Village of the Future
Agenda

• 15.45 The challenge of the integration of health, social care and welfare around the citizens as defined by the ESF – Keele report. **Michael Rigby**

• 15.55 The contribution of the INCA approach and the Blue Line to the 5 foundational pillars. **Jacob Hofdijk**

• 16.05 The proposed approach of the session of the three challenges leading the discussion for each of the pillar themes. **Dipak Kalra**
The OECD and ESF Reports provide keystones of the Caring Village of the Future

Professor Michael Rigby
Emeritus Professor of Health Information Strategy,
Keele University, UK
Consultant to European Science Foundation and OECD

Professor, Nordic School of Public Health
Adjunct Professor, Dublin City University
Care Delivery has to Change

- Demographic pressures
- New treatment and monitoring lines
- Economic (double) pressures
- Consumer expectations
- New Informatics Opportunities
OECD Action

New major OECD Publication now in press:

OECD-(US)NSF WORKSHOP:
BUILDING A SMARTER HEALTH AND WELLNESS FUTURE
15-16 FEBRUARY 2011
SUMMARY OF KEY MESSAGES

www.oecd.org/sti/smarterhealth

Also Special Issue of IJMI 2013

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
European Science Foundation

- January 2013
- Specifies in detail Social Science Research needed for effective e-health support
- Intended to stimulate action

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Projected Population % over 65 (Europe)
Projected Population % over 80 (Europe)
Working Adult : over 65 Ratio (Europe)
Four Dimensions of Care

1. The Citizen’s Needs
2. Informal Carers
3. Formal Care Providers
4. Society
Meet a 21st Century Older Person

Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Aged 79 years
Lives alone (family home)
Arthritis (legs and hands)
Long-standing digestive problem
Mitral valve leakage
Small mental lapses - ? TIAs
Technophobe (ATM, care alarm)
Sociable but Independent
Mary’s Health Support

General Practitioner – uninterested, repeat meds., nothing curable
Cardiologist – medication
Orthopod – undecided
Neurologist – unsure
Geriatrician – peace maker
Home nurse – monthly
Respite care – annually

No coordination
Mary’s Holistic Needs for Health

Nutrition support
Mobility support
Shopping
Bathing support
Socialisation support

Without all of these, her health will suffer

But not tasks of health services

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
... and her Informal Support

No children

Stepson, niece; each 90 minutes away; working

2 sisters – equally dependent, do not drive

Neighbours – elderly couples aged 70+, each husband with history of cancer
Who Manages her Health?

Health seriously compromised if not helped holistically
Health Care and Social Care need harmonising
Family carers’ own situations and needs are factors

Fit for ‘independent living’
Potential major risks
Disease monitoring not relevant

Test of modern society

Medinfo 2013 — Prof Michael Rigby. The OECD and ESF Reports provide keystones of the Caring Village of the Future
Proliferation causes Problems

Diagram after P. Hill

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
The Citizen Need

- Key information shared
- Harmony of care objectives and methods
- Appointments coordinated; also with informal carers’ input
- Preferences respected
- One general contact point (‘care manager’)

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Needy Citizen’s World

The OECD and ESF Reports provide keystones of the Caring Village of the Future
Panoply of Providers and Users of Individuals’ Health Data

- Education Provider
  - Employment
    - Occupational
    - Sheltered Emp.
  - Children
- Daily Living Monitoring
- Housing
- NGOs and other Voluntary Bodies
  - General and Specialist
- Social Care
  - Home Health Monitoring
    - Condition-specific
  - Multiple
- Health
  - Primary
  - Secondary
  - Mixed multiple-provider market
    - Mixed funding
- Mix of providers and users of health data

Mixed multiple-provider market
- Occupational
- Employment
- Sheltered Emp.
- Children
- General and Specialist
- Mixed funding

Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Society’s Need

• A good service
• Care at home where possible, but safely
• Family do not carry impossible load
• Demographic change accommodated
• An affordable service for all
• Quality; understanding
• Silos eliminated
• IT enabler, but no Digital Divide
Society Expects Holistic Respect

• New paradigm of client-focussed partnership
• Preference and choice, within reason
• Client specific agreement on controlled information sharing
• New concepts of shared consent, and agents
• Innovation in e-enablement

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Needy Citizen’s World

Community Groups

Informal / Neighbour Carers

Family
Traditional View of Health Sector

HEALTH

- Tertiary Hospital
- Acute Hospital
- Community Hospital
- Primary Care
Make a Poor Match

HEALTH
- Tertiary Hospital
- Acute Hospital
- Community Hospital
- Primary Care

CITIZEN
- Community Groups
- Informal / Neighbour Carers
- Family
Social Care just as Important

HEALTH
- Tertiary Hospital
- Acute Hospital
- Community Hospital
- Primary Care

SOCIAL CARE
- Specialist
- Social Work
- Day Care
- Meals
- Cleaning, etc.

CITIZEN
- Community Groups
- Informal / Neighbour Carers
- Family
Often other Services Too

HEALTH
- Tertiary Hospital
- Acute Hospital
- Community Hospital
- Primary Care

HOUSING

EDUCATION

SOCIAL CARE
- Specialist
- Social Work
- Day Care
- Meals
- Cleaning, etc.

CITIZEN
- Community Groups
- Informal / Neighbour Carers
- Family
## Mixed Characteristics of Health Support Services’ Data

<table>
<thead>
<tr>
<th>Data Source / Type</th>
<th>Data Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health</strong></td>
<td>Highly confidential; Single data subject; Mixed types</td>
</tr>
<tr>
<td><strong>Home Health Monitoring</strong></td>
<td>Vital signs or similar; Usually issue specific. High volumes; Needs critical threshold rapid analysis</td>
</tr>
<tr>
<td><strong>Social Care</strong></td>
<td>Shallower and simple; Largely text and terms Multiple data subjects; Multiple providers to an individual</td>
</tr>
<tr>
<td><strong>NGOs and other Voluntary Bodies</strong></td>
<td>Need records for delivering services; Increasingly important Autonomous</td>
</tr>
<tr>
<td><strong>Housing</strong></td>
<td>Provide shelter or support functions Warden needs to know limitations, risks, referral signs</td>
</tr>
<tr>
<td><strong>Daily Living Monitoring</strong></td>
<td>Data driven; Mixed data, different meanings and sensitivities Near-real time interpretation important; Algorithm or human monitor</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>Primarily for children Case management, limitations, risks, action needed</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td>Need to know to know limitations, risks, referral signs Independent of the health sector</td>
</tr>
</tbody>
</table>
What should Interoperability Bring?

Citizen at Centre

- Link health agencies and actors
- Integrate all services round ‘Care’
- Common care aims and care plans
- Diaries and Schedules
- Cross agency communication
- Common terms and meaning
- Empower the Citizen in Europe
The Achievable Citizen- and Society-Oriented Vision

Rules of Governance

Families

Consent

Friends and Neighbours

Voluntary Agencies

Health and Care practitioners

Private Care Providers

‘As Needed’

Key Data

Mary’s E-Enabled

Integrated Personal Care

Diagram after P. Hill

Medinfo 2013 - Prof Michael Rigby: The OECD and ESF Reports provide keystones of the Caring Village of the Future
Time to Vision

• ESF Report – Social Sciences research
• OECD
• Informatics
• EFMI and Medinfo

• and Copenhagen magic …
Prof Michael Rigby:

The OECD and ESF Reports provide keystones of the Caring Village of the Future.

E-Enabled Integrated Personal Care

- **Families**
- **Health and Care Practitioners**
- **Friends and Neighbours**
- **Voluntary Agencies**

Don’t do e-health, but if they did....
The contribution of the INCA approach and the Blue Line to the 5 foundational pillars.

Jacob Hofdijk

THE BLUE LINE CONCEPT LINKING PERSON AND PROVIDERS
Chronic Care Model

Community

Health System
Organization of Health Care

- Self-Management Support
- Clinical Information Systems
- Delivery System Design
- Decision Support

Informed, activated patient

Productive interactions

Prepared, proactive practice team

Outcomes
Improved outcomes
Chronic Raising Problem

Chronic diseases create 75% of the costs of care.

Patients with multiple health conditions -- co-morbidities -- create 80% of the costs of care.
The Message of Kaiser Permanente

Patients with co-morbidities and chronic conditions need --

TEAM CARE

We need the right care and we need consistent care... with teams of caregivers focused on the needs of individual patients.
What did Larry weed taught us?  
It is the Patient's problem, Stupid!

The focus should be on the patient’s health or health problem.

The Problem oriented approach best known from Lawrence Weed.

