IBD PATIENTS NEED IN QUALITY OF HEALTH CARE
ECCO Consensus

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on behalf of the
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Disclosures:

I do not have any relevant financial relationships with any commercial interests
IBD patients need in health quality of care
ECCO consensus

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AIM

- European Crohn Colitis Organization (ECCO) decided to supply the ECCO consensus guidelines in CD* & UC* with a similar consensus in Quality of Health Care
- 1st meeting in Copenhagen March 2007 to agree on the statements
- 13 European countries + Israel participated
- All countries presented their "needs"

*CD Consensus, GUT 2006
*UC Consensus, JCC 2008
Countries represented

• Austria
  - Gabrielle Moser
  - Walther Reinisch

• Czech Republic
  - Dana Duricova
  - Milan Lukas

• Denmark
  - Margarita Elkjaer
  - Vibeke Wewer
  - Pia Munkholm
  - Birgit Laugesen, nurse
  - Lene Neergaard, nurse
  - Dorte Marker, nurse
  - Bente Buus, CCF, Patients org

• Finland
  - Micke Lindholm, Patients org

• Germany
  - Susanne In der Smitten, Patients org

• France
  - Jean-Frederic Colombel

• Ireland
  - Colm O’Morain
  - Mary Shuhaibar
  - Yvonne Bailey, nurse

• Italy
  - Patrizia Politi

• Norway
  - Tomm Bernklev

• Russia
  - Elena Belousova
  - Inna Nikulina

• UK
  - Rod Mitchell

• Croatia
  - Boris Vucelic

• The Netherlands
  - Ingrid van der Eijk

• Israel
  - Selwyn Odes
METHOD

- Oxford criteria
  - EL, Evidence Level (1-5)
  - RG, Recommendation Grade (A-D)
- Delphi method
  - Literature search
  - Working party
  - Voting for statements ~80% agreement
METHOD

Literature search

- 1. literature search on Pub Med
- Key words:
  - “IBD AND health care”
  - “IBD AND Quality of Life”
  - “IBD AND patients need”
  - “IBD AND need of health care”
  - “IBD AND compliance”
  - “IBD AND adherence”
  - “IBD AND education”
  - “IBD AND Primary Care”
- All in all: 3298 articles
- Cochrane search: 6 articles
METHOD

- 76 articles fulfilled the criteria
  - Information
  - Education
  - Primary Care
  - QoL
  - Psychological help
  - Benchmarking of Health Care System

- 6 RCT, 7 overviews, 63 original articles
- Meta analysis: 0
- 23 relevant abstracts from the last 3 years of DDW and UEGW
DEFINITION OF QoC

- Quality of Care consists of the “degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”

Fig.1 Adopted from I van der Eijk (European Journal of Internal Medicine 2000;11:228-34)
ECCO Statement A
- QoHC depends on level of disease information to the IBD patient. The provision of patient-centred information is strongly recommended [EL 1b, RG B]

ECCO Statement B
- Education influences QoHC through increasing HRQoL, compliance and adherence [EL 1b, RG A]

ECCO Statement C
- Quality of Health Care in IBD is different in primary care in Europe and should be standardized [EL 2a, RG B]

ECCO Statement D
- QoHC is related to HRQoL, disease activity, psychological status coping, stressful life events and social support [EL 2b, RG B]
ECCO Statement E
- Physicians should assess (IBD) patient's psychosocial status and coordinate additional psychological care and recommend psychotherapy when indicated. Integrated psychosomatic care should be provided in IBD centres [EL2b, RG B]

ECCO Statement F
- Best practise in IBD has been assessed by Benchmarking [EL 2c, RG B] QoHC implies patient oriented process, Technical safety and Quality of medical standard to insure best practice in IBD. Benchmarking should be used to assess this [EL 2c, RG B]

ECCO Statement G
- Children and adolescents need special attention to increase QoL and QoHC: access to multidisciplinary paediatric specialist teams including paediatric psychologist, dietician and social worker is mandatory. Age related information and education is important (EL 2b RG B-C)
FUTURE ASPECTS

NEED FOR:

- **Increasing of general knowledge**
  1. In public and primary care through National TV and Radio to avoid “Patients delay-doctors delay”
  2. Consensus of simple guidelines to General Practitioners (European Primary Care)

- **Proper access**
  1. To the IBD clinics & specialists
  2. To “Help-line”
  3. To adequate time at consultancy at the specialist & IBD nurse
  4. To choose gastroenterologist at patients´ needs

- **Proper information & education for patients**
  1. Level of information has to fit patients different needs in different life cycles
  2. Disease related written Information in IBD clinics, GP´s and pharmacy
  3. PEC, patient education centre for patients and relatives
  4. Patient organisation courses for patients and relatives
  5. Independent leaflet written and special developed Web sites [www.ecco.healthology.com](http://www.ecco.healthology.com) about IBD for patients & physicians:
  f. ex.: AGA´s homepage about IBD- [www.gastro.org](http://www.gastro.org)
FUTURE ASPECTS

NEED FOR:

- **Proper education for medical providers**
  1. Recommend IBD nurse curriculum at European level (ECCO)
  2. Recommend IBD nurse network
  3. ECCO courses for any specialist
  4. Minimal standard for IBD specialist - ECCO Homepage: 
     www.chronic.disease.mangement
     f. ex.: www.health.gov.bc.ca/cdm/patients/managing.html

- **Proper Health Economics**
  1. Health Care authorities should facilitate the development of IBD network
  2. Health insurance has recognized IBD patients as complicated patient group needing special care
  3. Recommend maximum reimbursement of medical treatment & psychological care
  4. Employment rates should be kept high by the public
  5. Encourage studies to assess if QoHC is economical
Evidence based medicine in QoHC is limited

- Optimizing of QoHC by “information”; “education”, “benchmarking” & “psychological analysis” helps to improve patient's compliance, increase QoL and decrease depression & anxiety

- With lifelong chronic diseases as IBD - equal rights to same level of QoHC is mandatory

- Quality of Health Care measurements are needed to validate improvement in IBD worldwide
Thank you to

Austria
- Gabrielle Moser
- Walther Reinisch
Czech Republic
- Dana Duricova
- Milan Lukas
Finland
- Micke Lindholm
Germany
- Susanne In der Smitten
France
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- Margarita Elkjaer, PhD student
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- Pia Munkholm, head EpiCom