Decision systems in quality registries

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Jonas Halfvarson, MD, PhD
Dept of Gastroenterology, Faculty of Medicine and Health, Örebro University
Quality registries for chronic diseases

Chronic diseases
• Often heterogeneous, pronounced inter-individual differences in terms of prognosis
• Outcome dependent on disease history and present clinical status
• Treatment aim to improve long-term outcome

Challenges for QR in chronic diseases:
• A snapshot, without longitudinal data, of limited value
• Patient’s and doctor’s endurance, an administrative burden
• Selection bias influence outcome at different centres

A repository for data is not enough, additional value needed
Electronic health records and chronic diseases

Chronic diseases in the IT-era:

• >70 different electronic health record (EHR) systems in Sweden
• Poorly designed, not workflow-integrated and non-interoperable
• Reduce efficacy, do not fulfil the potential benefits

Assessment of different layers of longitudinal data demanding
EHR and Evidence-based medicine

**EBM**

Combining clinical skills, experience of the healthcare professional and preferences of the patient with the best external clinical evidence

- Balanced decisions about medical care

Theoretically, EHR could facilitate implementation of but...

- Search for alternative ways to implement clinical decision support systems
Decision support system (definition)

A Decision Support System (DSS) is a computer-based information system that supports business or organizational decision-making activities. DSSs serve the management, operations, and planning levels of an organization (usually mid and higher management) and help to make decisions, which may be rapidly changing and not easily specified in advance (Unstructured and Semi-Structured decision problems). Decision support systems can be either fully computerized, human, or a combination of both.

While academics have perceived DSS as a tool to support decision making process, DSS users see DSS as a tool to facilitate organizational processes. Some authors have extended the definition of DSS to include any system that might support decision making. Sprague (1980) defines DSS by its characteristics:

1. DSS tends to be aimed at the less well structured, underspecified problem that upper level managers typically face;
2. DSS attempts to combine the use of models or analytic techniques with traditional data access and retrieval functions;
3. DSS specifically focuses on features which make them easy to use by noncomputer people in an interactive mode; and
4. DSS emphasizes flexibility and adaptability to accommodate changes in the environment and the decision making approach of the user.

DSSs include knowledge-based systems. A properly designed DSS is an interactive software-based system intended to help decision makers compile useful information from a combination of raw data, documents, and personal knowledge, or business models to identify and solve problems and make decisions.
Clinical decision support

**Definition**
Providing clinicians/patients with computer-generated clinical knowledge and patient-related information, intelligently filtered and presented at appropriate times, to enhance patient care

Simple examples
- Patient-monitoring device (ECG or pulse oximetry)
- Deviating laboratory test results, electronic health records

Osheroff JA et al. 2005
Clinical decision support system

‘Clinical Decision Support systems link health observations with health knowledge to influence health choices by clinicians for improved health care’

(Robert Hayward)
Clinical decision support system in QR

- Electronic health record (laboratory data)
- Electronic health record (examinations)
- Electronic health record (medication)

Health care provider

Patient (electronically prior to/on site)

Clinical decision support system

- Patient engagement
- Patient-centred care

Treatment guidelines

Quality registry

- Biobanking
- National registers

A learning health care system
Välkommen till SWIBREG
Swedish Inflammatory Bowel Disease Registry

Ar du patient? KICKA HÄR

Antal registrerade patienter: 28186 (2014-11-20)

SWIBREG är ett nationellt kvalitetsregister med syftet att öka vår kunskap om och förbättra vården av Inflammatorisk Tarmsjukdom.

SWIBREG skall också...

- Utöra ett stöd för bedömning av effekten av olika behandlingar på lokal, regional och nationell nivå.
- Kunna synliggöra och väganda viktiga parametrar såsom sjukskrivning, innehållande vård och operationer på lokal, regional och nationell nivå.
- Ge statistik på den lokala klinikens patientpopulation.
- Mojliggöra deltagande i det nationella registret med påminnelse om när det är dags för uppföljning.
- Via frågeformulär ge patienterna ett sätt att förmedla information om sin sjukdom, dess aktivitet och hur det påverkar livet i allmänhet – på såväl individ- som gruppnivå.
Inflammatory bowel disease (IBD)