**Subjective**  **Objective**  **Analytical**  **and**  **Planning**  progress notes

The clinical care process

- Subjective
- Objective
  - Hx, PE, Lab
- Assessment
- Plan
  - Diagnostic
  - Therapeutic
  - Patient Education
- Structure similar to scientific argument
- Logic embedded in structure
- Continuity over time
- Three part plan reminds clinician of uncertainty, patient inclusion
From Care Standard to Individual Careplan
Integrated Care program is the key to integrated care

- From
  -care
  -standard
  -to
  -individual
careplan

Framework Individual careplan

- Diagnosis
- What?
- Carestandard Model
- Regional Implementation
- National Norm

- How? & Whom?
- When? & By whom?
- Individual care request
- INCA model = Modular Integrated Care Program
- Health Issues

- Individual careplanning
### Healthy lifestyle

- **Roken**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities
- **Bewegen**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities
- **Alcohol**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities
- **Voeding**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities

### Wellness

- **Stemming**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities
- **Stress**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities
- **Participatie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
  - Ziektespecifieke addities

### Cardiovasculair risk-management

- **Obesitas**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Hypertensie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Dyslipidemie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Nefropathie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4

### Diabetes

- **Glucose**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Retinopathie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Neuropathie**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
- **Voeten**
  - submodule 1
  - submodule 2
  - submodule 3
  - submodule 4
The Patient’s Health Issue Web

Lifestyle

- Roken
- Overgewicht
- Lichamelijke inactiviteit
- Ongezonde voeding
- Alcohol
- Stress
- Depressie
- Angst
- Somatisatie
- COPD exacerbaties
- Inspanningsvermogen
- Longfunctie / Dyspnoe
- Retinopathie
- Neuropathie
- Diabetische voet
- Glucose
- Cholesterol
- Somatisatie
- Bloeddruk
- Nefropathie
- COPD

DIABETES MELLITUS

COPD

PSYCHOLOGICAL

VASCULAIR
Individual Careplan for Patient

Individueel Behandelplan

Adviezen

Medicatie

Verwijzingen

Follow-up

Leef- en behandeldoelen

Smoking 2
- R2.A Leefstijladviezen
- R2.F Farmacotherapie
- R2.V Verwijzing

Obesitas 3
- O3.A Leefstijladviezen
- O3.F Farmacotherapie
- O3.V Verwijzing

Hypertension 3
- H3.A Leefstijladviezen
- H3.F Farmacotherapie
- H3.V Verwijzing
- H3.M Monitoring & Controle
The Holistic view on the Patient

The Body

The Mind

Social

Community
The Golden Circle
Simon Sinek
The INCA Coordination MODEL

- Life Goals
- Assessment
- Stepped Care Modules
- INCA Integrated Care Programs
- Body
- MIND
- SOCIAL
- Welfare

Citizen/Patient

Co Treatment

Care Coordination Team

Proactive Care and Treatment Plan

® BLUE LINE
Five Pillars
5 Pillars for the Caring Village of the Future

- Technological Interoperability
- Semantic Interoperability

Unstructured Clinical Note

Structured Data supporting Quality of Life

People and Expectations

Society Incentive Framework

Most Efficient, Affordable Care
Highest Quality Care
Focus on Wellness
Aaverage for All, Paid for by All

Human Factor Engineering
Village of the Future: Discussion questions

Dipak Kalra
Discussion questions after each Pillar

1. What is our present maturity for this pillar and how can we improve it?

2. What are the critical enablers or barriers to realising the scenario for this pillar?

3. What would be the first steps to support the day to day use of this scenario?
Pillar 1

Technical Interoperability

Technological Interoperability
Theme Technical Interoperability

Theme introduction Christian Lovis, Mobile devices in hospitals: enthusiasm versus evidence

Current Research

- DialBetics—Smartphone-based self-management for type 2 diabetes patients, progress. Kayo Waki, The University of Tokyo

- The transition from Messaging to true interoperability John Quinn, CTO of HL7 and of Accenture's healthcare division

Discussion on Pillar 1 Challenges for the future
Pillar 1
Technology
Interoperability
Pillar 1
Technology Interoperability

DialBetics—Smartphone-based self-management for type 2 diabetes patients, progress.

Kayo Waki, Dept of Ubiquitous Health Informatics, Graduate School of Medicine, The University of Tokyo

The transition from Messaging to true interoperability

John Quinn, CTO of HL7 and of Accenture's healthcare division
Technical integration, components, services and messages
Human interactions and semantic integration

structured and unstructured documents
More than 20 millions facts are stored annually, and 2'000'000 documents published each year, organized in about 1'500 model types according to env13606.

nursing care and observations
The nursing record, based on standards such as NANDA and NIC. The measure of predicted and effective nursing activity loads facilitates staff management and care efficiency. Daily, almost 15'000 nursing interventions are recorded.

labs and numerical results
All laboratories, including bacteriology and viral sequencing as well as other sources of numerical data are directly available and can be linked with other sources, such as reports or images. 20'000 lab results are stored each day.

non radiological images and signals
Non radiological images, such as histology, blood smear, dermatology or wounds, videos of endoscopy and surgery are becoming increasingly important in the patient record.

order entry
A generic order entry system for drugs, radiology, lab and other care requests. About 3'000 orders daily (inpatient only).

notifications and alerts
All events are notified. This represents around 100'000 notifications daily. Subscribers can be notified according to direct events, alerts or rule-generated notices. One million notices are sent daily to subscribers.

radiology
More than 60'000 images are added daily to the PACS, and directly available in the patient record, with advanced tools for image interpretation.
Time persistence and process management

- **Past**: Documentation
- **Present**: Decisions and acts
- **Future**: Scheduling and planning

**Workflow**

- **Population health**: The analysis and processing of consolidated events on a population basis allows a fine understanding of health and disease determinants.

- **Patient history**: The patient history is the sum of all events linked to his own timeline, including all events coming from the health system related to him.

- **Real-time whiteboards**: Whiteboards can deliver real-time information, such as ER load or hospital activity, and improve the work of care providers and the efficiency of managers.

- **Preventive medicine**: The ability to generalize future events, such as check-ups, immunization, and care, helps large population-based actions and follow-up.

- **Patient agenda**: A consolidated patient agenda summarizes all events to occur and helps care providers to manage time, care, and organize ward work. It is a precious patient’s empowerment tool.

- **Actual care planning**: Clear view of all present actions allows efficient care and better understanding of the case. It eases decision making.

- **Continuum of care**: The patient’s history includes all past actions in his own history.

- **Clinical pathways**: Care organized in clinical pathways that are planned and scheduled coherently according to patient and health system resources.

- **Order sets, decision support**: Well-organized order sets coupled with decision support leverage care providers’ efficiency and improves quality of care.
Madame Brigitte GALLAS née le 2/12/1980, 31 ans, Numéro patient 97008627
Hospitalisé depuis le 6/10/2011 dans le service de cardiologie
Episode de soins : 97016389
Poids : 73 kg, Taille : 175 cm, (selon méthode Mosteller : 1.88 m²)

Prescriptions

Rechercher médicament

<table>
<thead>
<tr>
<th>Médicament</th>
<th>Voie</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>siméthicone Platulex cp 42 mg 1 x/j</td>
<td>PO</td>
<td>Modifier</td>
</tr>
</tbody>
</table>

Feuille d'ordres

Tous signer  | Abandonner |

Prescriptions médicales actives :

<table>
<thead>
<tr>
<th>Médicament</th>
<th>Voie</th>
<th>Actions</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Patient</th>
<th>Message</th>
<th>Échéance</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyril MULLER</td>
<td>Antibiogram à ordre</td>
<td>10/11/2011</td>
<td>Détail</td>
</tr>
</tbody>
</table>

Terminé

Internet
MRSA - intersections
Hierarchical organization
- Reduced information displayed

Indexicality
- Information in context of time and space

Quick visual identification of tasks

Automatic sorting

Ehrler, Thursday, Room 3, 15:45
Average time .vs. nb actions for each vital sign

Average time for each model
Accuracy by interface

- NUMERIC_KEYBOARD: 100%
- STEPPER: 98%
- WHEEL: 96%
- CIRCLE: 94%
- COLUMN: 92%
- CHARACTER_RECOGNITION: 78%
DialBetics: Smartphone-based self-management for type 2 diabetes patients

Kayo Waki¹,², Hideo Fujita¹, Yuji Uchimura¹, Shigeko Kao¹, Eiji Aramaki³, Koji Omae⁴, Haruka Kobayashi⁴, Takashi Kadowaki², Kazuhiko Ohe⁵

¹Department of Ubiquitous Health Informatics,
²Department of Diabetes and Metabolic Diseases,
³Center for Knowledge Structuring,
⁵Department of Health Informatics,
Graduate School of Medicine
University of Tokyo, Tokyo, Japan
⁴Frontier Service Department, NTT DOCOMO, INC., Tokyo, Japan
Introduction & Background

Information technology (IT) is rapidly growing in the medical field, providing models of care for diabetes:

• a framework for monitoring patients’ data in real time
• frequent optimal feedback to patients

Smartphone offers continuous diabetes education through interactive communication but increases the healthcare providers’ workloads:

• develop a partially automated system without increasing physicians’ workloads
• evaluate the system’s value in diabetes self-management among patients.
Patient receives the email from DialBetics by smartphone; patient inputs exercise and diet information by speech-recognition device.

