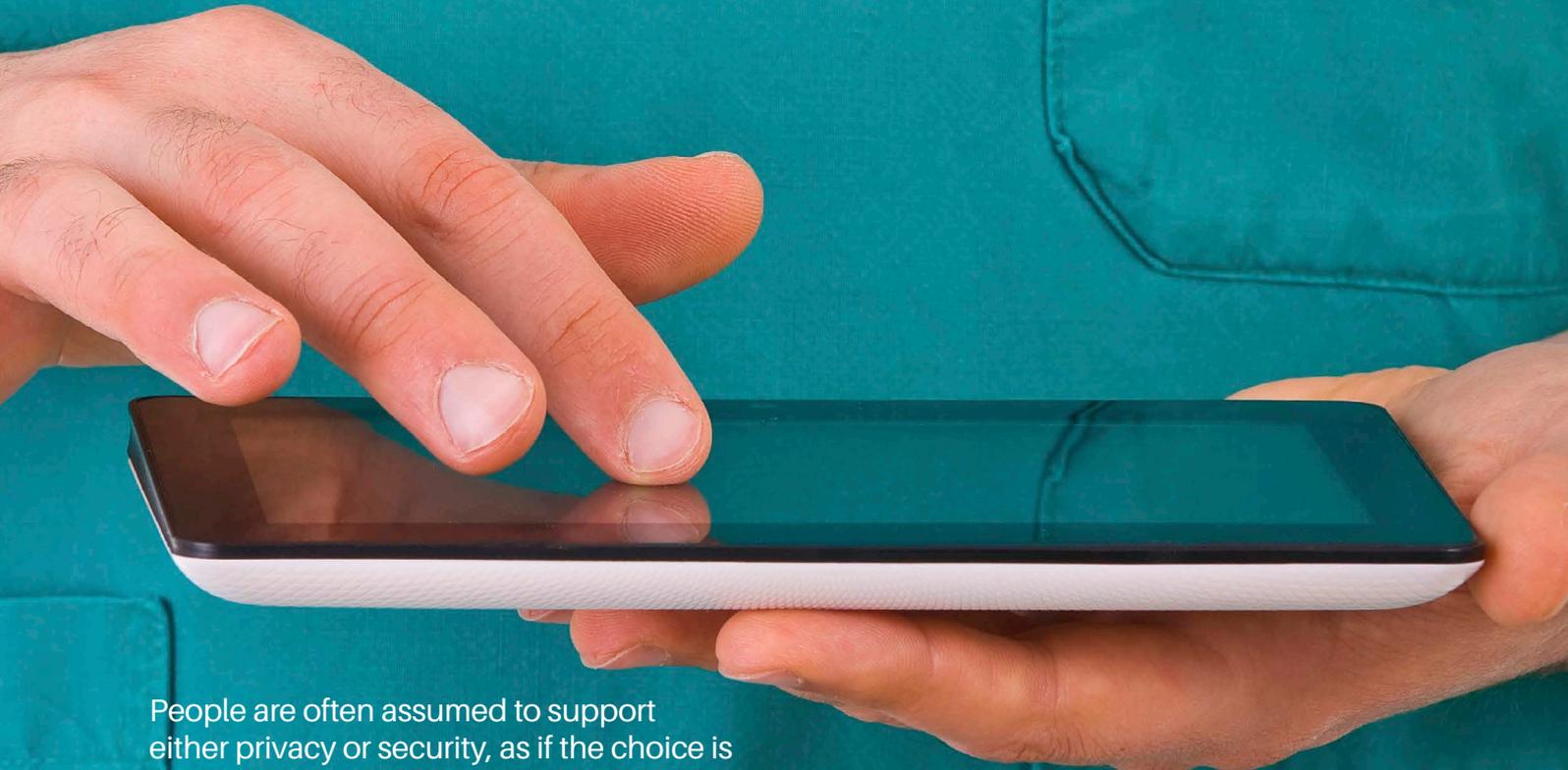


Privacy of health records

Europeans' preferences on
electronic health data
storage and sharing



People are often assumed to support either privacy or security, as if the choice is between one or the other. However, RAND Europe has collected evidence as part of the largest ever surveys of citizens' views across Europe on security, surveillance and privacy issues, and the results point to the general public having a much more nuanced understanding of those issues.

