Health First Europe Roundtable on

Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems

5 December 2017 from 13.00 to 14.30
European Parliament (room ATRIUM 03K002) – Brussels
Welcome & introduction by
MEP José Inácio Faria

HFE Roundtable on
Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems
Launch of the Health First Europe Declaration for Patient Safety

Sign the Declaration at
www.Declaration4PatientSafety.eu
HFE Roundtable on
Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems

Opening address by
Mr Ain Aaviksoo
Deputy Secretary General on e-Services Development and Innovation, Estonian Ministry of Social Affairs
Takeaway messages on eHealth from EU Presidency by Estonia

„Engaging patients in the digital revolution: A call to build smarter and safer healthcare systems“ | European Parliament, Brussels
05.12.2017

Ain Aaviksoo, MD MPH
Deputy Secretary General for E-services and Innovation (CIIO)
Future health and care is strongly influenced by digital approach

- Customisation / personalisation
- Data-driven discovery
- Prediction

- Improved quality
- New solutions
- Improved coordination

Active patient participation

Location-free care provision

INCREASED EFFECTIVENESS

INCREASED EFFICIENCY
Data-driven approach in healthcare is valuable source of better future for citizens by hitting the triple aim

1. Increased access and safety in healthcare can be achieved through empowered citizens and adequate data availability at the point of care

2. Sustainability of health systems will be supported by value-based approach.

3. Opportunities, jobs and investment will be created using data-driven health care innovation.

EU2017.EE
Most of Europeans want to and can use digital health services if offered

76% Europeans have access to fast internet

79% are using internet (of which 70% are using it every day or almost every day)

52% European citizens want access to their health data

70% ARE willing to share their data with others (incl 63% with their doctor)

23% ARE NOT willing to share their health data
eHealth focus areas for Estonian EU Presidency – free movement of health data

1. The right of citizens to control the processing of their health data comfortably and electronically should be realized in practice

2. Wider use of health data for research and innovation
EU General Data Protection Regulation facilitates **better use** of personal data.

Reform of EU data protection rules

The new Regulation will also guarantee **free and easy access to your personal data**, making it easier for you to see what personal information is held about you by companies and public authorities, and make it easier for you to **transfer your personal data** between service providers – the so-called principle of ‘data portability’.

Privacy means that **personal data** should not be secured from being used, but to be used **securely**.
Brussels, 28 November 2017  
(OR. en) 

14078/17 

SAN 399  
TELECOM 272  
DATAPROTECT 177 

**NOTE**

<table>
<thead>
<tr>
<th>From:</th>
<th>General Secretariat of the Council</th>
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</thead>
<tbody>
<tr>
<td>To:</td>
<td>Council</td>
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<tr>
<td>No. prev. doc.:</td>
<td>14076/17 SAN 398 TELECOM 271 DATAPROTECT 176</td>
</tr>
</tbody>
</table>
| Subject: | **Employment, Social Policy, Health and Consumer Affairs Council meeting on 8 December 2017**  
Draft Council conclusions on Health in the Digital Society - making progress in data-driven innovation in the field of health
  
  – Adoption |
Snippets from the council conclusions

„Remove obstacles to data exchange and sharing between health professionals for the safety and continuity of care“
„Improve the digital skills of citizens and health professionals“
„Make better use of Union funding mechanisms /…/ to support large-scale digital health implementation“
„Continue to support Europe-wide public-private partnerships and stakeholder engagement activities /…/ aimed at empowering citizens and facilitating the implementation of the digital single market for digital health and care“

EU2017.EE
100 Million Connected & Healthy Europeans by 2025

A vision of Health & Growth Strategy for Europe
100M Connected and Healthy Europeans by 2025 - CONNECTIONS

- **10 million travelling Europeans** getting best possible medical care abroad either by filling their prescription or having core health data available seamlessly at the point of care under their control

- **35 million Europeans with rare and complex diseases** getting the best treatment by centres of excellence (European Reference Network)