Photo of meal is also sent to DialBetics.

Nutritional value of meal is calculated by a dietician and sent back to the patient.

Advice on life-style modification, matched to patient’s input, is sent back to each patient.
Randomized Controlled trial

- Subjects: **54 type 2 patients** who were diagnosed more than five years ago
- Eligible: **no insulin injection**, no severe complications, ability to exercise
- Design: **randomized controlled trial** (DialBetics group 27, Non-DialBetics group 27)
  - DialBetics group: Age 57.1±10.3yrs, HbA1c 7.1±1.0%, BMI 26.1±6.0kg/m²
  - Non-DialBetics group: Age 57.6±9.4yrs, HbA1c 7.0±0.9%, BMI 27.3±7.5kg/m²
- Follow-up: **three months**
- Statistical analysis: **t test**
Results & Conclusions

1. Patients’ data measurement rate at home (%): \(91.0 \pm 15.6\)
2. Patients’ diet input rate at home (%): \(53.5 \pm 35.7\)
3. Patients’ exercise input rate at home (%): \(37.5 \pm 35.2\)
4. Patients’ diet photo input rate at home (%): \(77.1 \pm 35.1\)

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>DB group</th>
<th>Non-DB group</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>7.1±1.0</td>
<td>7.0±0.9</td>
<td></td>
</tr>
<tr>
<td>3 months later</td>
<td>6.7±0.7</td>
<td>7.1±1.1</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>-0.4±0.8</td>
<td>0.1±0.7</td>
<td>(p=0.01)</td>
</tr>
</tbody>
</table>

- DialBetics improved patients’ diabetes control by reducing HbA1c
- All patients were very satisfied with the system
- Need to improve the system’s usability based on patients feedback
The Transition from Messaging to True Interoperability

John Quinn
HL7 CTO
Medinfo 2013—August 22
HIT Interoperability & Standards

- The concepts of “messaging” and “true interoperability” are a variation of scope when considering the concept of HIT interoperability.
  - Messaging is a relatively simple instance of HIT systems interoperating at a minimal level.
  - The key components are:
    - The data contained in the unit of communication (a message) from the sending system that can also be parsed and then acted on by the receiving system.
    - A use case in the sending system that specifies the need for communication.
HIT Interoperability & Standards

- Any message supports:
  - A process (use case) that—given the right conditions—dictates the creation of the messaging from the sending system
  - A conditional set of data elements from the sending system—the set may be viewed from a perspective of “optionality”...different expected conditions may prescribe different sub-sets of the expected information. Not all conditions for a given message may support the maximum number of possible data elements.
HIT Interoperability & Standards

A message Supports (continued).

- Some level of **structured data** with associated source vocabularies supported by both systems and a associated permissible value set that is available to both the sending and receiving systems.

- The change event moved interoperation from being solely inside a provider organization to among all users for healthcare information.
HIT Interoperability & Standards

- Interoperation is now across all interconnected producers and consumers of healthcare information.

- The most significant step is the standardization of interoperability and the supported processes across all producers and consumers of healthcare information. This has lead to the ability to test for conformance and certify interoperability.
Discussions

What is the present maturity of technology interoperability, and how can we improve it?

- Establish a patient-centered team approach

What are the critical enablers of—or barriers to—realizing the implementation of an integrated care and treatment plan that coordinates formal and informal care for this pillar?

- Health insurance should provide benefit coverage
- Healthcare providers and organizations must be reimbursed

What is the first step in supporting the day-to-day use of this system and improving the quality of life for patients and the sense of accomplishment for providers?

- Let patients fully grasp the real benefit of the system
- Patients should be involved in the process of design and revision
Pillar 2

Semantic Interoperability

NLP + IMO + CDA

Unstructured Clinical Note

Structured Data supporting Collaborative Care

Semantic Interoperability
Integration and Semantics

Introduction to the theme Dipak Kalra, Interoperability for person centred care

Current research

• Weak Semantics, an overview Francesco Pinciroli

Discussion on Pillar 2 challenges for the future
Interoperability for person centred care

Dipak Kalra
Professor, Health Informatics, University College London
President, the EuroRec Institute

on behalf of the
eHealth Innovation project consortium
Care of the Chronically ill
Example - Cardiovascular Disease

- 80% of EU spending on healthcare goes on the chronically ill
- CVD alone costs the EU Economy €192 billion annually and accounts for 57% of healthcare costs
- Contributes to 21% of productivity losses and 42% of deaths in the EU
- A recent study across the Netherlands, UK and Germany showed that:
  - home tele-monitoring pilots (3 countries) have delivered
    - 26% reduction in hospital days per patient
    - 10% overall cost savings through nurse telephone support
    - 15% improved survival rates

Source: Dr. Paul Timmers, Director, Sustainable & Secure Society
DG CONNECT European Commission
Drivers for eHealth innovation in person centred care

• Existing models of health care services are unsustainable (rising needs and costs)
  - e.g. rising incidence of chronic diseases and increased complexity of their treatment

• Need for better integration across wellness, health care, public health, occupational health & social care

• Need to harness the immense contributions that patients and citizens can make in:
  - managing their own health and conditions
  - preventing illness
  - promoting well-being
EIP on Active and Healthy Ageing: paradigm shifts that are needed

- FROM societal challenge TO major opportunity
- FROM burden TO asset
- FROM acute reactive care TO proactive preventive care
- FROM curing diseases TO improving function

**Dependency Ratio**
- From 1:4 to 1:2
- 80+ doubles by 2025

**Cost of Care**
- Up by 4-8% of GDP by 2025

**Human Resources**
- Shrinking work force
- Lacking 20 mio carers by 2020

**Empowerment**
- Active Ageing

**New Care Models**
- Integrated care
- Large efficiency gains

**Growth and Markets**
- 3000 B€ Wealth
- 85 Million Consumers
Personalised health services

- Focus on prevention and support of patient self-care and lifestyle management
- Improve management of long term conditions
  - virtual teams
  - close to home and ambulatory health services
  - person-centric information capture and delivery
  - patient-tailored knowledge at the point of decision making
- Share power and responsibility with patients
  - co-production of health
Mary

- Mary, aged 79 and living in North London, wishes to visit her daughter in Barcelona to see her new grandson.
- Mary has chronic heart failure.
- Her condition is managed well by her GP and a heart failure nurse
- She also pays annual outpatient visits to her cardiologist.
- She has not needed any stay in hospital for over three years.
- Mary and her GP are concerned that the flight and the higher temperatures in Barcelona might impact negatively on her heart failure.
- They would like to ensure that any deterioration is promptly detected and managed.
Traditionally, Mary would have discussed her trip with her GP.

The GP would write her a short summary letter stating Mary’s condition and listing her medication.

Mary would need to make up her own mind, whilst in Barcelona, whether she is getting sufficiently ill to require medical help.

A treating clinician in Barcelona would only have Mary’s doctor's written note to inform him or her of any management decision.

Treatment would, of course, be covered by Mary’s travel insurance.
• In future Mary's electronic health record and her care pathway would be held in a universally accessible interoperable form.

• At home in London, Mary's daily body weights would be entered automatically from her scales into her personal health record.

• In addition she would use a user-friendly tablet computer to enter her heart rate and other daily symptoms.

• The personal health record and electronic health record would be sufficiently integrated with each other that Mary's heart failure nurse could monitor her status and be automatically alerted if any signs of early deterioration in cardiac function were identified.
When Mary travels she would continue to maintain this daily log, checking her weight using her daughter's weighing scales in Barcelona.

She and her practice will be alerted if her average heart rate or weight increase.

If a particular problem arises then her nurse and GP can decide to modify her treatment regime, using the PHR and its care pathway App to communicate this instruction to Mary.

If any greater concern arises, a clinician treating Mary in Barcelona could see Mary's complete EHR and trends, and could elect to follow the same care pathway.

As a result, Mary's treatment plan would remain consistent with what would have happened to her in London, and would enable a smooth handover when she returns.

