Patients Want Better Information

EPF European Patients Forum

PIL – a vital source of information about the medicines we take

- Good information essential for
  - Safe use of the medicine
  - Adherence & concordance to treatment plan
  - Effective self-management / patient empowerment
  - Monitoring of possible adverse reactions
- Sometimes the only information people have – especially with OTC medicines
- Important complement to information from Dr/nurse/pharmacists
- Information to "go back" to later on
 - But do we keep it – or just throw it away?

PIL – Role in Health Literacy

Understanding PIL is a component of health literacy

- Shortcomings known for a long time…

- HLS-EU survey: 27.5% found understanding PILs "fairly" or "very" difficult

- The most diverse item in survey – from 13.1% in NL to 48.3 in DE

  - HL relates not only to words, but also design and numbers
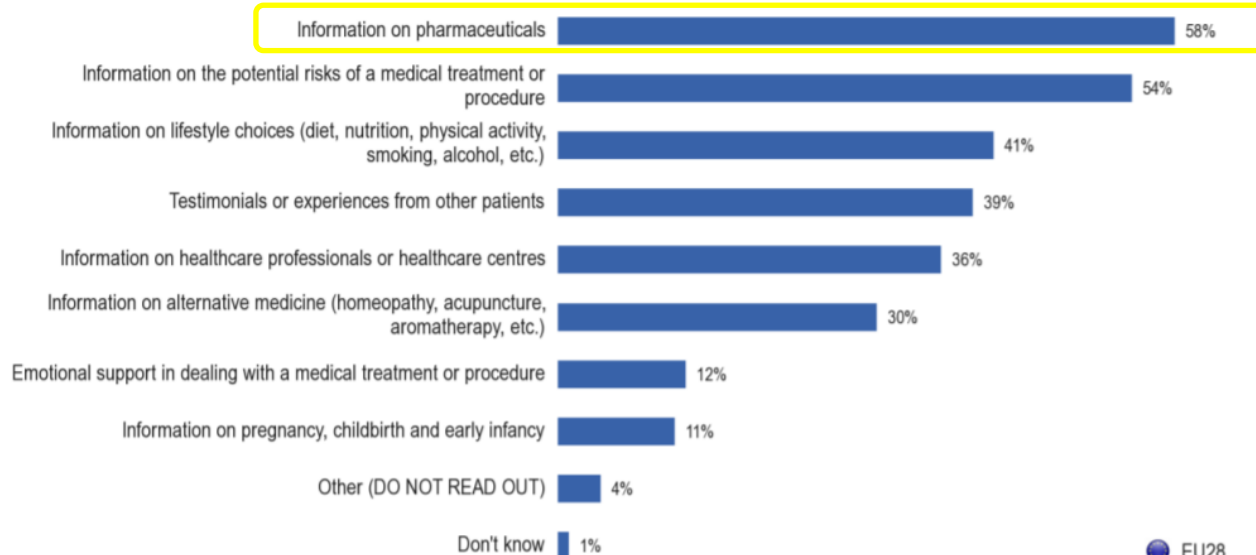 - PIL should be easy for all levels of HL

Q1.6: How easy is it to understand the leaflets that come with your medicine?