- Advances in research and innovation, such as (but not limited to):
  - **1 million sequenced European genomes** united for personalised medical research
  - **10 million European cohort** of all health data combined for new big data discoveries
  - **100 million Europeans contributing to a data-driven research** with their data in various European research projects

- Common European **market for digital health companies, addressing 500 million** and serving directly at least 100 million in Europe, but being competitive globally
100M Connected and Healthy Europeans by 2025 - STARTING POINT

Building support to existing initiatives, projects and infrastructure:

• European public and private research infrastructures & initiatives (eg EOSC, HPC, IC PerMed), EHDN (by IMI)

• European cross-border health care initiatives & relevant services
  • European Reference Networks for Rare and Complex Diseases (ERN)
  • eHealth Digital Service Infrastructure (eHDSI)

• Established European-scale projects
  • Big Data for Better Outcomes (BD4BO)
  • The European Institute for Innovation Through Health Data (I~HD)
  • BBMRI-ERIC, BBMRI-LPC

• National genomic & health data infrastructures

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100M Connected and Healthy Europeans by 2025 - CHALLENGES FOR GOVERNMENTS

In order to integrate health-and-related data from 100 million European citizens by 2025, we must...

… align national & European **health, research and industry strategies** at the highest **political** level;

Actualising European „**health data infrastructure service“** warrants willing governments to coordinate jointly:

- Data standards (semantics and integration/sharing) **implementation**
- Data privacy, security & governance **practices**
- Data management (one-stop-shop) **service**
Now what?

• Draft concept for implementation
  • from Million European Genome Alliance (MEGA)
  • … to 100 million
• Political support (national + European)
• **Draft plan (cost items + governance) … by May 2018**
• Broad consultations start - 2018 II half

…

• **Adoption - 2019 II half**
The Digital Health Society

A multi-stakeholders initiative
launched in July 2017
under the Estonian EU Presidency

The Task Forces

The Declaration

https://www.echalliance.com/digitalhealthsociety
The Digital Health Society

existing Task Forces

Convergence roadmap on interoperability standards and Digital Tele healthcare protocol
Led by Erik GERRITSEN, Secretary General of the Ministry of Health of Netherlands

Citizen-controlled data governance & Data Donors
Led by Angela Brand, Professor at Maastricht University

Legal framework facilitating the free flow and the 2nd use of health data
Led by Bleddyn REES, Digital health expert and lawyer at Osbourne Clarke

Digital transformation & change management in health and social care organisations
Led by Richard CORBRIDGE, CIO Health Service Executive and former CEO of eHealth Ireland

https://www.echalliance.com/digitalhealthsociety

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estonishing – dare to fulfill your desires safely!

further inquiries: ain.aaviksoo@sm.ee | @aaviksoo

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HFE Roundtable on
Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems

Presentations and roundtable discussion
What is the current situation of patient safety in Europe and how eHealth solutions can provide a safer and smarter system
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What is the current situation of patient safety in Europe and how eHealth solutions can provide a safer and smarter system

MEP Yana Toom
HFE Roundtable on
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What is the current situation of patient safety in Europe and how eHealth solutions can provide a safer and smarter system

MEP Indrek Tarand
HFE Roundtable on
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What is the current situation of patient safety in Europe and how eHealth solutions can provide a safer and smarter system

Niek Klazinga
Head of the Health Care Quality Indicators (HCQI) Project, OECD Health Division
OECD ACTIVITIES ON PATIENT SAFETY: STATE OF THE ART AND FUTURE PERSPECTIVES

Niek Klazinga

*Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems*

Brussels, December 5th 2017
OECD Activities on Patient Safety

- Patient Safety Indicators (PSI’s) based on administrative data-bases (since 10 years) and published in Health at a Glance
- Report on the implementation and use of PSI’s in OECD countries (2017)
- Patient Safety Indicators based on Patient Reporting (PRIMS) (since 2016)
- Safety indicators in PHC and LTC based on prescription data and point prevalence measurements (since 2016).
- The Economics of Patient Safety (OECD report for the ministerial conference on safety, Bonn, March 2017)
Patient harm is the 14th leading cause of the global disease burden. This can be compared to tuberculosis and malaria. The majority of this burden falls on the developing countries.