Mary is also rather pleased because her travel insurer has offered her a discount for being a "connected healthcare traveller".
Mini-symposium “Caring Village of the Future”

Weak Semantics: a Home Ontology for Cardiology Case

Stefano Bonacina, Sara Marceglia, Francesco Pinciroli
Table of Contents

1. Setting the scene of Personalized Health Informatics
   1. e-Health and Personalized Health Informatics definitions
   2. The Active and Informed Patient/Consumer
   3. Actions and Challenges for the Active Patient/Consumer

2. Developing an ontology-based lexicon connector for the Cardiology
   1. Objective
   2. Definition of the system specifications
   3. Methodological approach
   4. The home ontology for the Cardiology
   5. The “Medical Lexicon Connector / Cardio” website

3. Ongoing Conclusions
Setting the scene of Personalized Health Informatics
Setting the scene of Personalized Health Informatics
The Active and Informed Patient/Consumer

- **communicates** with healthcare professionals effectively

- **accesses and manages** health information and documents

- has **health literacy**

- **makes decisions** about personal health

- **supports self-care** (also in the case of chronic illness)
Setting the scene of Personalized Health Informatics
Actions for the Active Patient

- Content understanding
- Document filing
- Medication or therapy compliance
Digital divide & health inequalities

1. Health Literacy
2. Computer Literacy
3. Access to Information Technology
Developing an ontology-based lexicon connector for the Cardiology
Objective

Modelling, designing and implementing a computerized system for connecting specialized terminologies and familiar lexicons of the cardiovascular domain both in Italian and in English to improve the patient’s/citizen’s understanding of medical content

Development workflow:
1) Modelling, designing and implementing an ontology based on familiar medical lexicon in the cardiovascular domain from generalist accredited sources;

2) Collecting specialist medical terminology related to the familiar one, extracted from ontologies or specialist terminologies and dictionaries;

3) Implementing semantic connections between specialized terminologies and familiar lexicons using the Unified Medical Language System (UMLS) terminologies and the Consumer Health Vocabulary (CHV) dictionary;

4) Creating a Web interface to query the computerized system.
In the Healthcare realm it is possible to identify a lot of actors, each of whom can be a sender or a receiver of medical information.

To tackle the problem, we have investigated aspects related to the correspondence between “Familiar context” and “Specialist context”
METHODS
Methodological approach

Unified Medical Language System - UMLS

- CHV = Consumer Health Vocabulary;
- NCBO Bioportal = archive of commonly used biomedical ontologies

Consumer Medical Lexicons

Metathesaurus

Semantic Network

Conceptual correspondences

Specialist Medical Terminologies

Ontologies

- English from NCBO Bioportal
- Italian from UMLS

Translation

From English dictionary

Italian Consumer Medical Lexicon

Filter for Cardiovascular Domain
METHODS: Detailed description of relationship among terminologies

1. «Lexicon Camera» Source
2. Gold Standard
   Digitally Structured and Controlled Vocabulary
   UMLS
3. Translations ITA/ENG and CHV

Ontologies from Bioportal

Italian familiar medical vocabulary

Italian Specialist Medical Terminologies

English familiar medical vocabulary

English Specialist Medical Terminologies

Ontologies from Bioportal
### METHODS

## Terminologies and Sources

<table>
<thead>
<tr>
<th>Terminologies</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italian familiar medical lexicon</td>
<td>Lexicon Camera/Cleaned Cardio</td>
</tr>
</tbody>
</table>
| Italian specialist medical terminologies    | • Medical Dictionary for Regulatory Activities Terminology Italian (MedDRA ITA);  
                                           | • Medical Subject Headings Italian (MeSH ITA).                         |
| English familiar medical lexicons           | • Consumer Health Vocabulary (CHV);  
                                           | • Translations from Italian/English dictionary.                      |
| English specialist medical terminologies    | • Medical Dictionary for Regulatory Activities Terminology (MedDRA);  
                                           | • Foundational Model of Anatomy (FMA);  
                                           | • National Drug File (NDF-RT);  
                                           | • International Classification of Disease, 9\(^{\text{th}}\) revision (ICD-9). |
METHODS
A model of the care process

Class Diagram of the Unified Modeling Language (UML)

1 - Anatomy
2 - Pathologies
3 - Lifestyles
4 - Risk factors
5 - Procedures and Exams
6 - Therapies
7 - Biomedical Measurements
8 - Symptoms
An Ontology is a collection of entities in a specific domain and the relations that exist among them.

It’s a tool to realize a formal, shared and explicit representation of a chosen domain.
METHODS: Building the ontology for the family medical vocabulary. Protégé Ontology Editor
**METHODS:** Web application design

**Web application and graphical user interface:** Software, available on the web, that interacts with a database to provide a user with personal service

Software to develop the Web application: MS **WebMatrix**

**Schema of Web application functioning:** *server-side* makes treatment and storing operations of data which will be available on *client-side* for the final user

![Diagram](image-url)
RESULTS

The home ontology for the Cardiology

Representation of the familiar medical lexicon in Italian and relations among terms

1 - Anatomy
2 - Pathologies
3 - Lifestyles
4 - Risk factors
5 - Procedures and Exams
6 - Therapies
7 - Biomedical Measurements
8 - Symptoms
RESULTS:
Homepage of the “Medical Lexicon Connector / Cardio” website

Questo sito fornisce a medici e pazienti, e alle loro famiglie, un strumento che permette la traduzione da terminologia medico-specialistica a quella medico-familiare per migliorare la comunicazione tra medico e paziente durante il processo di cura.

La comunicazione medica infatti, avviene tramite un linguaggio specialistico con caratteristiche proprie che spesso rappresenta una barriera insormontabile nella trasmissione dell’informazione dal personale clinico al paziente interessato. Differenze nelle conoscenze e nella terminologia tra medico e cittadino - paziente creano un alto livello di complessità nella comunicazione, che è necessario ridurre per creare una mutua comprensione.

Questo semplice strumento, che si può definire un connettore di lessici medici, permette al medico di comunicare con il cittadino - paziente utilizzando termini a lui più adeguati, oltre che ai cittadino - pazienti di spiegare al medico con più facilità i sintomi e comprendere meglio le informazioni inerenti la sua salute. La connessione tra termini del lessico medico-specialistico e del lessico medico-familiare è disponibile anche in lingua inglese.
RESULTS
Enquiring terms correspondences
## RESULTS

### Resultset visualization

### CONNETTORE TRA LESSICI MEDICI

<table>
<thead>
<tr>
<th>TRADUZIONE</th>
<th>1° TERMINE</th>
<th>RELAZIONE</th>
<th>2° TERMINE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lessico medico specialistico:</td>
<td>Infarto miocardico</td>
<td>si tratta con</td>
<td>Inibitori della reduttasi del coenzima A idrossimetilglutarilico</td>
</tr>
<tr>
<td>Lessico medico familiare:</td>
<td>Infarto</td>
<td>ha come terapia</td>
<td>Statine</td>
</tr>
</tbody>
</table>

[ Nuova ricerca ](link)
RESULTS

Resultset visualization
RESULTS

Results in visualization

OGGETTO DELLA RICERCA:
Inibitori della reduttasi del coenzima A idrossimetilglutarilico

TERMINE DEL LESSICO MEDICO SPECIALISTICO ITALIANO: Inibitori della reduttasi del coenzima A idrossimetilglutarilico

Ontologia fonte:
Titolo: MeSH Italian

Relazioni:
Infarto miocardico
Patologia cardiovascolare
Angina pectoris
Ictus
Iperelesterolemia
Fibrillazione atriale
Patologia coronarica
Aterosclerosi

Definizione:
Ciascun rappresentante di una classe di farmaci utili a combattere la presenza accossiva di colesterolo nel sangue.

Fonti: De Agostini Scuola S.p.a.

Relazioni:
statine è un/una antidislipidemia
statine è una generalizzazione di atorvastatina
statine è una generalizzazione di pravastatina
statine è una generalizzazione di rosuvastatina
statine è una terapia per infarto
di statine è una terapia per patologia cardiovascolare
di statine è una terapia per ictus
statine è una terapia per iperelesterolemia
di statine è una terapia per fibrillazione atriale
di statine è una terapia per insufficienza cardiaca
di statine è una terapia per aterosclerosi
statine è una terapia per coronaropatia
Ongoing Conclusions
A **medical lexicon connector** to obtain an effective and unambiguous correlation between the familiar medical lexicon and Specialist Medical terminologies in the cardiovascular domain has been developed (both in Italian and in English). This also provides a quick and practical access to information. The present system is a part of the software tool for the empowerment of the citizen/patient.

The construction of **medical ontologies** as tools for integration and enhancement of biomedical data, allowed us to quickly and effectively create a systematization of medical terminologies.

The development of a **relational database** helped to create a correspondence between the familiar medical lexicon ontologies and the specialist ones.

