Citizens and Systems - are they Compatible?

Professor Michael Rigby

Emeritus Professor of Health Information Strategy, Keele University, UK

Professor, Nordic School of Public Health

Consultant to the European Science Foundation and OECD
Care Delivery has to Change

- Demographic pressures
- Consumer expectations
- New treatment and monitoring lines
- Economic (double) pressures
- New Informatics Opportunities
Projected Population % over 65 (Europe)
Projected Population % over 80 (Europe)

The graph shows the projected population percentage over 80 for various European countries for the years 2010, 2020, 2030, and 2040.
Working Adult : over 65 Ratio (Europe)
Københavns lufthavn, Kastrup, Terminal 2 - Nyborg st

<table>
<thead>
<tr>
<th>Søndag d. 1. december</th>
<th>Prisene gælder for alle rejserende</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tidligere afgang</strong></td>
<td><strong>Sammenlign billetter</strong></td>
</tr>
<tr>
<td>Kl. 21:02</td>
<td>01:44</td>
</tr>
<tr>
<td>Ank. 22:46</td>
<td></td>
</tr>
<tr>
<td>Kl. 21:39</td>
<td>01:50</td>
</tr>
<tr>
<td>Ank. 23:17</td>
<td></td>
</tr>
<tr>
<td>Kl. 22:02</td>
<td>01:50</td>
</tr>
<tr>
<td>Ank. 23:52</td>
<td></td>
</tr>
</tbody>
</table>

Vær opmærksom på, at ikke alle vores billetter sælges her på dsb.dk. Se oversigt.

<table>
<thead>
<tr>
<th>Din søgning: 1. december 2013</th>
<th>Afgang: 21:15</th>
<th>1 volken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ret søgning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
E-sundhedsobservatoriets Årskonference 2013:

Prof Michael Rigby: Citizens and Systems – are they compatible?

→ Læs mere om vores andre check-in-muligheder
Esundhedsobservatoriets Årskonference 2013:

Prof Michael Rigby: Citizens and Systems – are they compatible?
Espundhedsobservatoriets Årskonference 2013:

Prof Michael Rigby: Citizens and Systems – are they compatible?

Læs om diabetes type 1 og 2 (sukkersyge) - Diabetesforeningen ...

www.diabetes.dk

Har du diabetes? Så er der hjælp at hente i Diabetesforeningen, som hvert år hjælper 80.000 medlemmer. Du får en gratis kogebog når du møder dig ind.

Diabetesforeningen - Diabetes 2 - Velværekokkenet - Mad og fysisk aktivitet

Generelt om sukkersyge (Diabetes) - NetDoktor.dk

www.netdoktor.dk/sygeomdøde/faktor/diabetes.htm

02/11/2009 - Diabetes (sukkersyge) er en sygdom, hvor blodets indhold af sukker (glukose) er øget ud over det normale. Der findes tre væsentlige former for ...

Type 2 diabetes - Type 1 diabetes - Risiko for diabetes

Sundhedsguiden.dk - Diabetes er en folkesydom | type, 1, 2 ...

www.sundhedsguiden.dk > Temaer > Alle temae

Diabetes inddeles i type 1 og type 2, der begge har stort set de samme symptomer. Sygdommen bevirker, at sukkeret i blodet hverken optages i kroppens celler ...

Steno Diabetes Center - Steno

www.steno.dk

20/06/2013 - Nyheder fra Steno Diabetes Center - Danmarks ældste diabeteshospital.

Sukkersyge - Wikipedia, den frie encyklopædi
da.wikipedia.org/wiki/Sukkersyge

Sukkersyge, med den medicinske betegnelse diabetes mellitus, er en gruppe sygdomme, hvor blodets indhold af sukker (glukose) er øget ud over det normale.
Mary, a Typical Older Citizen

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

E-sundhedsobservatoriets Årskonference 2013: - Prof Michael Rigby: Citizens and Systems – are they compatible?
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 opportunity

Without all of these, her health will suffer

But not tasks of health services
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
Proliferation causes Problems

Diagram after P. Hill

E-sundhedsobservatoriets Årskonference 2013: - Prof Michael Rigby: Citizens and Systems – are they compatible?
Needy Citizen’s World

- Community Groups
- Informal / Neighbour Carers
- Family

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
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

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
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

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
Often other Services Too

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

HOUSING

EDUCATION
- Specialist
- Social Work
- Day Care
- Meals
- Cleaning, etc.

