ICT for Healthcare, Selfcare and Prevention
Challenges, Opportunities and Trends

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3 Areas of Health Informatics

- Patient-Centred Information Systems
- Health-enabling and Ambient Assistive Technologies
- Decision Support
CIS and EHR

**Vision**: To provide clinical information systems that adapt to changing healthcare environments

**Today**: Numerous systems are in use but clinician acceptance varies, interfaces are not open and the systems do not support patient-centered delivery of care

**Tomorrow**: Current and new CIS and EHR technology will help to provide international standards for interoperable applications that use health, social, economic, behavioral, and environmental data to communicate, interpret, and act intelligently upon complex healthcare information to foster precision medicine and a learning health system.

**Challenges**: Usability, Visualization, Interoperability, Data integration

**Opportunities**: Precision medicine and learning health system

Gardner RM. Clinical Information Systems – From Yesterday to Tomorrow. Yearb Med Inform 2016;Suppl1:S62-75

Patient-centred information systems

"Patient-centred care = Care that is guided by the individual patient’s needs, preferences and values"


Dimensions of PCC (from Gerteis et al)

(1) respect for patients’ values, preferences, and expressed needs;
(2) coordination and integration of care;
(3) information, communication, and education;
(4) physical comfort;
(5) emotional support—relieving fear and anxiety; and
(6) involvement of family and friends.
What is of value for patients?

- Participation
- Empowerment
- Communication
- Safety
- Trust
- Timeliness
- Accessibility
- Efficiency
- Individualization
- Continuity

Final report VIP-PA (Visualising patient-centred process- and business models for e-services in health and social care)
http://ki.se/ki/jsp/polopoly.jsp?d=36739&l=sv
Meet Oscar: Patient is not Just a Patient

• **Our agenda for Oscar:**
  – Medication adherence
  – Come to follow-up appointments
  – Improved self-monitoring
  – Participation in PT
  – Nutritious food choices and increased calories
  – Living Will
  – Participate in Shared Decision-Making

• **Oscar’s agenda for Oscar:**
  – Grieving for his wife
  – Transportation
  – Managing Rx side effects
  – Seeing his grandchildren
  – Reducing knee pain
How can informatics facilitate PCC?

Isolated and un-coordinated information processes need to be visualised and shared with the patient in a consistent and comprehensible way.

Contextual framework for integrated eCare. (Adapted from [Hägglund et al., 2012]).
Old@Home

http://www.medsci.uu.se/mie/projects/closecare

Home helper in action
Reads, writes and communicates!

District nurse at a patient's home
Gets online information!

Patient in his home
Participates and feels safe!

Relative
Participates and is updated!

General practitioner
Reads up to date information!

Collaborative Stroke Care

Nadia Davoody, HIC
My Care Pathways (2011-2013)

- Visualisation of care pathways:
  - Stroke - Stockholm
  - Lung cancer - Stockholm
  - Hip surgery – Skåne region
  - Heart diseases - Västra Götalands region

- Develop methods and guidelines that describe the process to develop further care pathways and support services
  - In co-production between research, public sector, industry and patient organisations

- Stimulate third parties to develop new products

Financial support: VINNOVA
Project leader: Nina Lundberg, SLL
Research leader: Sabine Koch, KI

Sabine Koch, 180618
Project principles

• Open source
• Reuse
• Use existing standards
• Make use of existing open health data
• Comply with existing regulations
The Swedish virtual portal for patients/citizens
Välkommen till Journalen

Här kan du läsa dina och dina barns journaluppgifter från vården, samt dela med dig av valda delar ur din journal till andra personer.

Visa min journal

Record notes
Medications
Maternity care
Lab results
Referrals
Warnings
Diagnoses
Vaccinations

Växla journal

Du har tillgång till följande personers journal:

Visa

Har du frågor?

Vad tycker du?
Journalöversikt

I tidslinjen ser du alla tillgängliga uppgifter ur din journal, i tidsordning med det nyaste överst. Klicka på en rad för att se mer detaljer om den. Saknar du någon uppgift?

Vad innebär Nytt/Ovidimerat och Nytt/Osignerat?