The **Web application** is easy and intuitive to use allowing users to access all the information stored in the database.
How to deal with **weak signals**

**AIM 1:** Select pertinent candidate variables for the personal pervasive ecosystem.

**AIM 2:** Collect candidate variables for the personal pervasive ecosystem.

**AIM 3:** Extract weak signals from the candidate variables for the pervasive ecosystem.

**AIM 4:** Analyze and model weak signals behaviors in the individual.

**AIM 5:** Build the personal pervasive ecosystem.

**AIM 6:** Select appropriate and reliable medical domain ontologies for risk assessment.

**AIM 7:** Define the relationship between weak signals in the personal pervasive ecosystem and the disease risk.

**AIM 8:** Detect significant changes in the weak signal.

**AIM 9:** Raise alarms and propose possible intervention strategy.
# Rules for assigning traffic-lights colors in **scoring Apps**

<table>
<thead>
<tr>
<th></th>
<th>GREEN</th>
<th>YELLOW</th>
<th>RED</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Responsible Promoters</strong></td>
<td>Trusted promoters well known as active in the field</td>
<td>Something in between (eg: promoters active out of the field of Medicine, etc.)</td>
<td>Untrusted promoters</td>
</tr>
<tr>
<td><strong>Offered Services</strong></td>
<td>The offered services are useful and appropriate for the field</td>
<td>Something in between (eg: the offered services are partially useful or appropriate for the field)</td>
<td>The offered services are nor useful nor appropriate for the field</td>
</tr>
<tr>
<td><strong>Searching Methods</strong></td>
<td>The searching methods are not trivial and the result-set presentation is effective</td>
<td>Something in between (eg: The searching Methods are not so trivial and the result-set presentation may make sense, etc.)</td>
<td>Both searching methods are trivial and result-set presentation is weak</td>
</tr>
<tr>
<td><strong>Application Domains</strong></td>
<td>The borders of the application domains are fully described</td>
<td>Something in between (eg: The operating dominion is only broadly described, etc)</td>
<td>The borders of the application domains are weak and may induce risks</td>
</tr>
<tr>
<td><strong>Envisaged Users</strong></td>
<td>The prospected users are clearly mentioned and user needs are profiled</td>
<td>Something in between (eg: prospected users needs are identified just broadly)</td>
<td>The prospected users are not mentioned nor their needs are profiled</td>
</tr>
<tr>
<td><strong>Qualifiers &amp; Quantifiers</strong></td>
<td>Availability of trusted positive evaluations</td>
<td>Something in between (eg: evaluations are available but it is difficult to say they are significant)</td>
<td>Availability of trusted negative evaluations</td>
</tr>
</tbody>
</table>
Thank you for your attention

Any questions?
DISCUSSION: interoperability that Mary needs: what is our present maturity, and how can we improve?

1. A standard for electronic health records in which the information structures, information provenance and semantics are consistent for both countries involved.

2. A standardised representation of a heart failure care pathway in which the recommendations for monitoring, escalation, changes in treatment and grounds for hospital admission are consistently understood in both countries.

3. Personal health record and electronic health record systems that are interoperable and share the monitoring progress and care pathway steps for heart failure (or, more generally, for some other chronic condition).

4. Automatic integration of weighing scale data. For data from an "uncontrolled" environment - such as Charlie's daughter's weighing scale - a kind of "inductive" coupling of data into the electronic health record will be needed.

5. Interoperable rules that track home monitoring data for trends of concern that generate alerts for specific personalised patterns and thresholds.

6. Pan-European identification of healthcare professionals and the implementation of appropriate access control policies to enable relevant staff to see the data they need.
What are the other critical enablers, or barriers to realising this scenario?

- Healthcare business and service models
- Legal clarity about self care, co-production, professional accountability
- Health ICT marketplace and procurement models
- Workforce skills
- Societal engagement, empowerment, value creation
- Benefits evaluations
Pillar 3

Human Factor Engineering

Human Factor Engineering
Human Factor Engineering

• Introduction to the theme Marie- Catherine Beuscart-Zéphir, Human Factors Engineering of the person systems interaction, usability and safety for all

Current research

• Persuasive eHealth to support person-computer-interactions.
  Lisette van Gemert-Pijnen

Discussion on Pillar 3 challenges for the future
Caring Village of the Future - Pillar 3

Human Factors Engineering: Usability and Safety for all

Marie-Catherine Beuscart-Zéphir
EVALAB INSERM CIC-IT, University Hospital of Lille, France
The essentials of Pillar 3 for the Caring Village
Human Factors Engineering

- “Ergonomics (or human factors) is the scientific discipline concerned with the understanding of interactions among humans and other elements of a system”*

- Ergonomists “apply theory, principles, data and methods to optimize human well-being, overall system performance”* and safety.

- Human Centered Design of work systems*

*International Ergonomics Association
Usability: focus on the technology

- Usability is the "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”

  (International Standard Organization: ISO 9241)

- effectiveness: accuracy and completeness (safety dimensions)
- efficiency: resources expended / accuracy and completeness
- satisfaction: comfort and acceptability of the work system

- A measurable dimension of the product
Main objective of HFE

**Optimization** of the entire Work System

- **Human well-being**

- **System performance:**
  - Safety (patient safety, users’ safety)
  - Usability (technology)

- Organization of the socio-technical system
Human Centered Strategy

Understand project’s goals

Understand the context of use

Evaluate design solutions

System satisfies specified requirements

Specify users’ requirements

Produce Design solutions
Human Centered Strategy

Understand project’s goals

Understand the context of use

Evaluate design solutions

System satisfies specified requirements

Specify users’ requirements

Produce Design solutions

Goals of the Caring Village project

Goals of projects of innovative integrated technologies to support various goals of the village project
The Caring Village « project »
Caring Village: a vision

- Patient Centered
- Integrated Social and Medical care

Our task as experts in HFE and Technologies for Health
- Find / Identify / Design / Develop / Implement / Monitor
- Advanced integrated technologies

To support the vision

→ Adopt the Human Centered strategy from the start to ensure usefulness, safety and usability of technologies
Key points (1)

○ **People** (persons, users, patients, healthcare professionals, social workers ...)
  - Fragile patients with complex and multiple needs
  - Multiplicity of other « users », many roles and actors (General Practitioner, Cardiologist, Orthopedic, Neurologist, Geriatrician, Home nurse, family, neighbors, etc.)

○ **Systems design:**
  - Adapted view of information for each role/actor + overview
  - Support Human-Human cooperation
Key points (2)

- **Integration of various technologies**
  - Medical devices
  - Information systems
  - Mobile devices

- **Usability** of each device in isolation AND when integrated with other technologies
Key points (3)

- The vision of the Caring Village points at a highly complex work system
  - Increases the difficulty of the HFE approach
Caring Village of the Future
Pillar 3  Human Factors Engineering

critical factors for Persuasive and Productive eHealth

Dr  J Van Gemert-Pijnen
MedInfo, 2013
Copenhagen 22-08-2013
eHealth – interventions

- Improving Health via people centred Technology
- Social sciences & engineering
- Different areas
  - independent and assisted living
  - better use of health data
  - empowerment for self-management of health and wellbeing
- Can be effective, but not always
- Critical factors for effective eHealth interventions: reach and adherence

aug/25/13
Low-adherence; barrier for productive eHealth

- Not all users stick to eHealth programs
- Not all users use all features of technology they can use
- There is a dose-response relationship
- But there is limited insight in the (non)use of eHealth interventions
- Limited insights in what factors influence usage of eHealth
The Proof is in the usage

Does IT work? Can IT help? Is IT productive? For whom?

We certainly have seen that disparity of cost and effectiveness (in the health care system)...It's like an inverse correlation between what we put in and get out.

- Sean Hogan
VP of IBM Health Care Delivery Systems

Black Box phenomenon in eHealth Evaluations

UNIVERSITY OF TWENTE.
Bad designs: Low adherence
Happy Feeling & Well-being Tech

Text Driven-content, Limited cues to motivate usage, users
Look and feel of a self-help-book
Standard format, Not tailored to users’ expectations
Not tailored to needs
Overestimation of interest in Self tracking
No incentives for usage
Inadequate business model
Limited access (clients insurance companies)
Stand alone apps: lack of interoperability and inter-usability with IT systems, medical devices
Sensors at home, caring village of the future?

Monitoring Daily life activities

UNIVERSITY OF TWENTE.
Usability problems

- Technical interruptions
  - No data received (server)
  - Overload phone line
  - Sensor too sensitive
- Activity Data hard to understand due to unclear interface
  - The presentation of data (graphs) was hard to understand
- Activity Data hard to interpret due to technical calibration (safety industry)
  - The value of data was disputable, activity patterns (deviations) are not traceable to medical evidence, standards, treatment programs
Holistic roadmap for productive and persuasive eHealth
(van Gemert-Pijnen, J Med Internet Res 2011 | vol. 13 | iss. 4)

Catalyst for innovations (holistic view, social, mental, physical care, beyond silo approach)
Value driven development (ethical and legal, feasible, realistic) through stakeholders dialogues
Persuasive designs for adherence
Adequate business models for safe and productive health
Advanced analytics to assess actual performance (beyond standard designs)
Next Steps: Data to improve eHealth

- Advanced analytics
  - Dose and exposure rate via log-ins (engagement)
  - Usability tests and interviews (does IT work)
  - Usage, user patterns via logfiles (how IT works)
  - Persuasiveness and Personality assessments (what works for whom)
- Business modelling (what is productive, HTA)
- Continuous measurement and regular evaluations (data-stream)
Persuasive Designs to inspire users
Different cues; what matters? For whom?