This brief presents people's preferences in the context of storage of electronic health records

Threats to our safety range from local street crime to international terrorism and cybercrime to pandemic disease. In confronting such threats, policymakers must weigh up individual rights against the collective needs of society. Decisions are often characterised as a trade-off between privacy and security, issues that are inherently difficult to measure and compare. Are people willing to accept intrusions into their private lives, such as third-party access to medical records or internet surveillance, in return for enhanced security and other benefits?

In 2014, RAND Europe completed a pan-European survey (of the then EU27 Member States) to explore citizens' views on these issues for the European Commission's PACT project (Public Perception of Security and Privacy: Assessing Knowledge, Collecting Evidence, Translating Research into Action). In autumn 2013, over 26,000 citizens across EU27 participated in the survey: 13,500 through face-to-face interviews and 12,800 through online surveys. The survey contained three stated preference choice experiments to quantify citizens' views on privacy and security issues in three real-life scenarios: travelling by train or metro, choosing an internet service provider and storing personal health data.

In this study

The stated preference method

A key benefit of the use of stated preference choice experiments is that the outputs provide quantification of the strength of preferences, including an estimation of citizens' willingness to pay for proposed initiatives. In this study, every respondent was presented with five questions, each with three options – Options A and B, and a 'None of these' option (please see an example of a stated preference question below). The first two options are described using dimensions relating to information on the types of health and personal information which might be recorded; on the professions, nationalities and countries accessing that information; and on any additional costs for data management. Across all respondents, the survey presented 120 unique questions, creating a wide range of scenarios and providing a detailed understanding of citizens' preferences. In total, over 18,900 people from across the EU27 provided more than 94,000 choice observations relating to their expectations of health records storage.

Which of the following options would you prefer for a health record storage device/system?			
Description	Option A	Option B	Option C
What information is stored on the device/system: Basic health status (blood group, allergies, diabetic status) Identification (name, address, age, photograph, nationality) Lifelong health conditions (asthma, disabilities, cancer, etc.) All health conditions (mental health, sexual health, addictions and medical history)	Basic health status information Identification Lifelong health conditions	Basic health status information Identification Lifelong health conditions All other health conditions and medical history	I would not purchase any such device/service
Who can access the information?	Doctors, nurses and emergency medical personnel (paramedics)	Only doctors and nurses	
In which countries can your information be accessed?	Worldwide	Across Europe	
Who else can view this information apart from the medical specialists?	Health insurance companies	Private-sector pharmaceutical companies	
Cost per month	€1 per month	€2 per month	

What do people want from electronic health record storage?



Respondents prefer storage of information on identification and lifelong health conditions along with basic health status

In general, compared to devices/systems that only store basic health status information, respondents prefer those that can also store additional information relating to their identification and/or lifelong health conditions. Depending on household income, they are willing to pay a premium of €0.31–€0.82 per month to store this additional information. However, respondents in general are averse to storage of information relating to all other health conditions and medical history apart from that mentioned above.



Apart from doctors and nurses, respondents prefer that paramedics also have access to health records

However, most respondents are averse to broadening of access to include fire and rescue personnel, thus preferring that access to health records is limited to medical personnel.



EU-wide access is preferred in most countries

Respondents prefer that health records can be accessed across the EU rather than in their home country alone. Depending on their household income, they are willing to pay a premium of €0.14–€0.38 for this Europe-wide access. However, respondents are averse to broadening access beyond the EU to include all countries worldwide.



In general, respondents are averse to any groups of individuals other than medical specialists viewing health records

The overall pattern is that respondents most dislike private-sector pharmaceutical companies being able to view their health records, followed by academic researchers and health insurance companies. Respondents have only negligible aversion to immediate family members and nurses providing home-care being able to view information on their health records.