SOCIAL CARE

CITIZEN
- Community Groups
- Informal / Neighbour Carers
- Family

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
Citizens and Systems

• The Citizen wants:
  – One picture of her/his health
  – Coordinated action
  – Her/his choice of access and of care
  – Easy interface to all services

• Personalised reliable quality delivery

• A complex system with a soft interface
Providers and Systems

• Providers want:
  – Business-like systems
  – Efficient use of resources
  – Matching of supply and demand
  – Optimal uniformity at component level
    • Training, Audit, Quality Assurance, Costing/reimbursement

• Systems interface uniformly with persons

• A complex system which enables personal care
Providers and Users of Individuals’ Health Data within Systems

- Education Provider
- Daily Living Monitoring
- Housing
- NGOs and other Voluntary Bodies
- Employment
  - Occupational
  - Sheltered Employment
- Social Care
  - General and Specialist
  - Mixed multiple-provider market
  - Mixed funding
- Home Health Monitoring
  - Condition-specific
- Primary Health
  + Secondary Health
  - Multiple Condition

PERSON

E-sundhedsobservatoriets Årskonference 2013: - Prof Michael Rigby: Citizens and Systems – are they compatible?
# 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>
The System-led Design Risk

• We design for People Like Us
• not for ill, bewildered, older and ill citizens
• We assume everyone knows the system
• User expected to learn to navigate -
• WHY? – they are ill and we are paid to look after them.
Prof Michael Rigby: Citizens and Systems – are they compatible?
E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
Four Dimensions of Care

1. The Client/Patient’s Needs
2. Informal Carers’ Needs
3. Formal Care Providers
4. Society
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’)

E-sundhedsobservatoriets Årskonference 2013: - Prof Michael Rigby: Citizens and Systems – are they compatible?
Developing a New Understanding of Enabling Health and Wellbeing in Europe

Harmonising Health and Social Care Delivery and Informatics Support to Ensure Holistic Care

Science Position Paper
From Organisation-based View
From Organisation-based View

Provider 1

- Patient A
- Patient B
- Patient C
- Patient D
- Patient E
- Patient F
- Patient G
- Patient H
- Patient T

Provider 2

- Patient U
- Patient V
- Patient W
- Patient X
- Patient Y

- Provider 2

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
To Holistic Client-Centric View

Electronically brokered and re-presented
Challenges to Health and Social Care Informatic Coordination

1. Usually different legal and funding entities
2. Health records deep and narrow; Care records wider (third parties), less depth
3. Different attitudes to sharing record
4. Need new paradigms of delivery coordination
Coordination Challenges

• Who coordinates care objectives for the individual citizen?
• Who coordinates the related records?
• Who coordinates Informatics policies and systems?
• Who runs cross-agency packages of care?
• Linkage with Monitoring, Pervasive and Ubiquitous Systems
Governance and Societal Issues

• Trusted advocacy for citizens not able to manage their affairs or electronic systems.
• Ensuring those not digitally enabled or empowered are not disadvantaged.
• Third party issues and rights
• Governance models and rules.
• Education, awareness, and training programmes.
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
OECD Policy Development

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
OECD Smarter Health

Smartness Needed for Quality and Efficiency

• Smart is:
  – Bringing service nearer to home
  – Citizen co-leadership
  – Harnessing societal support
  – ICT as a key enabler
    • Monitoring
    • communication
New Paradigm of Personalised Service

Families
Private Care Providers
Friends and Neighbours
Voluntary Agencies
Health and Care practitioners

ICT Enablement

E-Enabled
Integrated Personal Care

E-sundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
with Social Science Being Key

Trust and Consent
Rules of Governance
‘As Needed’ Data and Process Knowledge

Private Care Providers
Families
Friends and Neighbours
Health and Care practitioners
Voluntary Agencies

E-Enabled
Integrated Personal Care

Prof Michael Rigby: Citizens and Systems – are they compatible?
Compassionate Systems link Citizens

Families

Health and Care practitioners

Trust and Consent

Rules of Governance

‘As Needed’ Data and Process Knowledge

Private Care Providers

Friends and Neighbours

Voluntary Agencies

E-Enabled

Integrated Personal Care
Esundhedsobservatoriets Årskonference 2013: Prof Michael Rigby: Citizens and Systems – are they compatible?
Conclusion

• Citizens and Systems are Inter-dependent

• Person-centeredness in design is key

• Social Sciences are vital