Figure 1. Low income countries carry the heaviest burden of mortality and morbidity caused by adverse events (2015)

- High income: 25%
- Upper middle income: 19%
- Lower middle income: 38%
- Low income: 18%

Note: Percentage of average DALYs/country. Classification of countries based on the World Bank categories.
Source: IHME 2015
Most research on the cost of patient harm has focused on the acute care setting in the developed world where the disease burden can be compared to chronic conditions such as multiple sclerosis and some types of cancer.

### Table 3. Disease burden of 6 adverse event types compared to chronic conditions in England

<table>
<thead>
<tr>
<th>Disease</th>
<th>Annual burden per 100,000 pop/n</th>
<th>Total annual burden across England</th>
</tr>
</thead>
<tbody>
<tr>
<td>All adverse events*</td>
<td>86 DALYs</td>
<td>46,491 DALYs</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>80 DALYs</td>
<td>42,400 DALYs</td>
</tr>
<tr>
<td>6 adverse event types</td>
<td>68 DALYs</td>
<td>36,000 DALYs</td>
</tr>
<tr>
<td>HIV/AIDS and Tuberculosis</td>
<td>63 DALYs</td>
<td>33,400 DALYs</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>58 DALYs</td>
<td>30,740 DALYs</td>
</tr>
<tr>
<td>Interpersonal violence</td>
<td>57 DALYs</td>
<td>30,200 DALYs</td>
</tr>
</tbody>
</table>

Source: Hauck et al (2017); *IHME (2015)

### Table 5. Annual impact of 6 adverse events in a typical English Hospital

<table>
<thead>
<tr>
<th></th>
<th>Bed days lost</th>
<th>Cost of bed days lost</th>
<th>Admissions foregone</th>
<th>Salaried GPs</th>
<th>Hospital nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across England</td>
<td>495,020</td>
<td>GBP151 million</td>
<td>69,721</td>
<td>2,218</td>
<td>3,574</td>
</tr>
<tr>
<td>Avg English Hospital</td>
<td>2,024</td>
<td>GBP 617,000</td>
<td>285</td>
<td>9</td>
<td>15</td>
</tr>
</tbody>
</table>

Source: Hauck et al (2017); OECD.stat

- sepsis
- pressure ulcers
- inpatient hip fractures due to falls
- VTE
- central line infections
- deaths in low-mortality conditions
The financial impact of safety failure is considerable. Approximately 15% of total hospital activity and expenditure is a direct result of adverse events. The most burdensome adverse event types include venous thromboembolism, pressure ulcers, and infections.

### Table 6. Economic burden due to adverse events in acute care or hospital care (as share of public hospital spending)

<table>
<thead>
<tr>
<th>Adverse events in hospitals</th>
<th>Share of public hospital spending</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brown, P. (2002) New Zealand</td>
<td>32%</td>
</tr>
<tr>
<td>The results suggest that treating adverse events costs hospitals over $870 million.</td>
<td></td>
</tr>
<tr>
<td>Rafter et al., (2016) Ireland</td>
<td>4%</td>
</tr>
<tr>
<td>Adverse events relate to adult inpatient amounted to 194 million€ in 2009</td>
<td></td>
</tr>
<tr>
<td>Etchells et al (2012) Canada</td>
<td>4.2%</td>
</tr>
<tr>
<td>Financial burden of adverse events in Canada in 2009–2010 was $CAN 1,071,983,610</td>
<td></td>
</tr>
<tr>
<td>Jackson (2009) Canada</td>
<td>14%</td>
</tr>
<tr>
<td>Administrative data.</td>
<td></td>
</tr>
<tr>
<td>Health Policy Analysis, Australia (2013) Australia</td>
<td>12% – 16.5%</td>
</tr>
<tr>
<td>Hospital-associated conditions modelled to range between AUD 634 million and AUD 896 million</td>
<td></td>
</tr>
<tr>
<td>Ehsani et al (2006) Australia (Victoria)</td>
<td>15.7%</td>
</tr>
<tr>
<td>Impact of adverse events modelled from hospital administrative data was AUD 6,800 per episode or AUD 460 Million in aggregate.</td>
<td></td>
</tr>
<tr>
<td>Zsifkovits et al (2016) Europe</td>
<td>0.2%-6% *</td>
</tr>
<tr>
<td>Direct costs for the public care sector ranged from 2.8 billion euros to 84.6 billion euros</td>
<td></td>
</tr>
<tr>
<td>Hoonhout L. et al (2009) Netherlands</td>
<td>1.8%</td>
</tr>
<tr>
<td>Costs estimated at a total of €355 million for all adverse events in hospitals</td>
<td></td>
</tr>
</tbody>
</table>