- Crohn’s disease and ulcerative colitis
- Age-specific incidence peak 15-35 y
- Symptoms like diarrhoea, urgency, blood and mucus in stool, abdominal pain, weight loss, fatigue
- Medical treatment 5-ASA, corticosteroids immunomodulators, biologics
- Surgery approximately 10% in ulcerative colitis and 40% in Crohn’s disease 10 y after diagnosis
Disease course in Crohn’s disease

Curve 1: Decrease in the severity of bowel symptoms during the follow-up period (43%)

Curve 2: Increase in the severity of bowel symptoms during the follow-up period (3%)

Curve 3: Chronic continuous bowel symptoms during the follow-up period (19%)

Curve 4: Chronic relapsing bowel symptoms during the follow-up period (32%)

Progression of digestive damage and inflammatory activity in Crohn’s disease

Pre-clinical  Clinical

Disease onset  Diagnosis  Early disease

Inflammatory activity (CDAI, CDEIS, CRP)

Digestive damage

Treatment

Surgery

Stricture

Fistula/abscess

CDAI: Crohn’s disease activity index, CDEIS: Crohn’s disease endoscopic index of severity,

Treatment goals in Crohn’s disease are evolving

Response

Clinical remission
Treating to manage symptoms

Mucosal healing

Deep remission
Treating beyond symptom control (clinical remission + mucosal healing)
How to capture the information?

**Diagnosis**
Small bowel and colon, non-traditional distribution (2011-02-27)

**Montreal Classification**
- **Age at diagnosis**: A2, between 17 and 40 years (2011-02-27)
- **Location**: L3, ileocolonic (2011-02-27)
- **Behaviour**: B1, non-structuring and non-penetrating (2011-02-27)

**CRP data** recorded below

**Endoscopy data**

**QoL data**, using Short Health Scale (SHS)

**Graph showing calpro, HBI and medication**

No information is more than 2 clicks away from the graph
Clinical decision support system in SWIBREG

Prior to the consultation
• The patient reports his/her own symptoms, health, and quality of life
• Self-reported data, synthesized and graphically displayed
  ➡ A snapshot; current health status and a longitudinal image of personal health and treatment trends over time

At the consultation
• Clinical data added
• A clinical decision support tool (a dashboard) generated
  ➡ The patient and the provider can work together to optimize health according to the matters of the patient

Export to the QR
• Structured data immediately exported to the QR
A patient case

18-year-old man; referred from GP in early December 2011

- Born in Sweden to Chinese parents
- Non-smoker
- In his last year of high-school; wants to become a professional pianist
- Had had diarrhoea for 2–3 months (6 bowel movements a day), weight loss, abdominal pain
- Stool samples negative
- CRP 45 mg/L
- Calprotectin 540 µg/g
A patient case

2 December 2011

- Ileocolonoscopy carried out
  - Inflamed mucosa with superficial ulcers in ileum
  - Deep and superficial ulcers in the right colon
  - Superficial ulcers in transversum
  - Aphtoid and small superficial ulcers in the rectum

- Findings macroscopically consistent with ileocolonic, non-stricturing, non-penetrating Crohn’s disease (CDEIS 10.6)

- Biopsies taken for histology
A patient case

5 December 2011

- Informed about the diagnosis of Crohn’s disease
- Treatment options discussed with the patient
- Established contact with IBD nurse
- **Prednisone 40 mg** (tapered 5 mg/week, 8 week course) initiated
- **Azathioprine 150 mg** (corresponding to 2.3 mg/kg) initiated
A patient case

3 January 2012

- MR enterography: thickening with contrast enhancement of distal 25 cm of ileum; proximal right colon and distal left colon; no proximal involvement
- Histology consistent with Crohn’s disease
- CRP started to drop

17 January 2012

- Responded to corticosteroids; HBI improved; CRP 15 mg/L
- Prednisone 15 mg, but some diarrhoea, about to relapse?
- Identified as incomplete corticosteroid response
- Remained on prednisone 15 mg for 3 weeks to allow AZA more time
- Discussed possibility of anti-TNF therapy (if no AZA response)
A patient case

Harvey Bradshaw Index (HBI) 14 2

F-Calprotectin (µg/g)

CRP mg/l

Prednisolone
Azathioprine


0 10 15 20 30 45 60 75 90 105

0 10 100 1000
A patient case

23 February 2012

- Tapered prednisone (5 mg) again
- Relapsed with diarrhoea and fatigue
  - Negative impact on his ability to play the piano, especially during concerts
- CRP 39 mg/L
- Calprotectin 739 µg/g
- TGN 405 pmol/8x10^8
- Identified as steroid-dependent
- Planned to initiate anti-TNF, but about to travel (China), anti-TNF postponed
- Prednisone temporarily escalated to 20 mg
A patient case