Fractional factorial designs; what persuasive feature(s) matters most...
Hot triggers that Fit with different users
eHealth is the use of information and communication technologies to support health and healthcare. It is also a school of thought about connectivity, social participation and networked innovation. Policy makers, health care professionals, patients, insurers, researchers and citizens alike, believe that eHealth will contribute to the solution of today's health issues and to the innovation of health care systems.

In this book, specialists from the Center for eHealth Research and Disease management (University of Twente) and the National Institute for Public Health and the Environment (RIVM) explain what needs to be done to increase the impact and uptake of eHealth interventions. They do so by treating a range of hot subjects such as human centered design, business modelling, persuasive technology and current trends at the intersection of health, social sciences and technology. These topics converge in a holistic approach to the development and design of successful eHealth technologies. Improving eHealth is written for high school and university students, health professionals and all those interested in contemporary health care.
Contact: dr. J (Lisette) van Gemert-Pijnen
J.vanGemert-Pijnen@utwente.nl
www.ehealthresearchcenter.nl

For understanding users
Medieval helpdesk in English - YouTube
Logdata: prompts for persuasion

- Log-data identify **critical moments** for persuasion to support human-computer interactions
  - willingness, awareness, adoption of new behaviors/skills
  - triggers for support (e.g. praise, social support)
- Log-data show prompts for persuasive **triggers during usage**
  - hot triggers to use other non-visited features
  - personalized persuasive features to intervene in early stage of treatment and to support continuation

**UNIVERSITY OF TWENTE.**
Translation of medical protocols into tailored designs

High Risk communication to increase safety

Persuasive designs, tailored to tasks HCWS

Bed side tech; right moment, right format

Reduces errors, saves time

Prudent usage of antibiotics
Persuasive Features to increase adherence
eMental Health interventions

Personalization
- Feedback
- Reminders
- Self-monitoring
- Social learning
- Social facilitation

Tunneling
Fractional factorial design; what persuasive feature(s) matters most…
Next steps: analyzing usage data

- Machine learning:
  - predict adherence/effect from use pattern of week 1; enables early action for groups at risk
  - what categories appear from the use data and can we match those to a certain group of participants (and can we adapt the system to those participants)
  - can we visualize usage information in an easier way?
- Markov models: what is the dominant path through the system (and should we adapt the system based on this insight)
- Market-basket analysis: what features are often used together?
Diabetes eCoach

logfiles to identify drop outs and usage patterns

Mean number of hits

Appendix X. Overview of activity patterns in month

Start & Restart

prompts for persuasion
<table>
<thead>
<tr>
<th>Performance system&amp;content</th>
<th>Productive</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the reach and adherence rate?</td>
<td>What values are achieved?</td>
</tr>
<tr>
<td>What usage patterns emerge?</td>
<td>How service oriented is the eHealth intervention?</td>
</tr>
<tr>
<td>What features are used?</td>
<td></td>
</tr>
<tr>
<td>What aspects of use provide more benefits?</td>
<td></td>
</tr>
<tr>
<td>Who are the hard-core users? Who are the drop outs? Who are the re-starters?</td>
<td>What are the net benefits according to the stakeholders?</td>
</tr>
<tr>
<td>What user profiles can be identified?</td>
<td>Health and well being; QOL, Knowledge, Insight in healthier living</td>
</tr>
<tr>
<td></td>
<td>Productivity (utilization costs; just in time care; adequate use of care)</td>
</tr>
<tr>
<td>Is the technology easy to use?</td>
<td>What kinds of business models can be developed to achieve the added values?</td>
</tr>
<tr>
<td>Is the technology persuasive? (triggers to support self-management)</td>
<td></td>
</tr>
<tr>
<td>Is the technology inter-usable with other devices in use?</td>
<td></td>
</tr>
<tr>
<td>Is the technology interoperable with other information systems in use by the users?</td>
<td></td>
</tr>
</tbody>
</table>
to intensify cooperation with (inter)national research centres and healthcare institutes

to contribute to the solution of global health problems, like ageing and chronic care, via persuasive designs and business modelling

multidisciplinary development & implementation approach (social sciences & technology)

http://ehealthresearchcenter.org
The three challenges
1/ Maturity

- Positive role and impact of patient safety initiatives on technologies usability, e.g. EU regulation on Medical Devices*
  - Many stand alone software considered MD
  - Safety-oriented Usability file mandatory for CE marking (EN 62366:2007 standard)

- Standard progressively implemented
  - Lack of HF expertise and experience (industry, health authorities and certification bodies)
  - Training and cooperation with academic teams necessary

2/ Barriers and Enablers (1)

- **Difficult** to apply *patient-driven innovation*
  - Fragile patients, not usually listened to
  - Multiplicity of users with contradictory / conflicting needs

- Interesting approach: (network of) **Living Labs for Health and Autonomy**
  - Example of the French network of LLHA and the Humanicité initiative in Lille
2/ Barriers and Enablers (2)

- **Difficult** to evaluate integrated complex technologies and work systems
  - Requires complex clinical simulations and field studies

- Explore the possibility of integrating HF dimensions in clinical studies
The complexity of the envisionned work system makes it even more resitant to change

- Cf. Enrico COIERA, “Stasis and adaptation”
- in Context Sensitive Health Informatics, Human and Sociotechnical approaches

- Beyond the reach of standard HF approach
3/ Next steps?

○ User-driven innovation

○ Clinical simulation of integrated technologies / integration of HF dimensions in clinical studies

○ Support implementation of regulations on patient safety (prevention of use errors related to technologies)

○ ....
Pillar 4

Peoples Expectations

People and Expectations
Peoples Expectations

• Introduction Michael Rigby The holistic approach of ESF study on Social and Healthcare provides the keystones of the Caring Village of the Future.

Current Research

• Mobile Health and Remote Monitoring: the challenges ahead to meet the expectations of the people Mrs. Catherine Chronaki,

• Empathy by design? Reflections on people-systems interaction in agent assisted therapy Claudia Pagliari, The University of Edinburgh

Discussion on Pillar 4 challenges for the future
Mobile Health and Remote Monitoring: the challenges ahead to meet the Expectations of the People

Catherine Chronaki
HL7 International Foundation
euoffice@HL7.org
People and expectations: What is my point?

- people have great expectations from eHealth technology
  - Societal
  - Financial
  - Health, wellness and social care

- health and wellness technology weaves into the fabric of life: disruption
  - Protect & prepare people
  - Shape expectations
  - Build trust, comfort

- We need invest in interoperability - change in mindset:
  - technical, semantic, organizational, legal
  - business models to sustain and mainstream innovation
  - Assessment/ monitoring/ evaluation / reliable indicators
  - Education and training
    - Certified ePatients, ehealth professionals and e-care givers?
Q1: What is our present maturity for this pillar and how can we improve it?

- A non sustainable situation
  - technology is weaving itself into the fabric of life
  - get people on board!
Cardiovascular Costs in Europe

EURIKA study [Guallar2011]:
With improved CVD management
Up to 30% of CVD-deaths can be averted

remote monitoring of cardiac implants

Shifting resources from scheduled to need-based informed personalized contacts!

Remote follow-up

- doing things differently to reduce the clinic workload [faster, cheaper, better]

Remote Monitoring and Patient initiated interrogation.

- doing different things to improve patient outcome [innovative new processes and integrated care protocols]

Mainstream adoption requires:

- mastering the operational costs e-Health,
- creating value for taxpayers, and
- supporting the care givers with a solid legal & regulatory framework.
Q2: What are the critical enablers or barriers to realizing the scenario of the implementation of an integrated care and treatment plan for the coordination of formal and informal care?

- Interoperability
- Education
- Business models
- Indicators
Hugo Campos: empowered professional; has been implanted a defibrillator

- A native of Rio de Janeiro, Hugo Campos moved to the United States in the 1990s to study graphic arts.

- Hugo Campos at risk of cardiac arrest, became implanted with a cardiac defibrillator

- This made Campos realize how crucial it is for patients to engage in their own health care and in shared decision-making with clinicians.

- In the months that followed, Campos started a blog, founded the ICD User Group and embraced a new world of patient advocacy through social media. Campos is passionate about participatory medicine, connected health and patient empowerment through the use of technology. [http://icdusergroup.blogspot.gr/](http://icdusergroup.blogspot.gr/)

- He also advocates for the rights of patients with pacemakers and implantable defibrillators to gain electronic access to the data collected by their cardiac devices. [http://www.tedxcambridge.com/thrive/hugo-campos/](http://www.tedxcambridge.com/thrive/hugo-campos/)
ePatients: Monitoring our life

Activity
- Fitbit
  - $99

Blood Pressure
- Withings BP Monitor
  - $129

Weight
- Withings WiFi Scale
  - $159

Sleep
- Zeo Sleep Manager
  - $149

- Empowered
- Equipped
- Engaged
- Enabled

We all have the right to our health information!