Preferences for those having access to health records

Increasing dislike →



Health insurance companies



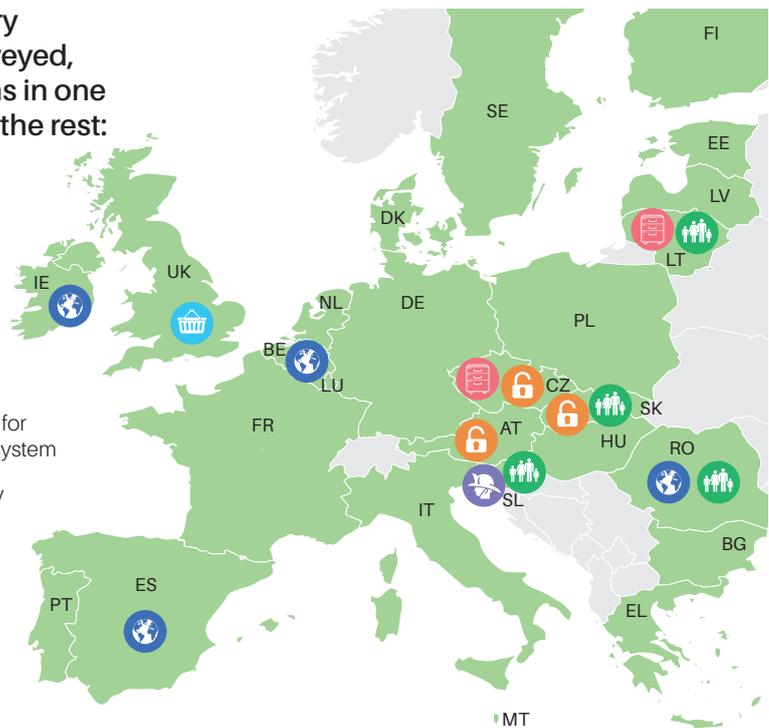
Academic researchers



Private-sector pharmaceutical companies

Although preferences are generally very consistent across the 27 countries surveyed, this map shows on what points opinions in one country are significantly different from the rest:

-  Dislike storage of additional health- and identity-related information
-  Prefer storage of information related to all health conditions and identity
-  Dislike EU-wide access to information on the device/system
-  Stronger preference for EU-wide and preference for worldwide access to information on the device/system
-  Dislike additional access to health information by paramedics and fire and rescue
-  Prefer immediate family can also view the information on the device/system
-  Surveyed countries



Summary for policymakers

In this large, objective pan-European stated preference study, respondents gave a range of preferences regarding health information storage, access and sharing, indicating a nuanced understanding of privacy. This work clarifies and explains public perceptions on privacy, in particular how the risks to privacy of electronic data storage are understood alongside perceived individual and collective benefits. Access to and sharing of health information beyond those who are involved in immediate care is perceived negatively.

A synthesis of overall PACT project findings (including travel security/surveillance and internet use scenarios) indicates that:

- From a regulatory perspective, the issues most at stake concern creating a **culture of accountability**, particularly where public and private organisations are involved in **collecting and using personal data**.
- While on average the preferences across Europe are consistent, it is important to **take account of diversity in preferences by country and by demographic group**, when designing and deploying security and surveillance.
- European preferences relating to security and privacy **are much more nuanced than a straightforward inverse relationship** that assumes additional security or surveillance must come at the cost of privacy and liberty.

This summary describes work done by RAND Europe documented in *Public Perception of Security and Privacy: Results of the comprehensive analysis of PACT's pan-European Survey* by Sunil Patil, Bhanu Patrui, Hui Lu, Fay Dunkerley, James Fox, Dimitris Potoglou, Neil Robinson, RR-704-EC, 2015 (available at www.rand.org/t/rr704). To view this summary online, visit www.rand.org/t/RB9843z3. RAND Europe is a not-for-profit research institute whose mission is to help improve policy and decisionmaking through research and analysis. RAND Europe's publications do not necessarily reflect the opinions of its research clients and sponsors. RAND® is a registered trademark.

Limited Print and Electronic Distribution Rights: This document and trademark(s) contained herein are protected by law. This representation of RAND intellectual property is provided for noncommercial use only. Unauthorised posting of this publication online is prohibited. Permission is given to duplicate this document for personal use only, as long as it is unaltered and complete. Permission is required from RAND to reproduce, or reuse in another form, any of its research documents for commercial use. For information on reprint and linking permissions, please visit www.rand.org/pubs/permissions.html.