

Patient Engagement in Practice

Country example – Iceland

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Involvement and decision making

- Information on diseases and treatment options is provided orally to patients (and relatives) or in form of brochures available on wards, outpatient clinics (many of which are private)
- Most of the brochures are available on-line from the university hospital
- Some private websites provide general information and discussion on heart related problems
 - www.hjartalif.is , www.doktor.is, www.hjartaheill.is
 - Those are not necessarily quality controlled
- Of course some patients seek information about their symptoms, diseases and treatment options on the internet – mostly by “googling”
- Many patients hear of treatment options from other patients – “hot tubs”
- On the individual level it is very common that the patients leave the decision more or less to the doctor *“well doctor you are the specialist, I do what you recommend”*

Involvement and decision making, cont

- **The heart patient organization arranges:**
 - Information campaigns – mainly by arranging “prevention days” where they inform about and measure risk factors such as blood pressure, blood sugar, cholesterol, PEAK flow
 - Collects money to partly pay for new equipment, like coronary angiography, etc (this is becoming less important)
 - May give their opinion on how health care is provided in Iceland, i.e. changes in reimbursement, subventions, organization of health care to authority’s
- **Patient organizations have been involved in establishing rehabilitation clinics in Iceland**
- **Private persons / companies:**
 - Often decide to pay for new health equipment in smaller places, often without proper analyse of how the equipment will be utilized, f. ex. buying Echo-machine where no cardiologist is working

Patients involvement on national level

- **We have no patients representatives in the national cardiac society**
- **Patients and their representatives have generally very easy access to the board of the Icelandic Cardiac society**
- **Present president of the Icelandic national society has been a board member of the heart-patient organization**

What needs to be done?

- **More comprehensive web- based information on diseases and treatment**
- **A web-based education, f. ex. In heart failure**
- **A web-tool for self-care, f. ex. In heart failure**

- **Information in other languages, like polish and english**

- **Train health care providers in how to involve patients in decision making**