Campos TEDx Cambridge 2012x
iCARDEA healthcare ecosystem

Interoperability with external systems

Adaptive Care Planner Engine

Inform doctor via SMS or email

Doctor uses

Patient Parameter Monitor (PPM)

uses

Inform patient via SMS or email

Inform

Clinical Guideline Defs (GLIF)

Care Plan Editor

Care Plan Monitoring Tool

Personalized Adaptive Care Planner

Doctor

iCARDEA

An Intelligent Platform for Personalized Remote Monitoring of the Cardiac Patients with Electronic Implant Devices

Inform

Patient

PHR

GP System

Hospital IS

Emergency

Data centers
**Mobile (m-)Health: e-Health going mobile**

m-Health refers to the practice of medicine and public health providing access to health and health related information, through the use of mobile devices. (ITU2010: 6B phones, 1B with broadband)

- Remote health monitor
- Video conferencing
- Online consultations
- Personal health devices
- Wireless access to patient records and prescriptions
- Epidemiological monitoring & surveillance

![mHealth on Gartner Hype Cycle](image)

30,000 e-Health apps, 40-250 M projected downloads in 2012
- 67% stopped using it in six months
- 74% stopped auto collection apps
m-Health: colliding interests

42% worry patients will be too independent (53% young doctors)

13% discourage use of m-Health (24% among young doctors)

68% doctors in emerging markets recommend m-Health (59% patients use it vs. 35% in developed world)

http://www.pwc.com/gx/en/healthcare/mhealth/index.jhtml
People and Expectations

Q3: What would be the first steps to support the day to day use of this scenario and to improve the quality of life for both patients and providers by providing more empathy?

- Deal with social / financial/ technological aspects in tandem
A nudging health style: Health prevention can have long term health impact

“..Information technology focus has been on care delivery and that may be responsible for the underperformance of our predictive and preventive capacity at this time..”

Call for a knowledge-based community-centric approach building on preventive health measures and crowdsourcing: a nudging health style

Key issues/questions when formulating a reimbursement model

<table>
<thead>
<tr>
<th>Scope</th>
<th>Payment</th>
<th>Payer</th>
<th>Price &amp; Allocation</th>
<th>Goal alignment</th>
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</thead>
<tbody>
<tr>
<td>What is funded?</td>
<td>What is the basis of payment?</td>
<td>Who pays?</td>
<td>Who is paid?</td>
<td>How does it align to broader health system goals and policies?</td>
</tr>
<tr>
<td>Support</td>
<td>Block contract</td>
<td>Public funding</td>
<td>Payment</td>
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<tr>
<td>Equipment</td>
<td>Fee for service</td>
<td>Patient</td>
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<tr>
<td>Patient</td>
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<tr>
<td>segments</td>
<td>Episode of care</td>
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<td>equity</td>
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<td></td>
<td>Capitation</td>
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<tr>
<td></td>
<td>Outcome</td>
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<td></td>
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</tr>
</tbody>
</table>

Costs and Rewards for Remote Follow-up

© Reimbursement schemes for re-mote monitoring of Cardiac In-plantable Electronic Devices, White Paper, PwC 2012 for Eucomed (Draft version Aug 2013)
Our village of the future is here!

“..Unless personal electronic health records align closely with people’s attitudes, self management practices, identified information needs, and the wider care package (including organizational routines and incentive structures for clinicians), the risk that they will be abandoned or not adopted at all is substantial.”

Greenhalgh T et al. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace, BMJ 2010;341:bmj.c5814


Let’s make eHealth technology transparent and integrated, a beautiful soothing pattern weaved into the fabric of our life!
Fear: could this be our future?

F. Pohl, Man plus (1976)
Empathy by design? Reflections on people-systems interaction in agent-assisted therapy

Claudia Pagliari PhD FRCPE
claudia.pagliari@ed.ac.uk

eHealth Interdisciplinary Research Group
University of Edinburgh, UK
Depression widespread
Too few mental health professionals
Clinical encounters episodic
Online CBT effective, but patients drop out
Innovative methods needed to maintain engagement & inform clinical care
Embodied Communicative Agents

- Simulate human services where humans are too expensive and tasks are straightforward
  - Sales & marketing
  - Product help desks
  - Online education
  - Therapy?

- Driven by protocols & algorithms, rather than people
They may be more or less

Abstract or humanoid
Passive or responsive
Detached or emotional
Questions

• Are they appropriate for supporting patients with mental health problems?

• How do users perceive them and believe they’ll fit into their lives?

• What do they expect of them and is this realistic and safe?

• How should they be configured to maximise engagement whilst minimising risk?
Help4Mood

- Virtual agent for depressed patients
- Supports self-monitoring & therapy tasks between clinic visits
- Helps clinician plan treatment based on recent data
- Not safety monitoring (e.g. suicide)
- Not directive advice on self-care/drugs


http://help4mood.info
Core components

**Virtual Assistant**
- embodied communicative agent
- synthetic speech (NLP to follow)
- facial expression

**Decision Support System**
- data interpretation
- reporting and feedback
- Planning interaction

**Personal Monitoring System**
- activity/sleep (sensors)
- mood (questionnaires)
- behavioural activation (cognitive games)
Considerations for design

• How real is real enough?
• Is ‘like me’ really best?
• Is ‘empathy’ meaningful?
• Dependability & negativity bias
• How to gain trust ... of the right type
• How do users expectations influence function?
Pre-design: resolving expectations

- Commercial developers
- Doctors
- Psychologists
- HCI specialists
- AI researchers

Em, no..

Probably here..

Caring Village of the Future Workshop  MedInfo, Copenhagen Sep 2013
Stakeholder consultations

• 3 locations (UK, Spain, Romania)
• 4 constituencies
  – Patients
  – Psychiatrists
  – Psychologists
  – Community psychiatric nurses

• Similar themes
Configurability & personalisation

- Choice of character important
  - Gender, age, voice

- Preference for
  - Humanoid form
  - Empathic expression
Trustworthiness

• Patients – Should look like the kind of person they’d be happy to confide in
  • Not just attractive or ‘like me’
    • Issue – Balance of group similarity & role expectations
Refined Character Set

User preferences

- No glasses
- Not too elegant, fancy, or trendy
- Not too young
- No doctor's coat

Virtual characters selected by users

Roger    Emily    Paul
Kevin    John
Anne    Sally
Functional role of the agent

• Should be empathic but not leading
  – Avoid reflecting negative emotion

• Should be ‘guiding’ rather than directive
  – Except where suicide risk indicated

Issue – Balancing user-centred support against Patient safety, responsibility & liability
Agent as professional ally (HPs)

• Should look trustworthy and fit expected type

• Agent as member of therapy team
  • Issues – anthropomorphism, trust, expectations
Agent as ‘sensible friend’

• Patients spontaneously formed social expectations of the agent as person and trustworthy friend

– Expectation of wisdom & vigilance
  • Issues: trust, misrepresentation, safety, projection, (transference?)
Fear of replacing humans

- Patients & Professionals –
  - Anxiety about care substitution
  - Human interaction important
  - Need to integrate with clinical care
Balancing preferences

• DS experts were keen to integrate safety alerts
• Patients wanted clinicians to receive regular progress updates

...but

• Professionals keen to cap responsibilities & promote self-coping
  • Issues – managing workload, integrating with lifestyles...
Understanding the social

• Human-Agent relationship is complex

• More than ‘interaction’

• Automated but endowed with human & social characteristics

• Expectations for wisdom, protection, watchfulness
Wider issues

- Rights to truth and honesty
- Controlling the flow of personal data
- Finding an acceptable balance between human and machine support
- Facilitating empowerment and social integration vs. further isolation
- Knowing when humanoid agents are right for the context and users and when they are not
Contact

http://www.help4mood.info

Claudia.pagliari@ed.ac.uk
Considerations for design

• How real is real enough?
• Empathy vs. sympathy (agents can ‘do’ but not feel)
• Benefits and risks of NVB
• Dependability & negativity bias
• Trust
• Unintended consequences
Questions

• Are they appropriate for supporting patients with mental health problems?
  • How do users perceive them and believe they’ll fit into their lives?
  • What do they expect of them and is this realistic and safe?
  • How should they be configured to maximise engagement whilst minimising risk?
Pillar 5

Societal Incentive Framework

Health for Life: Better Health, Better Health Care

- Coverage for All, Paid for by All
- Focus on Wellness
- Best Information
- Most Efficient, Affordable Care
- Highest Quality Care
Societal Incentive Framework

• The Integrated Care (INCA) on the Blue Line
  Jacob Hofdijk, Casemix

Current Research

• "The Epital: an example of redesigned healthcare carried by service transformation and citizen centricity”

• Anders Skovbo Christensen, Copenhagen University

Discussion on Pillar 5 challenges for the future
Changing the paradigm for healthcare Budget

Supply

Integrated Care

National Care Budget

9,5 % of GNP
Still growing

1. GP
2. Specialist
3. Hospitals
4. Dentists
5. Allied Nurses
6. Drugs
7. Lab
8. Home care
9. Mental Care

Citizens require
Better health
Outcome

Burden of Diseases

Demand orientation

Outcome

?
Who is accountable?

