

13th European Patients Rights Day

Digital Health and Personalized Medicine The role of Health Literacy

10th April 2019

Brussels

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European Patients Forum



@eupatientsforum

“ A STRONG PATIENTS’ VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”




Digital Health and the Patient's Conundrum

The healthcare landscape is becoming more complex

- People increasingly told to “take more responsibility” for their health... but not supported to do so
- Information landscape is changing – impact on the ways people interact with the system
 - Electronic health records
 - Dr Google, online portals
 - Social media, influencers
- Navigating the information maze is challenging ... even if you are highly educated



The European Commission and Digital Health

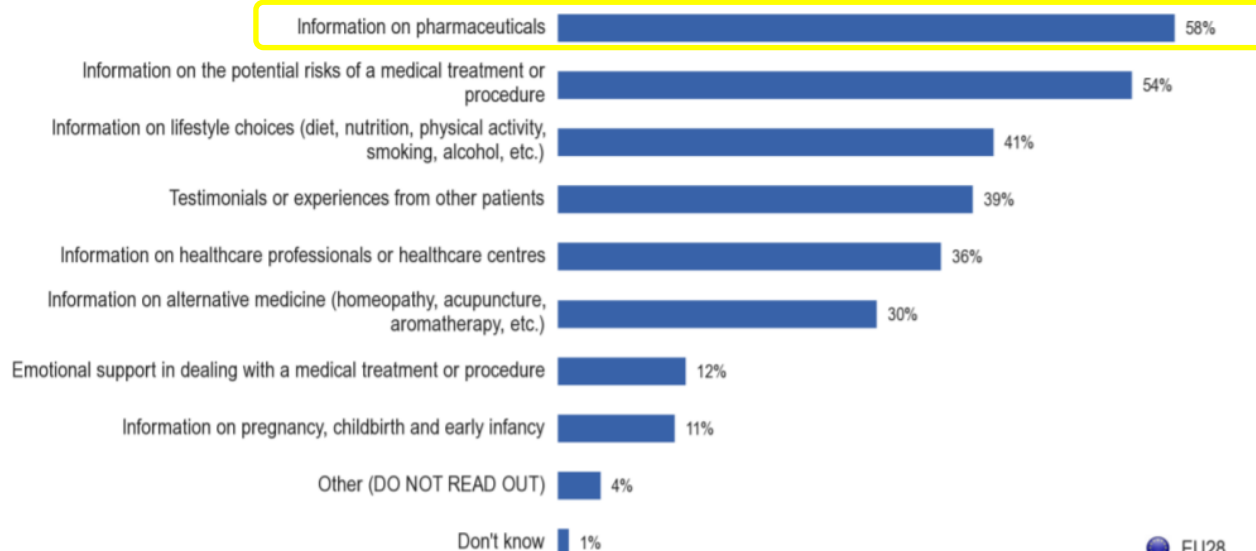
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- I. Secure access to and sharing of data
 - Access to health data is a citizen's right
 - Cross-border patient summaries, ePrescriptions, proposal on full EHR
 - II. Citizen-centred healthcare solutions and services
 - Common principles and certification; support uptake healthcare providers, mobilise public funding
 - Emphasis on integration and coordination of services along the “continuum of care”
 - III. Pooling of data for effective and efficient research
 - Voluntary collaboration mechanisms, e.g. “one million genomes by 2022”. specifications for secure access and exchange of health data; pilot actions, e.g. rare diseases



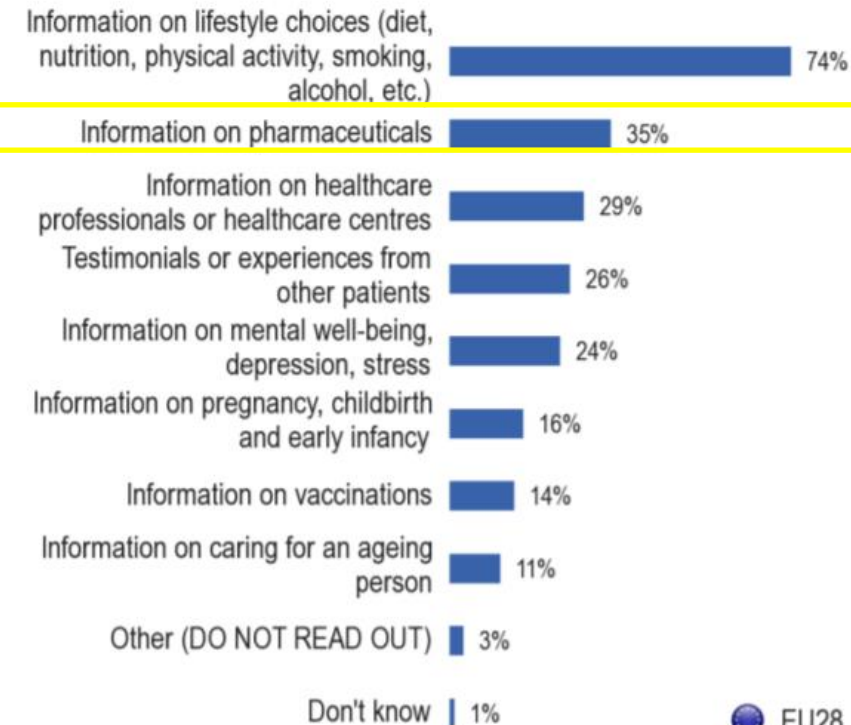
Patients, the Public and Digital Information

- 6 in 10 Europeans look for health information online
- Medicines information is a top search topic
- Most people think they can distinguish high from low-quality information online – 17% think they cannot

Q16. More specifically, when trying to find specific information on a medical treatment or procedure, which of the following types of information did you look for? (MULTIPLE ANSWERS POSSIBLE)



Q4. More specifically, when trying to access general information on health-related topics or ways to improve your health, which of the following types of information did you look for? (MULTIPLE ANSWERS POSSIBLE)



Eurobarometer, Sept 2014

Health Literacy – an essential ingredient



“patient-centred”
(passive patient)



Participatory
Collaborative
Partnership

Active patient
and Citizen

Conclusions and Recommendations

- Digitalisation will transform our health systems – patients want a person-centred system where technology and data bring real added value
- Patient participation is key in the development of technologies, data governance, implementation, evaluation – policy and research
- EPF recommends:
 - Include digital Health Literacy actions under COM pillar "patient & citizen empowerment"
 - EMA & national regulators → recognise Health Literacy and improve communication and public engagement approaches
 - Patient organisations, natural allies → “translating” scientific information into lay-friendly formats & disseminating



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