### Adverse events in long term care

| Levinson, D. (2014) United States | 2% |
| Long-term care spending is associated with treatment of adverse events. |
Patient safety interventions included in the snapshot survey (scoring of perceived impact and costs by 8 experts and policy makers in 15 countries)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Safety Standards linked to accreditation and certification</td>
<td>2.1 Clinical governance systems and frameworks related to safety</td>
<td>3.1 Medication management / reconciliation</td>
</tr>
<tr>
<td>1.2 Public reporting of patient safety indicators</td>
<td>2.2 Clinical Incident reporting and management system</td>
<td>3.2 Transcribing error minimisation protocols</td>
</tr>
<tr>
<td>1.3 Mandatory reporting of specified adverse events</td>
<td>2.3 Integrated patient complaints reporting system</td>
<td>3.3 Smart infusion pumps and drug administration systems</td>
</tr>
<tr>
<td>1.4 Pay-for performance schemes for patient safety</td>
<td>2.4 Monitoring and feedback of patient safety indicators</td>
<td>3.4 Aseptic technique protocols and barrier precautions</td>
</tr>
<tr>
<td>1.5 Professional education and training</td>
<td>2.5 Person- and patient-engagement initiatives</td>
<td>3.5 Urinary catheter use and insertion protocols</td>
</tr>
<tr>
<td>1.6 Electronic Health Record (EHR) systems</td>
<td>2.6 Clinical communication protocols and training</td>
<td>3.6 Central line catheter insertion protocols</td>
</tr>
<tr>
<td>1.7 No-fault medical negligence legislation</td>
<td>2.7 Digital technology solutions for safety</td>
<td>3.7 Ventilator-associated pneumonia minimisation protocols</td>
</tr>
<tr>
<td>1.8 System-level public engagement and health literacy initiatives</td>
<td>2.8 Human resources interventions</td>
<td>3.8 Procedural / surgical checklists</td>
</tr>
<tr>
<td>1.9 National interventions based on specific safety themes</td>
<td>2.9 Building a positive safety culture</td>
<td>3.9 Operating room integration and display checklists</td>
</tr>
<tr>
<td>1.10 A national agency responsible for patient safety</td>
<td>2.10 Infection detection, reporting and surveillance systems</td>
<td>3.10 Peri-operative medication protocols</td>
</tr>
<tr>
<td></td>
<td>2.11 Hand hygiene initiatives</td>
<td>3.11 VTE prevention protocols</td>
</tr>
<tr>
<td></td>
<td>2.12 Antimicrobial stewardship</td>
<td>3.12 Clinical care standards</td>
</tr>
<tr>
<td></td>
<td>2.13 Blood and blood management protocols</td>
<td>3.13 Pressure injury (ulcer) prevention protocols</td>
</tr>
<tr>
<td></td>
<td>2.14 Medical equipment sterilisation protocols</td>
<td>3.14 Falls prevention protocols</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.15 Acute delirium &amp; cognitive impairment management programs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.16 Response to clinical deterioration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.17 Patient hydration and nutrition standards</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.18 Patient identification and procedure matching protocols</td>
</tr>
</tbody>
</table>

Source: OECD patients safety snapshot survey 2017
Most frequently selected for OECD countries

