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 analysis of how the equipment will be utilized, f. ex. buying Echo-machine were 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