

## CONFERENCE ABSTRACT

### **From Good to Great – insights, learnings and a change of perspective on patient involvement at Karolinska University Hospital (KUH)**

ICIC20 Virtual Conference – September 2020

Anna Blommengren<sup>1</sup>, Eskil Degsell<sup>1,2,3,4</sup>

1: Karolinska University Hospital, Stockholm, Sweden

2: Karolinska Institute, Stockholm, , Sweden

3: Regional Cancer Center, Stockholm, Sweden

4: Swedish Brain Tumour Association, Stockholm, Sweden

---

#### ***Introduction***

Many hospitals and organizations “educate patients” to perform a representative patient-role in management and research. This traditional patient participation and representation have shown limited success and are of questionable cost-effectiveness.

In 2015 a new operation model was implemented at Karolinska University Hospital (KUH). An important part of the model is that patients and informal caregivers shall influence the decision-making process and priority settings throughout the whole organization on equal terms. The different areas where patients shall be a part is in decision-making and priority settings is in the individual care meeting, management teams, different cross-organization projects, strategic patient- and family council and in a resource group.

#### ***Short description***

The method for patient involvement has so far been based on a hospital perspective. The patients were invited to participate in quality improvement, to develop the way of leading the hospital and to define what to measure as a value of given care. Now the patient’s role is evolved, with a 180-degree switch in philosophy. We are now going from having patients involved in health care to have the health care involved in patient’s self-care and co-care. In patient involvement we are moving “from good to great”.

#### ***Aim and theory***

The theory and aim behind the change are the three components in Evidence Based Medicine; best evidence, clinical expertise and patients’ values, preferences and knowledge (real world data). The patient’s knowledge is based on lived experience and need to be better implemented in daily and organizational practice.

#### ***Population and stakeholders***

The population for this project has been all patients, informal caregivers and health care providers who is working in different parts at KUH.

### ***Timeline***

2015-2019

### ***Highlights***

The most important insight is a tendency that we better capture patients' voice. As an outcome of this organizational change we now also see some concrete examples that patients are developing and implements interventions.

### ***Sustainability***

Health care systems overall are changing to involve more and more patients and informal caregivers to be a part in leading and developing. This initiative has an important role to take a leading role and develop how the future patient involvement can take part.

### ***Transferability***

We have found that the new perspective of patient involvement is transferrable to many health care systems and integrated care pathways.

### ***Conclusions***

If you really believe in Evidence Based Medicine, you can't exclude the patient component.

### ***Discussions***

We are moving to involve patients as colleagues and are moving to involve health into patient's self-care and co-care.

But there is some risk that we need to consider. For example; how do we recruit the patient representatives? How do we develop a system that capture all patient voices not only the strongest and best educated patients?

We can't stop critically question our self in this important matter.

### ***Lessons learned***

It takes time to make a difference and if you want to have an impact of some-one's way of thinking takes even more time.

Strong leadership and a multidisciplinary teamwork in an organization with an fully integrated approach.