Listan visas filterad på datum, från 2013-12-01 till 2016-03-31.

23 mar 2016
Besök
Samanterhemmets vårdcentral

17 mar 2016
MIRENA
Samanterhemmets vårdcentral

25 feb 2016
Konsultremiss
Fälhagens vårdcentral

22 feb 2016
Besök
Fälhagens vårdcentral

15 feb 2016
Administrativ
Fälhagens vårdcentral
What are barriers to adoption of patient centered informatics tools?

<table>
<thead>
<tr>
<th>Main issue</th>
<th>Action needed</th>
<th>Pitfalls</th>
<th>Possible solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absence of provider coordination and process owner</td>
<td>Harmonisation at policy level; Coordinated service provision at strategic management level</td>
<td>Lack of stakeholder involvement</td>
<td>Harmonise at the care professional level within the care providing teams</td>
</tr>
<tr>
<td>Uncoordinated involvement of several actors and disruptive information chain</td>
<td>Support collaboration between different actors through informatics to achieve continuity of care</td>
<td>Patient perspective lacking in process descriptions; Agreed processes and specifications are missing or not detailed enough</td>
<td>Describe care processes / scenarios of use and standardise their information content; Patient journey mapping</td>
</tr>
</tbody>
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<tr>
<td>Lack of a common picture between different users</td>
<td>Elicit the needs of ALL users</td>
<td>Diverging and conflicting user needs are elicited</td>
<td>Agree on common principles; Apply collaborative methods for user needs elicitation and work analysis</td>
</tr>
<tr>
<td>System development leads to replacement of existing routines without extra value</td>
<td>Describe future care processes / scenarios of use and estimate their value</td>
<td>Pre-definition of all processes is not possible; Change management is not taken into account</td>
<td>Identify intersection and touch points and define shared data sets; Make changes explicit and agree upon them</td>
</tr>
</tbody>
</table>

Koch S, Hägglund M, Scandurra S. *Informatics and Socio-technical Challenges when Designing Solutions for Integrated eCare*. in: Meyer I, Müller S, Kubitschke L. Achieving Effective Integrated E-Care Beyond the Silos. IGI Global, June 2014
What are barriers to adoption of patient centered informatics tools?

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<th>Main issue</th>
<th>Reason</th>
<th>Action needed</th>
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</thead>
<tbody>
<tr>
<td>Insufficient use of collaborative IT support</td>
<td>Insufficient usability</td>
<td>Increase usability</td>
</tr>
<tr>
<td></td>
<td>Lack of incentives</td>
<td>Create incentives for use</td>
</tr>
<tr>
<td></td>
<td>Lack of education</td>
<td>Educate users</td>
</tr>
<tr>
<td></td>
<td>Physician resistance</td>
<td>Prepare for change management</td>
</tr>
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Lessons learnt

• Stakeholder involvement is mandatory
• Development is driven by local (technical) prerequisites & existing legacy systems
• Risk for digital divide and health inequalities
**Decision support**

**Vision:** CDS is viewed as an essential component of a Learning Health System where a virtuous cycle is created from data generation, to aggregation, analysis, knowledge creation, knowledge dissemination and use, and ongoing measurement for continuous feedback and refinement.

**Today:** CDS that are implemented in practice are essentially rule-based; more traditional rule-based knowledge base is rapidly being complemented by knowledge resulting from using data mining techniques for discovery.

**Tomorrow:** the clinical encounter between a clinician and a patient will be supported by a wide variety of cognitive aides to support diagnosis, treatment, care-coordination, surveillance and prevention, and health maintenance or wellness.

**Challenges:** CDS systems must provide a rationale or explanation to the end-user for the recommendation proposed with an assessment of certainty or confidence in the recommendation.

**Opportunities:** Precision medicine

Grand Challenges for CDS

- Improve the effectiveness of CDS interventions
  - Improve the human-computer interface
  - Summarize patient-level information
  - Prioritize and filter recommendations to the user
  - Combine recommendations for patients with co-morbidities
  - Use free-text information to drive clinical decision support
- Create new CDS interventions
  - Prioritize CDS content development and implementation
  - Mine large clinical databases to create new CDS
- Disseminate existing CDS knowledge and interventions
  - Disseminate best practices in CDS design, development and implementation
  - Create an architecture for sharing executable CDS modules and services
  - Create Internet-accessible CDS repositories

(Sittig, 2008)
Why are CDSS not used?