- 1.5 Professional education and training (14 times)
- 2.1 Clinical governance systems and frameworks (13 times)
- 1.1 Safety standards linked to accreditation and certification (11 times)
- 2.5 Person- and patient-engagement strategies (9 times)
- 1.6 EHR systems (9 times)
- 1.9 National interventions based on specific safety themes (9 times)
- 1.7 No-fault medical negligence legislation (8 times)
- 1.10 A national agency responsible for patient safety (8 times).
Foreign body left in during procedure, 2015 (or nearest year)

Note: Given very low incidence of events, 95% confidence intervals have been calculated for all countries as represented by grey areas.
Postoperative pulmonary embolism (PE) or deep vein thrombosis (DVT) in hip and knee surgeries, 2015 (or nearest year)

Postoperative sepsis in abdominal surgeries, 2015 (or nearest year)

**Source:** OECD Health Statistics 2017.

This document, as well as any data and any map included herein, are without prejudice to the status of or sovereignty over any territory, to the delimitation of international frontiers and boundaries and to the name of any territory, city or area.

Information on data for Israel: http://oe.cd/israel-disclaimer
Obstetric trauma, vaginal delivery with instrument, 2010 and 2015 (or nearest year)

1. Based on registry data.

Obstetric trauma, vaginal delivery without instrument, 2010 and 2015 (or nearest year)

Crude rates per 100 vaginal deliveries without instrument assistance

1. Based on registry data.

1. Based on registry data

Information on data for Israel: http://oe.cd/israel-disclaimer

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Prescription of sedatives (benzodiazepines) among elderly people also varies widely

Elderly people prescribed long-term benzodiazepines or related drugs, 2015 (or latest year)

<table>
<thead>
<tr>
<th>Country</th>
<th>Per 1 000 persons aged 65 years and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ireland</td>
<td>67</td>
</tr>
<tr>
<td>Portugal</td>
<td>54</td>
</tr>
<tr>
<td>Israel</td>
<td>52</td>
</tr>
<tr>
<td>Norway</td>
<td>44</td>
</tr>
<tr>
<td>Sweden</td>
<td>34</td>
</tr>
<tr>
<td>Finland</td>
<td>27</td>
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<tr>
<td>OECD15</td>
<td>26</td>
</tr>
<tr>
<td>Slovenia</td>
<td>18</td>
</tr>
<tr>
<td>Slovak Rep.</td>
<td>18</td>
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<tr>
<td>Netherlands</td>
<td>18</td>
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<tr>
<td>Denmark</td>
<td>17</td>
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<tr>
<td>Canada</td>
<td>11</td>
</tr>
<tr>
<td>New Zealand</td>
<td>10</td>
</tr>
<tr>
<td>Korea</td>
<td>5</td>
</tr>
<tr>
<td>Estonia</td>
<td>3</td>
</tr>
<tr>
<td>Australia</td>
<td>0</td>
</tr>
</tbody>
</table>

Elderly people prescribed long-acting benzodiazepines or related drugs, 2015 (or latest year)

<table>
<thead>
<tr>
<th>Country</th>
<th>Per 1 000 persons aged 65 years and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Korea</td>
<td>192</td>
</tr>
<tr>
<td>Estonia</td>
<td>150</td>
</tr>
<tr>
<td>Slovenia</td>
<td>113</td>
</tr>
<tr>
<td>Spain</td>
<td>102</td>
</tr>
<tr>
<td>Slovak Rep.</td>
<td>95</td>
</tr>
<tr>
<td>Ireland</td>
<td>82</td>
</tr>
<tr>
<td>Portugal</td>
<td>85</td>
</tr>
<tr>
<td>OECD16</td>
<td>67</td>
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<td>Norway</td>
<td>57</td>
</tr>
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<td>Australia</td>
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<td>Sweden</td>
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<td>Canada</td>
<td>13</td>
</tr>
<tr>
<td>Finland</td>
<td>9</td>
</tr>
</tbody>
</table>

Source: OECD Health Statistics 2017

How much of these prescriptions are inappropriate?
➢ Need to be able to link prescription data to diagnosis
## Nine priority questions/areas for further R&D

