Cystic Fibrosis - a rare multiorgan progressive disease. 
Identification of health promoting factors from new research.

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Aim of the study

- Investigation of new research and knowledge on health promoting factors regarded to:
  - intersectoriel work
  - interprofessional team
  - rare diseases as cystic fibrosis

- A literature study

Harmonic or disharmonic interaction?
Background

• Several large reorganizations of health and social care systems in Norway have resulted in system changes and following consequences with..

• different conditions for individual care receiver (patients, families) and professional care givers.

• Most often health care professionals and social care systems have limited knowledge and experience of rare diseases.
Intersectorial health care

• Changes have resulted in an increased differentiation of roles, tasks and responsibilities together with decentralization, specialisation and professionalisation towards a development where patients disappear in an increased fragmentation of health care services (Ahgren 2011).
Patient Bermuda Triangle
B Ahgren, Dissolving the Patient Bermuda Triangle 2011

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Coherence & chain of care

• Coordination and continuity are core activity in a complex health care service heading towards an integrated health care for best patient outcome
  – Coordination focus on organisational coherence
  – Continuity is patients experience and perspective of coherence

• Closely connected to competence and power to act in leadership

(Vinge, Strandberg-Larsen 2010).

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Interprofessional work

- Different academic & disciplines & professions
- Prefix “inter” characterize a greater degree of collaboration and integration compared to..
- “multi” equivalent to multiprofessional collaboration between organisations and services.
Competentia & expertise

• Competentia (latin) means to know and be able to do something (skills and knowledge).
  – Level of competence and top specialized is connected to a persons tasks..
  – followed by long experience together with tacet knowledge.

• Expertise is a persons ability to do a task or master a profession in the face of complex requirements, situations and challenges.
A difficult patient

• A decentralized health care results in a very small patient volume of rare diseases in local specialist health care, and in competition with other larger groups of patients, rare diseases will not be prioritized.

  – It is in hospitals the volume of patients is big enough for a doctor (and a team) to develop specialist competence (Grue 2008).
Cystic Fibrosis Care

• International CF guidelines promote centralized care of high quality with an experienced core team as essential for best prognostic disease outcome (Colombo, Littelwood 2011).

• While several new medications for CF lung disease have been introduced in the last decade, improvements have been largely due to refinements in the delivery of care (Schechter 2010).

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CF Care in Norway – at risk

- Norwegian CF care is at risk of loosing its opportunity for a better prognostic outcome for patients.

- when the current organisation as rare centre and decentralization with shared care is compared to...

- international guidelines with recommendation of centralization to CF centre for best CF care.

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Health promotion factors for improvements of care

• Integrated health care in combination with:
  – different kinds of interprofessional collaboration adapted to reel needs for health care..
  – should be applied to patients with rare diagnoses & lifelong progressive diseases.

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Health promotion factors for improvements of care

- Rare diagnosis & different needs for health services should be met with
  - a patient coordinator,
  - an innovated use of professional resources and
  - consecutive interaction within organisational and economic frames.

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