The Care Group!

- Insurer
- Market 1
- Market 2
- Nurse
- GP
- Dietary
- Internist

Care Group

Care Standard

Structure
Process
Outcome
Integrated Care Funding!

Reference
Integral Care Program

Generic Modules
Lifestyle - Wellness

Diabetes Specific Modules

COPD Specific Modules

Vasc Risc Management Modules

Social Care Specific modules
INCA for Population contracting based Casemix

Integraal Referentie Zorg Programma Chronische Ziekten

Leefstijl

Welbevinden

Diabetes Specifiek

VRM Specifiek

COPD Specifiek

Maatschappelijke ondersteuning
From Patient to population casemix and health needs

Modulaire benadering van de zorgstandaarden:

Gezondheids-problemen

Leefstijl modules
- Leefstijl modules
  - Alpape
  - Gewogen
  - Alcohol
  - Voeding

Psychologie
- Psychologie
  - Stress
  - Angst

Vascular risicomanagement
- Vascular risicomanagement
  - Aterosclerose
  - Hypertensie

Nefropathie
- Nefropathie
  - Glucose

Diabetes mellitus
- Diabetes mellitus
  - Diabetische voet

Assessment modules

Stepped-care modules

Aggrereren van patiëntprofielen...

...inzicht in aard en volume te leveren zorg
Care standards links to IT req.

Indexed Prevention

Care related Prevention & treatment

Clinical Parameters
DCM

Reporting Datasets

eHealth Requirements

Stepped Care Modules

Implementation Dimensions
So silo’s will break

Integrated Care Management
A good old day

PGGM, an association for health care and social services
To advance this, two ways are essential:
1. Increase everyone’s social network
2. Optimize the network by offering the adequate supporting tools,
Three step approach

1. **Establish a coalition**: After Rabobank and CZ, other organizations joined: Achmea (2011), Vita Valley, Bureau50, Menzis (2012)

2. **Construct a declaration**: three-pager in May 2011: “Building a valuable and worthy future”

3. **Joint approach**: 3yr guarantee; hired staff; establish a cooperative; a business model; pilots; and a roadmap
“We want to make it more easy to help one another: help to help”

Helping each other should be self-evident. That potential help is everywhere around us. Important is to make this transparent and to connect.

To advance this, two ways are essential:
1. **Increase everyone’s social network**, p.e. by matching supply and demand (people that needs support and those who want to give) and introduce community currency
2. **Optimize the network** by offering the adequate supporting tools, like tools to activate your personal network, sharing care, exchange information (agenda and logbook), etc.
There are four indispensable elements:

1. An **online infrastructure** that matching demand and supply (eBay) for informal care. This infrastructure offers also a range of practical supportive tools like an agenda, logbook and access to information (FAQ’s, tutorial info, peer-to-peer info, etc). It will be an open system that other tools can connect to.

2. Introduction of a **community currency** that stimulates support. It can be a local currency, but is exchangeable nationwide.

3. Bring, increase and promote **social interaction** in local communities.

4. **The cooperative as platform** (social venture):
   - A platform for exchange of experiences and practices, and further development
   - We can use the members (like municipalities, health insurers, health institutes) of the cooperative to activate their citizens, insured, patients and family.
   - A cooperative is about reciprocity: sharing knowledge and sharing costs, in stead of maximizing revenues.
The Epital: Redesigned healthcare carried by service transformation and citizen centricity

Anders Skovbo Christensen
University of Copenhagen
The Epital project in the municipality of Lyngby-Taarbæk

- Population 5.4 million
- HC expenditures:
  - 8.5% of GNP
  - 3,000 US $ pr. inhab./year
  - Funded by taxes
- Private GPs:
  - Gatekeepers
  - Fee for Service (public)
- Hospitals:
  - 63 hospitals
  - Almost all public (97 %)
  - Owned & run by 5 regions
- Long term & home care:
  - Run by 98 municipalities
Objectives

• Triple Aim
  – Reduce Cost, Enhance outcome, Improve Experience

• Connect social and medical care

• Personalized support, standard elements

• Unleash the potential of the citizen
  – Smooth transition from own control to intensified observation
Think big, start small

- Building a citizen centric health care concept
- Start with COPD
- Growing from a confined environment
The new DNA of Health Care

Classical paradigm

- patient
- disease
- diagnose

Resignation of responsibility

- treatment
- admitted
- planned control
- fragmented
didactive

Responsibility of treatment

- activity (volume) reimbursement
- sector segmented
- centralized

Citizen / user centric paradigm

- citizen
- pathway
- condition

Empowerment

- service / prevention / procrastination
- outmitted
- available when needed
- coordinated
- consulting/coach

Responsibility of service

- value reimbursement
- sector neutral
- Citizen centric
Organisation and services

Mobile unit
- Home calls
- System installation and support services
- Blood sampling
- On-site diagnostics and treatment

Citizen’s epital

Epi-callcenter
- Coordination of clinical pathways
- Emergency calls
- Outfitting
- Second opinion
- Population monitoring

Health Coach

Hospital
- Diagnostics
- Initiating treatment
- Outpatient visits
- Rehabilitation (COPD level 3)

Municipality
- Nursing
- Rehabilitation (COPD level 2+3)
- Nursing efforts
- Citizen services

Empowerment
- Communities
- Education
- Lifestyle changes

General Practitioner
- Diagnostics
- Initiating treatment
- Outpatient visits

Services initiated by citizen demand
Coordinated by ECC
Inside out
Universal, personalised health plan

The Epi-plan – Pre-defined service elements

Services plug into Epiplan from providers’ catalogue

Hospital
Municipality
GP
Empowerment
4. sector
ECC

Cross sectorial Service providers

Clinical pathway and activities transformed into a unified procedural language

The Chronic Care model
Outside In
Re-design healthcare services, start in the citizen’s home

Services

Citizen with chronic condition

Self caring
Empowerment
IT support
Own treatment
Own Monitoring
Asynchronous

Online support
+ EpiCallCenter
+ Synch. TM

Offline Support
+ Outgoing teams

Managed Intensified observation

Controlled

1. Nursing@home
2. Mobile specialist team

Intensified specialist observation and interaction

Moving to “acute” beds in the community

Connection to ECC
Instant gratification
Surveyed monitoring
Optional services
Coaching
Coordination

Evidence

Bourbeau et al. (Arch Intern Med 2003;163)
TeleKat Denmark

Fernandez et al. Basque Country HMS
WSD
Stockholm - Callcenter

Acute team Frederiksberg
Acute team Kolding
Acute team Amager
Acute team Vejle

The Virtual Hospital - FH
Tryghedshotellet Randers Patienthoteller

70% reduction

Admitted citizen
1. What is our present maturity for this pillar and how can we improve it?

2. What are the critical enablers or barriers to realising the scenario for this pillar?

3. What would be the first steps to support the day to day use of this scenario?
First steps & present maturity

1. 15 citizens have active devices and use it only for self-monitoring – and they are satisfied!
2. Call-center (single point of contact) embedded in and growing from existing framework of a municipality control center in the elderly sector. 40 HC personnel certified
3. Organizing medical services and make preparations for organizational cultural change.
4. Steering group engagement of project, municipality, local GPs and Universities
5. Support by local pharmacies and patient unions
Enablers for the municipality

1. History: Structural reform of local government in 2007 gave direct financial responsibility of health cost in the hospitals => search for new ways to reduce the increasing cost to health services.

2. Windows of opportunity: Financial crisis and reduced local community budget calls for new ideas and new solutions => The idea of a project involving cross-sectorial cooperation and citizen empowerment (in combination) using new technology had a strong political impact.
The critical issues

1. Creating sufficient knowledge and technical competence in the front-personnel
2. Establishing robust standard procedures that fit the tasks and objectives of the existing organization and “gives comfort” to the colleagues
3. One point of contact - redirect and offer services to the citizens through the call-center.
1. Extending the epital-concept to other citizen groups (other chronic conditions, mentally ill citizens, socially vulnerable families)

2. Providing better and a higher quality health services to the citizens through a coherent and coordinated effort

3. Discuss partnerships with neighboring municipalities.
More Heroes wanted!
To achieve a sustainable system for my grandson Mick and yours

Do Care
Join the Village
Next Stop
MIE2014