<table>
<thead>
<tr>
<th>Domains</th>
<th>Sub-domains</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incident Prevention</td>
<td>Information sharing/management</td>
<td>1. Did the health professional you consulted know important information about your medical history? Yes; No; Not Sure; Not applicable; Decline to answer</td>
</tr>
<tr>
<td>Incident prevention</td>
<td></td>
<td>6. Did a member of staff confirm your identity prior to administering your medication? Yes; No; Not Sure; Not applicable; Decline to answer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Did a member of staff confirm your identity prior to your procedure/operation/surgery? Yes; No; Not Sure; Not applicable; Decline to answer</td>
</tr>
</tbody>
</table>
## Nine priority questions/areas for further R&D

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<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incident Prevention</td>
<td>Medication safety</td>
<td>12. Did a member of staff explain the purpose of the medications you were to take at home in a way you could understand? Yes; No; Not Sure; Not applicable - I did not need an explanation; Decline to answer.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13. Did a member of staff explain to you how and when to take the medications? Yes; No; Not Sure; Not applicable - I did not need an explanation; Decline to answer</td>
</tr>
<tr>
<td>Patient-reported Incidents</td>
<td>Diagnosis and treatment-related incidents</td>
<td>19. Did you experience a medication-related error (e.g. wrong prescription, wrong dose, wrong time, dispensing error in pharmacy, wrong administration route, reported allergic reaction, omitted by mistake)? Yes; No; Not Sure; Not applicable; Decline to answer</td>
</tr>
</tbody>
</table>
Nine priority questions/areas for further R&D

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<thead>
<tr>
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<th>Sub-domains</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incident Management</td>
<td>Incident reporting</td>
<td>27. Did you see, or were you given, any information explaining how to provide feedback or complain to the clinic/hospital about the care you received? Yes; No; Not Sure; Decline to answer</td>
</tr>
<tr>
<td></td>
<td>Incident handling</td>
<td>28. If you experienced mistakes or unnecessary problems in connection with your clinic visit/hospital stay, did the staff handle the mistake or problem in a satisfactory way? Yes; No; Not Sure; Not applicable; Decline to answer</td>
</tr>
</tbody>
</table>
Future directions

- Strengthening person centered care (PRIMS, PROMS, PREMS)
- Optimize administrative data-systems
- Optimize data-linkage and use of electronic health records for patient safety
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What is the current situation of patient safety in Europe and how eHealth solutions can provide a safer and smarter system

Katja Neubauer
Team Leader - Digital Single Market & eHealth, European Commission
Health and Care in the Digital Single Market

Katja Neubauer
Team leader DSM and eHealth
European Commission – DG Health
The European Commission has placed digital at the core of its strategy, by setting the Digital Single Market as one of its 10 priorities.

The aim is to open up digital opportunities for people and business and to make the EU's single market fit for the digital age.
Mid-term review (May 2017)

- The Commission has delivered **35 legislative proposals** and **policy initiatives**
- **Data economy, cybersecurity** and **online platforms** are the three key areas where further action is needed
- **Specific action on health and care** announced, including a **Communication** for the end of 2017
3 Priority areas on Health and Care in the DSM

- Give citizens better access to their health data, everywhere in the EU
- Use digital services for citizen empowerment and person-centred care
- Connect and share health data for research, faster diagnosis and better health outcomes
Public Consultation on Health and Care in the Digital Single Market

Open between: 20 July – 12 October 2017

1464 respondents – 30% organisations + 70% individuals

Replies from 35 countries – also from beyond Europe

Health and care organisations are the largest group of respondent organisations

Consciously structured based on the 3 pillars
Public Consultation – Summary of results

Citizens should be able to manage their own data:

>90% strongly agree or agree

Sharing health data can be beneficial:

>80% strongly agree or agree

Not having access to digital health services:

Nearly 60%

Citizen feedback to healthcare providers is essential to improve services:

>80% agree
Public Consultation
Main concerns and expectations:

- Privacy
- Cybersecurity
- Data quality
- Standardised electronic health records
Public Consultation – Commission tasks to stimulate use of data and digital

Most frequently used terms:
Pillar I: Give citizens better access to their health data

The eHealth Digital Service Infrastructure (eHDSI)