- Lack of trust
  - On the knowledge base
  - On system reasoning
- Lack of integration with EHR
- Lack of integration with work processes
- Deficiencies in the Human-Computer Interface
Explainable AI

Today

- Training Data
- Machine Learning Process
- Learned Function

Task

- Why did you do that?
- Why not something else?
- When do you succeed?
- When do you fail?
- When can I trust you?
- How do I correct an error?

User

XAI

- Training Data
- New Machine Learning Process
- Explainable Model
- Explanation Interface

Task

- I understand why
- I understand why not
- I know when you succeed
- I know when you fail
- I know when to trust you
- I know why you erred

User

Slide credit: DARPA XAI
Lessons learnt

• Incentives need to be aligned
• Standardized clinical terminology and ontology needed
• Knowledge maintenance is crucial
• Explanatory CDS is mandatory
Health-enabling and Ambient Assistive Technologies

- 1995 first elderly home care project in New South Wales (Celler et al)

**Vision:** Ambient use of sensor-based information and communication technologies, aiming at contributing to a person’s health and health care as well as to her or his quality of life.

**Today:** aging patients, who live alone, can now be monitored 24/7 by sensor networks; Analysis techniques are still in their infancy; limited generalizability and usefulness of some of the analyses and models reported in the literature; patients are becoming the main drivers in the collection of sensor data (quantified self-movement).

**Tomorrow:** H-E&AAT will be used for population screening; patients with chronic diseases use them continuously to track their health or temporarily to achieve a specific aim, e.g. adjustment of medication; Sensors will become capable of measuring medically relevant parameters unobtrusively and non-invasively

**Challenges:** proof of diagnostic relevance and therapeutic efficacy is still lacking

**Opportunities:** to close the loop between research in health-enabling and ambient assistive technologies and the practice of health care and safe living

Lessons learnt

• overly-optimistic results in light of small sample sizes
• impact studies for diagnostic relevance and therapeutic efficacy are still missing
Consumer Health Informatics

• 1993 Conference by Tom Ferguson et al

Vision: Patients will be in charge of their own health care using informatics tools

Today: Patient engagement and shared-decision making through online communities, social media, portals and PHRs

Tomorrow: personalized information source and decision aid to facilitate tailored monitoring of wellness, disease prevention, and treatment for informed and engaged consumers

Challenges: Health literacy and digital divide
Opportunities: Precision medicine

e(mpowered)-Patients

Hugo Campos
Programming his ICD
(implantable cardioverter defibrillator)

Emily Kramer-Golinkoff
Managing advanced stage cystic fibrosis

Dana Lewis
creator of the “Do-It-Yourself Pancreas System” (#DIYPS) to manage her diabetes

To manage my Parkinson's disease I spend 1 hour in neurological healthcare and 8765 hours in selfcare per year

Christian Farman
Managing self dialysis

Sara Riggare, (im)patient, entrepreneur & PhD student
Lessons learnt

- Clinicians might be reluctant to receive large amounts of data
- Improved data analytics needed
- Improved data visualization needed for patients and clinicians
Decision support

Personal Health

Health-enabling and ambient assistive technology

Patient-centred information systems

Sabine Koch, 180618
Conclusion

“The health informatics community needs to find ways to build data models to systematically extract and link data along the continuum of care including their contexts and deliver the results according to research agendas that are driven by patient needs.”

Want to read more?

IMIA International Medical Informatics Association

www.imia.org

Yearbook of Medical Informatics (open access)

Submit your research

MEDINFO 2019, 26-30 Aug, Lyon, France
Submission deadline: Nov 12, 2018
http://www.medinfo-lyon.org/en/

Methods of Information in Medicine – impact factor journal publishing new methodological informatics approaches in biomedicine and healthcare
Questions?

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