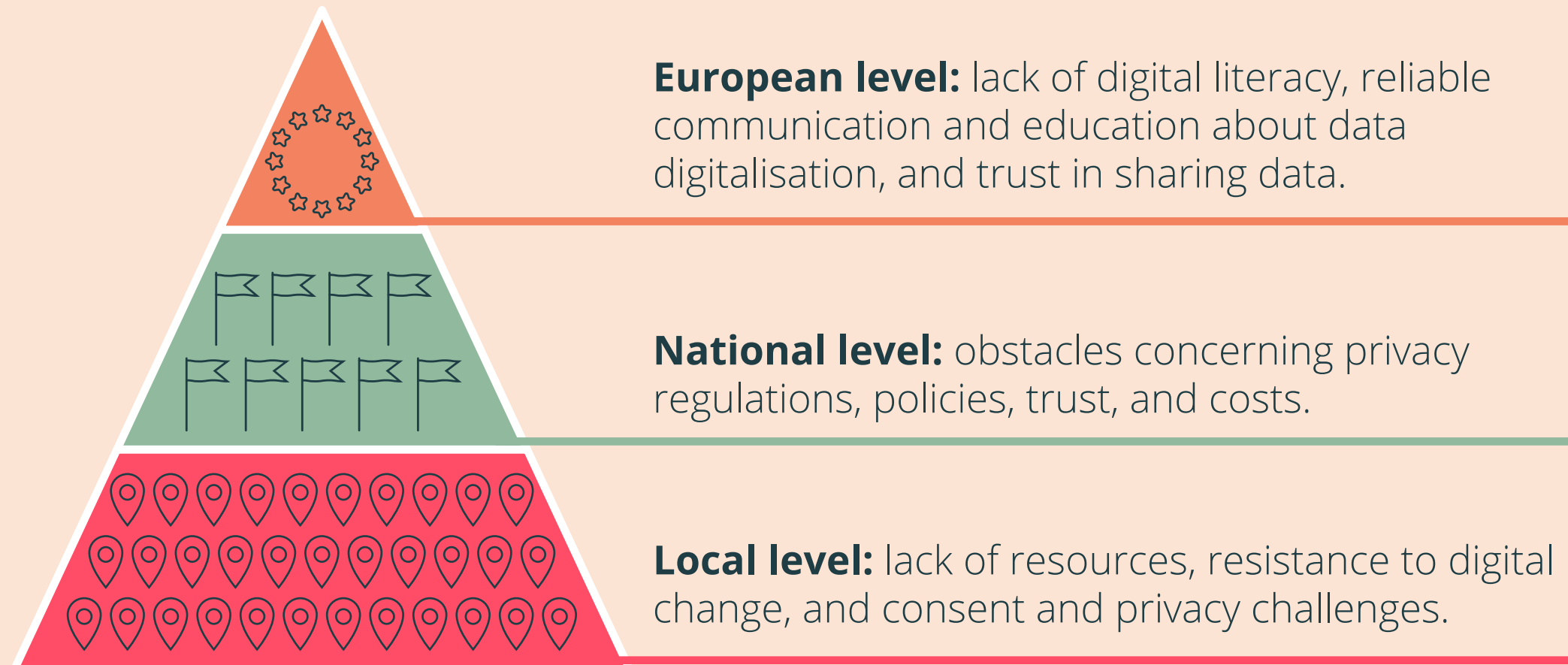


What are the main issues in the digitalisation of health data?



CONFIDENCE
STANDARDISATION
ACCESSIBILITY UNIFORM CONSISTENCY
INTRANSPARENCY
REVOLUTION
PRIVACY
SECURITY
ORGANISATION
UNIFORMITY INTEGRITY ACCESS TECHNICAL TECHNOL
CONNECT OWNERSHIP
EFFICIENCY TRUST ANONIMIZATION
ACCESSABILITY KNOWLEDGE UNDERSTANDING

“ As patients, we should be able to see who is accessing our data and know which data remain personalised and which anonymised. Patients should have to give consent for their anonymised data to go into a database and be able to opt out at any moment they wish. ”

Christina Fasser,
Retina International, Switzerland

“ In Estonia, our Nationwide Electronic Health Records system allows any doctor to access a patient’s health data in principle, but they have to have a solid reason to do so and face sanctions if they access it without a valid reason. This helps with trust in the system on the part of citizens. ”

Prof. Tõnu Esko,
Institute of Genomics, University of Tartu, Estonia

“ We need to inform patients and generate trust. When you do not trust in something, you will not do it. It is important to bring people together via webinars, hackathons or face-to-face meetings to help raise awareness about health data sharing ”

Birgit Bauer,
European Multiple Sclerosis Platform (EMSP), Germany

How can the issues around the future of health data sharing be overcome?



Accountability: integrate tools into digital systems that show people who has accessed their data. Sanctions and fines should be imposed for inappropriate access to build trust.



Communication: positive stories about health data must be disseminated in mainstream media, not just negative stories about data leaks and scandals.



Informed consent: explain the benefits of health data sharing to people and obtain broad informed consent for multiple secondary uses.



Patient advocacy: work together to advocate for positive change in Europe – the conversation is currently dominated by experts and much technology infrastructure is run by US companies.

“ It has been very important for me to build national collaboration and to have close contact with my colleagues throughout the country. ”

Line Kessel,
Rigshospitalet, Denmark

Footnotes: 1. The EPIS 2021 Webinar #2 was attended by over 140 community members across 35 different countries, including those in Europe, Asia, North and South America.