

# All.Can Norway

Changing cancer care together

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**REPORT – FOCUS GROUPS:**

# **PATIENT-PERCEIVED QUALITY IN CANCER CARE**

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# BACKGROUND

- All.Can Norway is passionate about cancer treatment in Norway, with the goal of contributing to a better and more effective cancer treatment.
- The Norwegian steering group, with representatives from patient organizations, industry and health personnel, intends to define better what the term “patient-perceived quality” means in cancer care.
- This report is thus a contribution to clarifying this important concept – with input from the patients themselves, health personnel and their families.



# INTRO

All.Can Norway is a not-for-profit organization with the goal of promoting patient-centered health care for cancer patients. Patient-perceived quality is an important quality dimension in cancer care but must be clearly defined in content.

All.Can Norway's contribution to this work is important because this is a voice that represents the interests and needs of cancer patients.

All.Can Norway's input helps to better adapt the health services to patients' needs.

By participating in political decision-making processes and collaborating with decision-makers, health professionals and other stakeholders, All.Can Norway contributes to ensure that the needs of cancer patients are included in the important health decisions.

***Geir Arne Larsen, MD PhD MBA***

***Head of cancer development program at Akershus University Hospital (Ahus).***



# MAIN FINDINGS

A collection of medical supplies including a white surgical mask, a clear hand sanitizer bottle, a blister pack of white pills, a white pill bottle, a white keyboard, a white thermometer, and a blister pack of yellow pills, all arranged on a teal background.

## SYSTEM FAILURE

- It breaks in transitions – healthcare software mismatch, lack of continuity of treatment.
- "Being out of the hospital" is a tough transition. The "angry voice" must often be used.
- The information and follow-up is good while inside, but everything becomes much heavier on the "outside".

## MENTAL HEALTH

- Doctors count tumors, but "nobody cares" about the mental.
- Next of kin have too little space during treatment.
- Quality of life is about more than "a wig and the patient pathway progress".

## INEQUALITIES

- The focus groups revealed differences in treatment.
- Geographical differences.
- Late effects and side effects are prioritized differently.



# ABOUT THE REPORT

- **BACKGROUND**
- **PURPOSE**
- **METHOD**

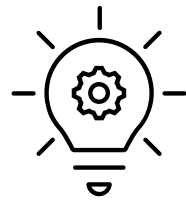
# PURPOSE

Here's how you can use this report.

We want you to read the report and be inspired to realize new ideas and think in new ways in relation to quality in cancer care.

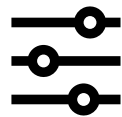
NB:

This is not a scientific research report, but an inspirational document to help ensure that cancer treatment hits the best possible target.



## Inspiration, not documentation

Cancer care is complex – and successful treatment depends on many variables. We hope you will use this report as inspiration to rethink quality.



## Three different perspectives

Patients, relatives and healthcare professionals have different perspectives when it comes to treatment. This report is a panning from all three vantage points.



## Opinions, not facts

This is not a quantitative report, but a qualitative report that focuses on what does not work in cancer care. It's a stone-in-the-shoe report from those who have their shoes on.

# METHODOLOGY

## Focus Groups

All.Can Norway wanted to approach this topic using qualitative methods and therefore decided to conduct the survey via focus groups.

It was found appropriate to examine the topic from three perspectives – patients, next of kin, and healthcare personnel. Three digital meetings were invited, and the conversations were moderated.

The participants contributed in relation to the various talking points that were planned, and there was a good opportunity for the participants to raise what they perceived as important in relation to the quality of cancer care.



Report from focus groups:

# PATIENTS

The focus group consisted of 11 patients with different diagnoses.

Some were waiting for treatment; others had recently been treated while others had received treatment some time ago.

Some had serious diagnoses with a fatal outcome expected within a short period of time, while others had good prognosis.

What they all had in common was that they all had a cancer diagnosis and have experienced cancer care from the patient perspective.



Report from focus groups:

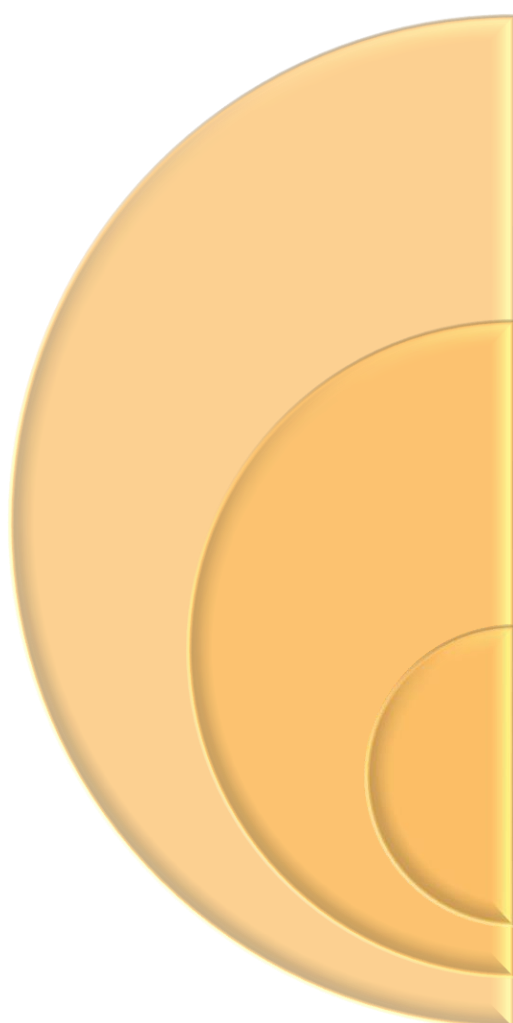
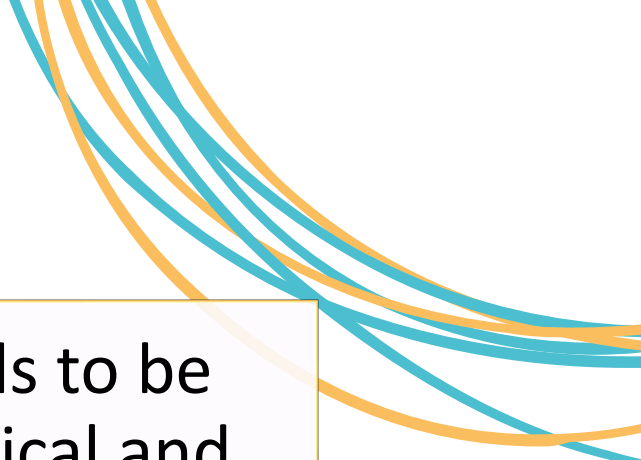
# PATIENTS

## MAIN FINDINGS

**The focus group highlights the lack of focus on mental health in treatment.**

**The mental health perspective needs to be a priority.**

# PATIENTS



Patients have a mental health that needs to be taken care of. Quality is about both physical and mental health.

The participants feel that tumour-directed treatment is extremely well taken care of, but not their mental health.

Such a serious diagnosis should automatically provide mandatory psychological follow-up.

Report from focus groups:

# PATIENTS

**"I was turned down by a psychologist because I had 'normal' reactions to my cancer diagnosis."**

Report from focus groups:

# PATIENTS

**"I was offered a massage and wig for 1.500 € during chemotherapy, but no questions about the mental part."**

Report from focus groups:

# NEXT OF KIN



The focus group consisted of 11 relatives, all of whom were affected by cancer.

There were mothers, fathers, children of cancer patients, as well as spouses and partners of someone affected by the disease.

Some were in the middle of treatment just now, while others had progressed further in their treatment.

Report from focus groups:  
**NEXT OF KIN**



## MAIN FINDINGS

The focus group highlights bureaucracy, rigid rules and confidentiality as major obstacles to the day-to-day care tasks of next of kin.

Report from focus groups:

# NEXT OF KIN / DUTY OF CONFIDENTIALITY

The focus group is concerned that confidentiality is a major challenge for next of kin.

The duty of confidentiality is more of a disadvantage than a benefit.

The law stands in the way of a good relationship between the health service and relatives. It's about law and practice.



Report from focus groups:

# NEXT OF KIN // CARE

The focus group wants it to be easier to accompany relatives for treatment and check-ups.

Next of kin must take time off without pay or get sick leave to join the check-up.

Requires the possibility of absence from work without asking for care allowance or that the doctor must hook the sick leave to a "mental" ward.

Report from focus groups:

## **NEXT OF KIN**

**"My daughter fell ill when she was 12 and I don't get access to reports and medical records until she turns 16. As a mom, I don't get access between the ages of 12 and 16. It's painful and unreasonable."**

Report from focus groups:

# NEXT OF KIN

**"I've never found  
confidentiality helpful."**

Report from focus groups:

# HEALTHCARE PERSONNEL



The focus group consisted of 4 people working in cancer care.

Both nursing, nutrition and the coordinator role.

Report from focus groups:

# HEALTHCARE PERSONNEL



## MAIN FINDINGS

The focus group states that prehabilitation is not well enough known yet and is not given priority.

The group believes the health care system is failing in its "transitions."

# HEALTHCARE PERSONNEL // PREHABILITATION

If the doctor does not mention prehabilitation, then it does not seep in. If only physio or nutrition mentions prehabilitation, it has little effect.

The doctor **MUST** say it. It is not the doctor who should do it, it is the other therapists who will perform.

It is difficult to reach the patients who need it most. They are sick, struggling to get to class and are not concerned with prehabilitation.

Report from focus groups:

# HEALTHCARE PERSONEL // TRANSITIONS

It fails in the transitions.

The quality of the treatment is good, but the flow of information is inadequate, and communication fails during the transitions.

Not having a common ICT system is critical.

