

# HEALTH IN THE DIGITAL SOCIETY DIGITAL SOCIETY FOR HEALTH

16-18 OCTOBER 2017  
TALLINN, ESTONIA

## *“Citizen-Controlled Data Governance and Data Donors” Opportunities & risks for consumers*

Francesca Cattarin, Health Policy Officer, BEUC

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*"Sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU", do you...*

- Strongly agree
- ✓ Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

## OPPORTUNITIES

- What happens in the real world
- Avoid unnecessary duplications
- Increase patients 'safety
- Contribute to medical public research

## OPPORTUNITIES

*“For which purpose would you agree to make your health data available provided this is in compliance with data protection legislation?”*


- ✓ Improving health care organisation
- ✓ Improving clinical practice
- ✓ Improving social care organisation
- ✓ For your own treatment
- ✓ Progressing research and innovation
- ✓ Developing health insurance schemes
- ✓ Informing public health programmes
- ✓ Supporting public health policy making
- ✓ Helping products development
- ✓ Increasing efficiency of health and social care
- ✓ Helping developing countries' health care systems

## RISKS

*“What are the major barriers to electronic **sharing** of health data?”*

- ✓ Heterogeneity of electronic health records
- ✓ Risks of privacy breaches
- ✓ Legal restrictions in Member States
- ✓ Lack of infrastructure
- ✓ Cybersecurity risks
- ✓ Lack of technical interoperability
- ✓ Data quality and reliability

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**..WHERE DATA PROTECTION MIGHT LOOK OUT OF PLACE..**



## MAIN RISKS FOR CONSUMERS..



### HEALTH DATA FOR SALE?


Consumer protection and privacy in blood pressure monitors and blood glucose meters for home use

28.09.2017

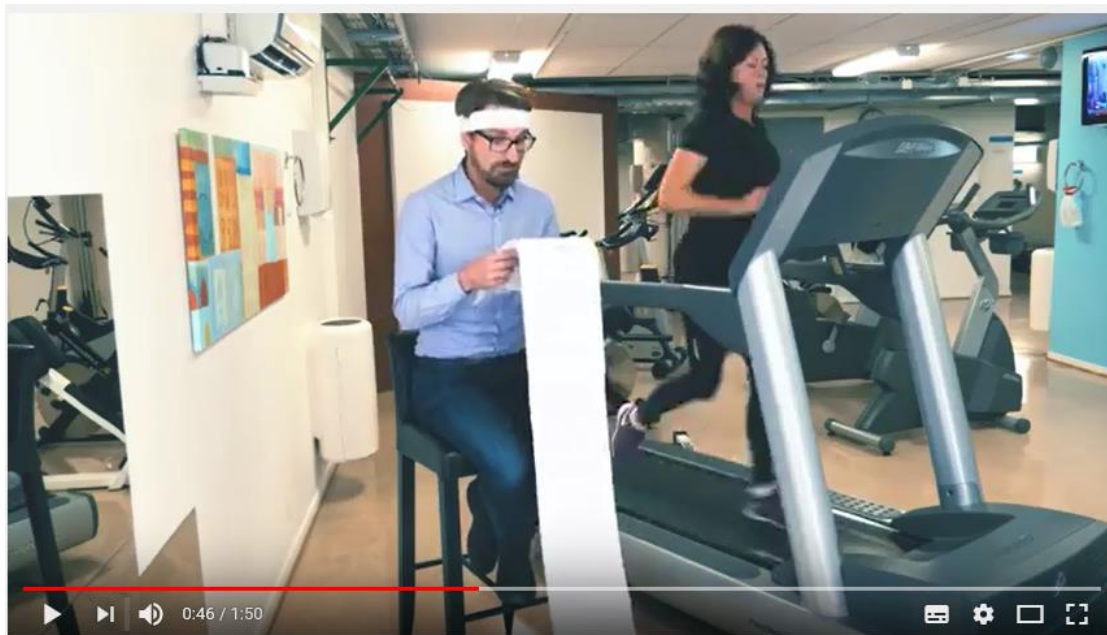
 FORBRUKERRÅDET

- Transmission of data to companies. To whom? For which purpose(s)?
- Use of unsecure channels
- Long and indecipherable terms and conditions

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## ..AND NOT ONLY



Minister on the run



## OUR DEMANDS

- Consumers in charge of their own files
- Truly informed consent
- Technology should ensure reliable identification
- Information campaign about the potentials and the risks
- Cost/benefit analyses

## FUTURE OPPORTUNITIES

- Estonian Presidency
- Digital Single Market Strategy
- European Commission's communication on eHealth

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Thank you!

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