2   [VALUE]   20.7   28   42.6

■ Very difficult ■ Fairly difficult ■ Fairly easy ■ Very easy ■ Don't know
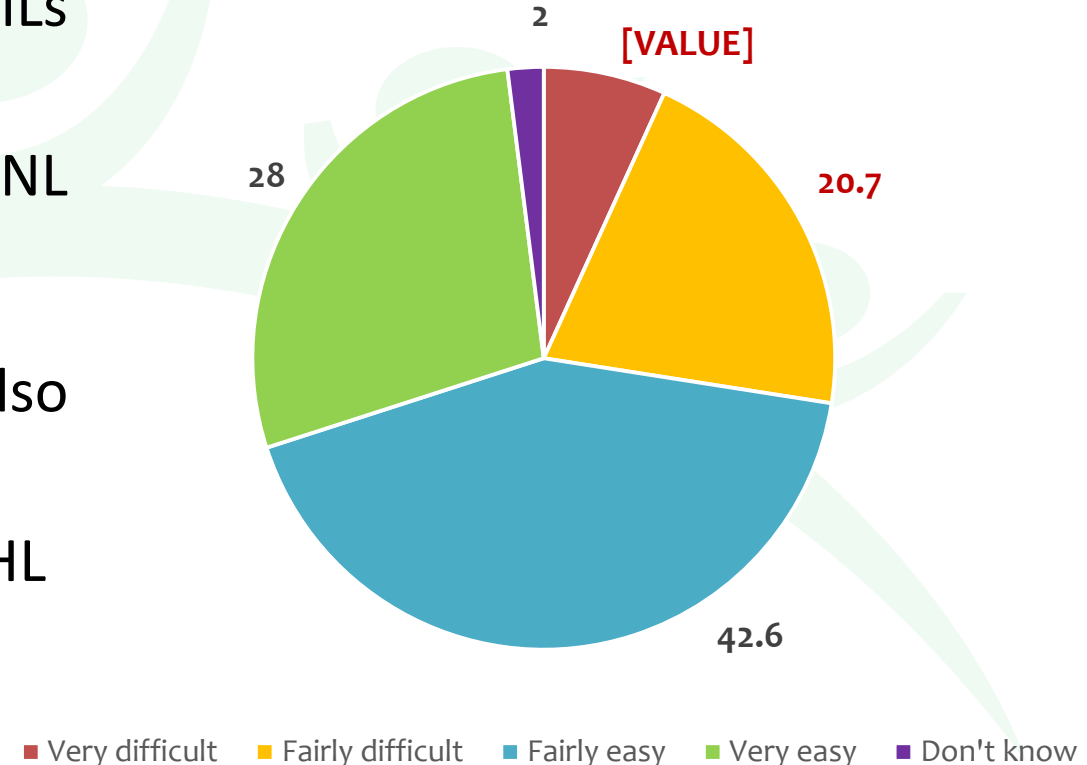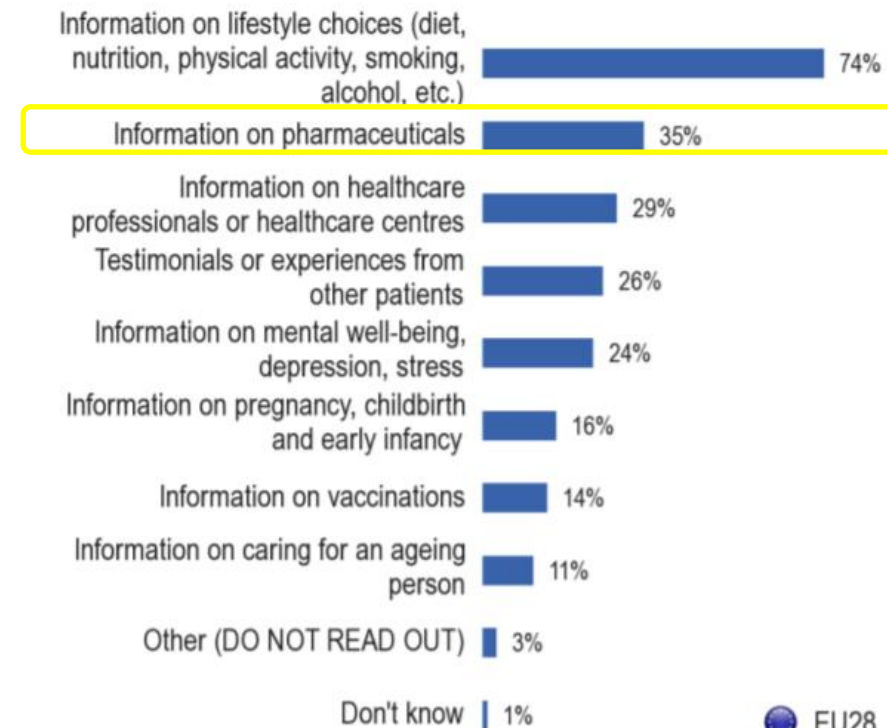
People look for information digitally