1. Enabling the exchange of patient data across borders
   - **Patient Summary**: provides access to health professionals to verified key health data of a patient during an unplanned care encounter while abroad
   - **ePrescription**: enables patients to receive equivalent medication while abroad to what they would receive in their home country

2. To be expanded to full Electronic Health Records
Pillar II: Connect and share health data for research, faster diagnosis and better health outcome

- **Connect** different health data sets, scientific expertise and computing capacity federated across borders – through a decentralised European digital health infrastructure

- Advancement of **high-performance computing, big data analytics** and **cloud computing** for health research and personalized medicine
Pillar II: Connect and share health data for research, faster diagnosis and better health outcome

• **Use cases:**
  
  • For **rare diseases** (European Reference Networks)
  
  • For **anticipating** epidemics and accelerating EU-wide identification of infectious threats
  
  • To develop **shorter lead times** for therapy developments
Pillar III: Use of digital services for citizen empowerment and patient-centred care

- Working with Member States and regions to deploy solutions:
  - that support **user feedback** and **interaction** between patients and healthcare providers,
  - that **engage citizens** in the prevention and management of chronic diseases

- **Mobilize relevant EU funding** (from EFSI, ESIF, Health Programme and H2020) and **implement patient-centred integrated care**
Thank you!

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DG Health and Food Safety

DG Connect
HFE Roundtable on
Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems

Presentations and roundtable discussion

eHealth into practice: digital revolution in city lab

Prof. Benoît Macq
Professeur ordinaire
at the Université Catholique de Louvain
City-Labs : mHealth to bridge the gap between patients and labs

Benoit Macq
Guillaume Gustin and Damien Gruson
Point-of-cares and self-tests are changing the landscape

Monitoring and empowerment of chronic diseases
Heart Failure - Diabetes

Proximity Labs
Point-of-care testing

mHealth App
Self-monitoring tools
Deliberative Medicine

« Help the patient to determine his (her) best health related values and help him (she) to implement a care trajectory according to them »
Blood Glucose Monitoring

22 Factors That Affect Blood Glucose

**FOOD**
- ↑ 1. Carbohydrates
- ↑ 2. Fat
- ↑ 3. Protein
- ↑ 4. Caffeine
- ↓ 5. Alcohol

**MEDICATION**
- ↓ 6. Medication dose
- ↑ 7. Medication timing
- ↓ 8. Medication interactions

**ACTIVITY**
- ↓ 9. Light exercise
- ↑ 10. High-intensity and moderate exercise

**BIOLOGICAL**
- ↑ 11. Dawn phenomenon
- ↑ 12. Infusion set issues
- ↑ 13. Scar tissue and lipodystrophy
- ↑ 14. Insufficient sleep
- ↑ 15. Stress and illness
- ↑ 16. Allergies
- ↑ 17. A higher glucose level
- ↑ 18. Periods (menstruation)
- ↑ 19. Smoking

**ENVIRONMENTAL**
- ↑ 20. Insulin that has gone bad
- ↑ 21. An accurate blood glucose reading
- ? 22. Altitude

**Effect on Blood Glucose Levels**
- ↑ Increase
- Neutral
- ↓ Decrease
User Centered-Design
Agile&UX (Suzanne Kieffer)
Eglé*

*Αἴγλη, goddess of radiant good health
Foster empowerment
Modular
Personalized
Easy to use
Connected to EHR
A video presentation of Egle
“Not using Eglé for a week significantly increased my hyper/hypoglycemia throughout this period.”

– Patient #3
https://beta.egle.be/signindoe
Technology
HTML5 web app
Customizable widgets
WebRTC video/audio chat
FIHR (Fast Healthcare Interoperability Resources) from HL7.org
Planing
Bayesian Network
Profiles
Email & in-app notifications
References


HFE Roundtable on
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Discussion with audience moderated by MEP José Inácio Faria
HFE Roundtable on
Engaging Patients in the Digital Revolution: A Call to Build Smarter and Safer Healthcare Systems

Closing remarks by
MEP Alojz Peterle
THANK YOU!