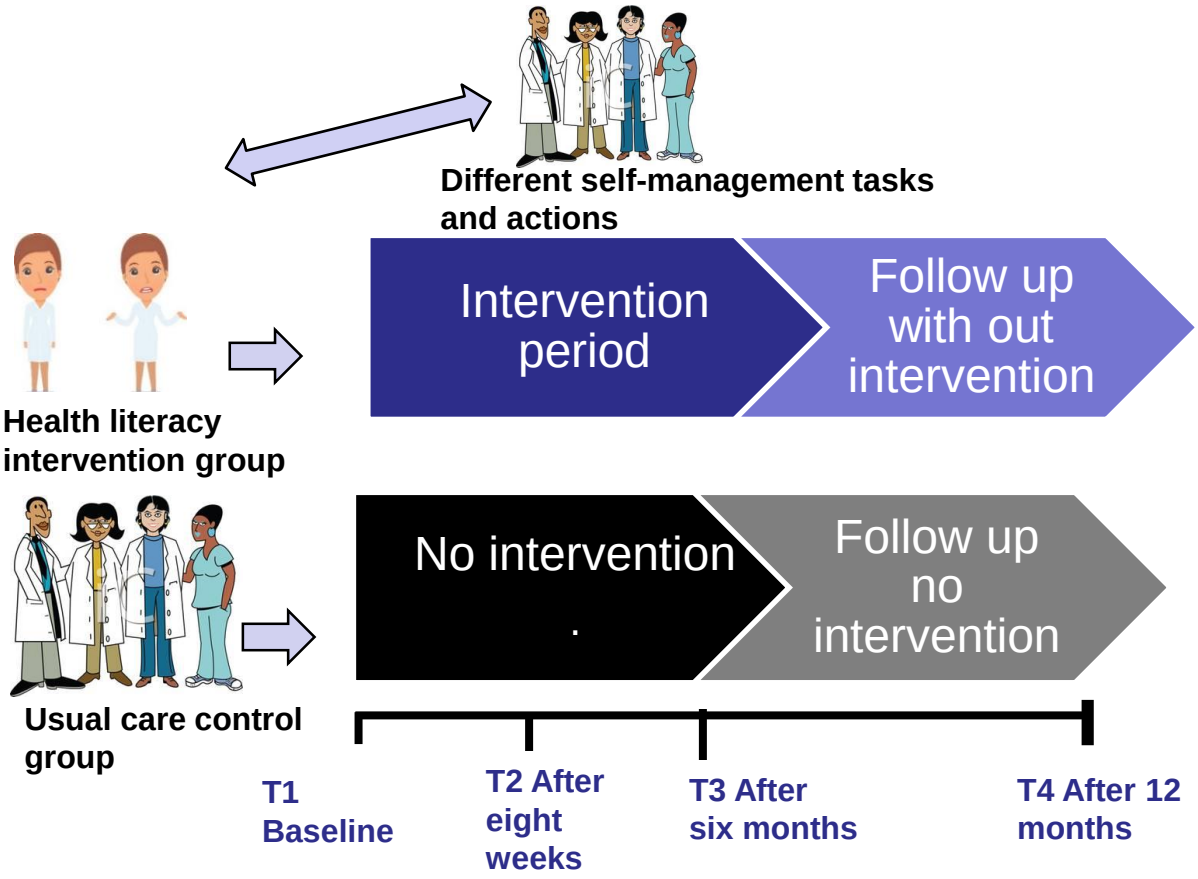
Evaluate possible effects of the “health literacy intervention” after hospitalization on:

- hospital re-admission,
- health literacy,
- self-management,
- quality of life and costs

in people with COPD compared to usual care.

Design:

An intervention on information and health care for people with chronic obstructive pulmonary disease



Status January 2019;

- The implementation of the RCT is presently ongoing and the inclusion of patients is expected to end in December (n=80 of 200).

- If the intervention leads to positive clinical effects and is cost-effective we hope that the intervention is expanded to ordinary practice.

What have we learned?

- Developed new toolkits /strategies for health care professionals and patients in order to focus on health literacy.
- Improved the system by implementing new collaborative relationships and communication systems across different health care service actors.
- Increased involvement of a broader range of health personnel competence, for instance nutritionists.
- Working with health literacy has become a prioritized practice where time and resources are set aside, both in the hospital and in the municipality. Hence, the system responsiveness to health literacy has increase.
- The intervention has potential to be transferred to other contexts.