- 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

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)

Type	%
Information on lifestyle choices (diet, nutrition, physical activity, smoking, alcohol, etc.)	74%
Information on pharmaceuticals	35%
Information on healthcare professionals or healthcare centres	29%
Testimonials or experiences from other patients	26%
Information on mental well-being, depression, stress	24%
Information on pregnancy, childbirth and early infancy	16%
Information on vaccinations	14%
Information on caring for an ageing person	11%
Other (DO NOT READ OUT)	3%
Don't know	1%

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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)

Type	%
Information on pharmaceuticals	58%
Information on the potential risks of a medical treatment or procedure	54%
Information on lifestyle choices (diet, nutrition, physical activity, smoking, alcohol, etc.)	41%
Testimonials or experiences from other patients	39%
Information on healthcare professionals or healthcare centres	36%
Information on alternative medicine (homeopathy, acupuncture, aromatherapy, etc.)	30%
Emotional support in dealing with a medical treatment or procedure	12%
Information on pregnancy, childbirth and early infancy	11%
Other (DO NOT READ OUT)	4%
Don't know	1%

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Eurobarometer, Sept 2014

Opportunities of Electronic Product Information

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- Accessibility
  - Availability – when and where you want, all EU languages
  - Designed for readability
  - Adapting to people with disabilities, e.g. large text, design features
  - Portability – have it on your mobile phone
- Enhanced information & functionalities
  - Devices: video instructions, visuals
  - Search functions
  - Hover -over "glossary"…
- Up-to-date info
  - Changes communicated right away
- Interactivity → link to ADR reporting, other portals

Alert: new information on your medicine!

Potential Challenges / Caveats

- Limited access to computers & internet
  - Make it mobile gadget-friendly
  - Paper must remain available to those who need it
- Ideally single portal at EU level as "one stop shop" for information
  - Should be controlled by public authority – EMA & national regulators
  - Important to ensure public trust and confidence
- Patient involvement in PILs needs improving
  - Patient review comes too late / is not incorporated
  - More precise guidance from EMA to companies needed?
  - How to get more patient input into the process from the start → make it iterative ?

PIL = communication tool
or
PIL = legal document?

Expectations   Reality
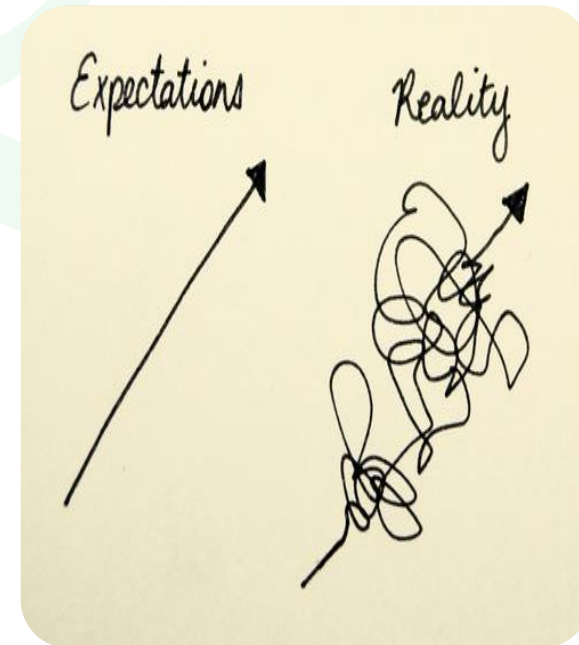
Concluding points

- Digital technology = a tool, not an end in itself

- Content of PIL needs improvement – taking into account recent knowledge on health literacy and particularly communication of benefits and risks

- Solutions must be:
  - Patient/person-centred
  - Equitable
  - Trusted
  - Easily accessible and user-friendly (technical interface)
  - Effectively communicated so people will know about it

- Aim: better, more accessible information for patients on the medicines we take

PERHAPS FIGURING OUT WHAT MATTERS MOST MATTERS MOST

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"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"

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