Report from focus groups:

# HEALTHCARE PERSONELL

**“Prehabilitation is groundbreaking, I don't feel that all colleagues know enough and maybe don't believe in it. It's worked like it has before...”**



Report from focus groups:

# HEALTHCARE PERSONEL

**"We don't have the right expectations of each other as healthcare professionals during the transitions."**

# SUMMARY

The patient's perceived quality in cancer treatment is perceived relatively equally by patients. In short, it is a matter of time, and that the health service keeps its promises. As soon as the patient is discharged, the fight against the "system" begins.

Next of kin often must assume a role and be a "lawyer". But what about those who do not have good helpers? Or those who don't ask for help? The focus groups point to inequalities and All.Can Norway wants measures that can help to even this out.

Peer support and the importance of bringing both patients and their families together are crucial for raising quality. All.Can wants to contribute to a better and more effective cancer treatment in Norway.

This report shows the need for individual follow-up. No two patients are alike. No two patients or relatives view the treatment in exactly the same way. There is no definitive answer. All.Can Norway is concerned with the individual patient. Not only during treatment, but intensified efforts both before, during and after treatment.

**WHAT HAVE  
WE LEARNED?**

# All.Can Norway's platform: Intensified efforts – before, during and after treatment

All.Can Norway is a broad-based initiative, across patient organizations, healthcare professionals and industry. Our goal is to contribute to a better and more effective cancer treatment in Norway.

Together, we want politicians and the health care service to step up their efforts in these two main areas:

## Prehabilitation

- Prehabilitation is about optimizing efforts in the time from diagnosis to treatment.
- A better and more effective preparation of patients will provide better treatment results and a faster rehabilitation after treatment.
- Exercise, diet, smoking cessation and knowledge should be included as part of rehabilitation.

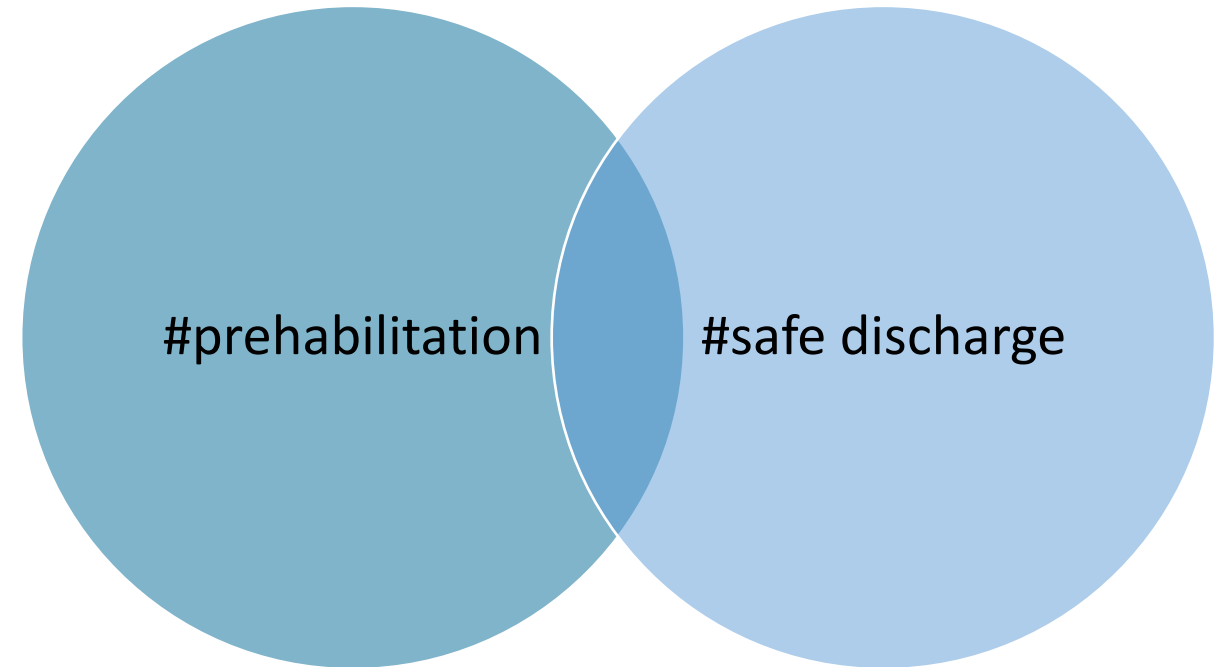
## Safe discharge

- All cancer patients who are discharged must be given a clear description of their individual follow-up and way forward in the health service.
- Contact persons, follow-up plans and rights must be presented as part of the discharge. It must be clear what the patient is responsible for following up – and what will be followed up by other resource persons.
- All cancer patients who are discharged must be given a clear description of their individual follow-up and way forward in the health service.
- Contact persons, follow-up plans and rights must be presented as part of the discharge.

# All.Can Norway

*For a more effective cancer treatment with the patient in the center*

A part of an international initiative across patient organizations, industry, healthcare professionals, policymakers and research.



**Patient-perceived quality**