Harvey Bradshaw Index (HBI) 14 2 5

F-Calprotectin (µg/g)


100 110 120 105 100 90 80 70 60 50 40 30 20 10 0

CRP mg/l

Prednisolone
Azathioprine
4 April 2012

- Back in Sweden, on prednisone 20 mg
- Fairly asymptomatic, but calprotectin and CRP high
- Anti-TNF (adalimumab) initiated
  - 160/80 mg induction, followed by 40 mg eow maintenance
  - In combination with azathioprine
A patient case

Harvey Bradshaw Index (HBI)

F-Calprotectin (µg/g)

CRP mg/l

Prednisolone
Azathioprine
Adalimumab

Dec 11
Jan 12
Feb 12
Mar 12
Apr 12
May 12
Jun 12
Jul 12
Aug 12
Sep 12
Oct 12
Nov 12
Dec 12
Jan 13

0
10
15
30
45
60
75
90
105

0
10
100
1000

0
10
20
30
40
50
60
70
80
90
100
110
120

A patient case

8 May 2012

- **Rapid biochemical response to anti-TNF (adalimumab)**
  - CRP normalised within 16 days
  - Patient in clinical remission

14 August 2012

- **Sustained clinical and biochemical remission**
  - CRP <1.0 mg/L and calprotectin 50 µg/g
A patient case

Harvey Bradshaw Index (HBI)

Calprotectin (µg/g)

CRP mg/l

Prednisolone
Azathioprine
Adalimumab
A patient case

15 January 2013

- Still in clinical biochemical remission
  - CRP <1.0 mg/L
  - Calprotectin 63 µg/g

- Endoscopic remission
A patient case

Harvey Bradshaw Index (HBI)

F-Calprotectin (µg/g)

CRP mg/l


Prednisolone
Azathioprine
Adalimumab
Bästa möjliga hälsa för personer med IBD

Tillgänglighet, delaktighet, kontinuitet och optimalt resursutnyttjande

Person med misstänkt IBD

Inom 2 veckor

Ingången kan vara:
- Primärvård
- Akutsjukvård
- Annan ingång

IBD-team

Inom 1 vecka

Skov

Inom 2 arbetsdagar

Vecka 0

Vecka 2

Vecka 4–6

Vecka 8–16

Vecka 26

1 Initial diagnostik/ karaktärisering/ åtgärd

2 Patientsäkerhet

3 Respons

4 Patientsäkerhet

5 Respons

6 Patientsäkerhet

Syntomfri utan steroider och/eller blokemisk normalisering

Optimering av behandling/egenbehandling

Kontinuerlig inrapportering till SWIBREG (SHS, Hb, CRP, kalprotektin, klinisk aktivitet)

Uppföljning enligt individuellt vårdplan som uppdateras minst årligen
Impact of decision support systems in QRs

Dashboard
• Facilitate patient engagement and patient-centred care
• The systematic and graphic presentation of longitudinal data, a decision-making tool in daily clinic

Presentation of grouped clinical data
• A foundation for patient-care that reduces unnecessary scheduled visits
Additional value for the health care profession
Impact of decision support systems in QRs

Dashboard
- Facilitate patient engagement and patient-centred care
- The systematic and graphic presentation of longitudinal data is a support-decision-making tool in daily clinic

Presentation of grouped clinical data
- A foundation for patient-care that reduces unnecessary scheduled visits
- Outcomes for individual doctor’s patient panel or the entire clinic
  - Benchmarking and quality of care assessment

Aggregated national data
- Displaying data for quality of care assessment, benchmarking, public reporting, industry-commissioned analyses and research
  - Improved health for patient populations
Clinical decision support system in QR Pitfalls

• Integration with a healthcare organization's clinical workflow
• Lack of interoperability with reporting and electronic health record systems
• Incorporation of large amounts of data into existing systems places significant strain on application and infrastructure maintenance
Clinical decision support system in QR

Conclusions

Innovative, replicable, and spreadable system to improve:

• Patient engagement
• Patient-centred care
• Health outcomes
• Practice based learning and improvement
• Research