



# The Patients' Perspective on Access to and Use of Personal Health Records

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# Reasons for PHR use

PHR have been championed as a way to improve the access, delivery and the quality of health care services.

PHRs play a role in empowering patients by facilitating a better health information exchange, thereby enabling patients to be proactive and to engage more effectively as partners in their care (European Commission 2013).

The provision of PHRs will further help with self-care, facilitate the better coordination of healthcare services and improve health outcomes (Kaelber et al. 2008; Doocy et al. 2017)



# The APPS questionnaire study

- Harmonized cross-sectional study in the border regions: Lorraine (France), Luxembourg, Rhineland-Palatinate and Saarland (Germany), and Wallonia (Belgium)
- A self-administrated questionnaire, developed with patients' representatives in each country, offered in four different languages: French, German, Luxembourgish and English.
- Survey participants (above 18 years), recruited online, in person, and via various patients' associations, hospitals and health clinics.
- A total of 829 individuals completed the questionnaire



# Overview of access to PHR in the Greater Region

## FR

Dossier Médical Partagé since 2004, but only wide uptake since 2016 (after transfer to the national sickness insurance)

## DE

“elektronische Gesundheitskarte” since 2015 to share information among health professionals; patient access to Personal Health Record mandatory for insurers starting January 2021

## BE

Patients have the right to consult their Health Record since 2002; national portal MaSanté/MijnGezondheid since 2018

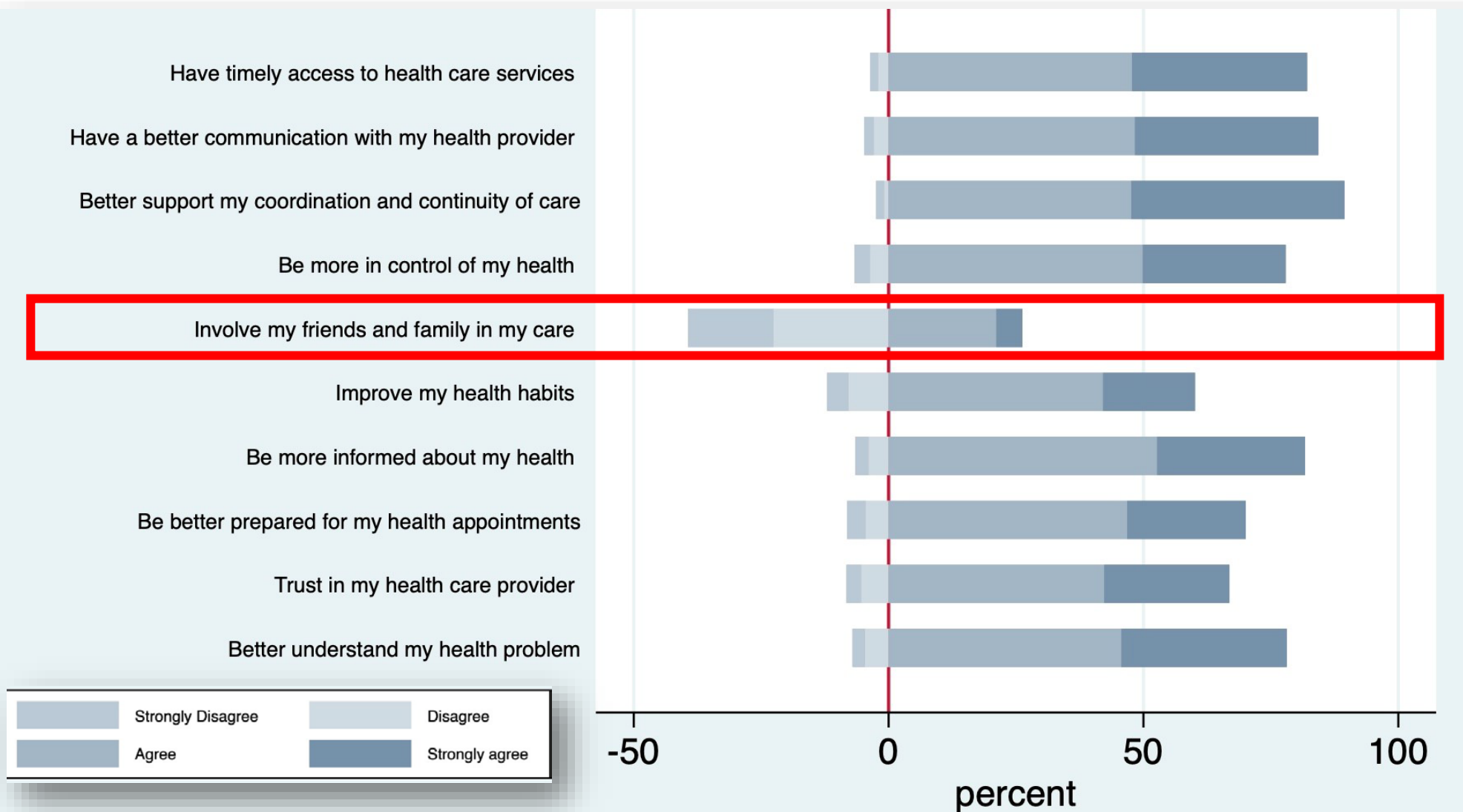
## LU

Pilot project on Dossiers de Soins Partagé in 2015; on-demand access since 2019; 2020-21: wide deployment to all adults and (caretakers of) children



# PHR and Patient-as-Partner Approach

## Use of my PHR will enable me to...



# Intentions and Expectations in using PHR

I think It will be easy to use my PHR

I am hesitant to use my PHR for fear of exposing my health information

I think that using my PHR is a good idea

I have the digital knowledge necessary to use my PHR

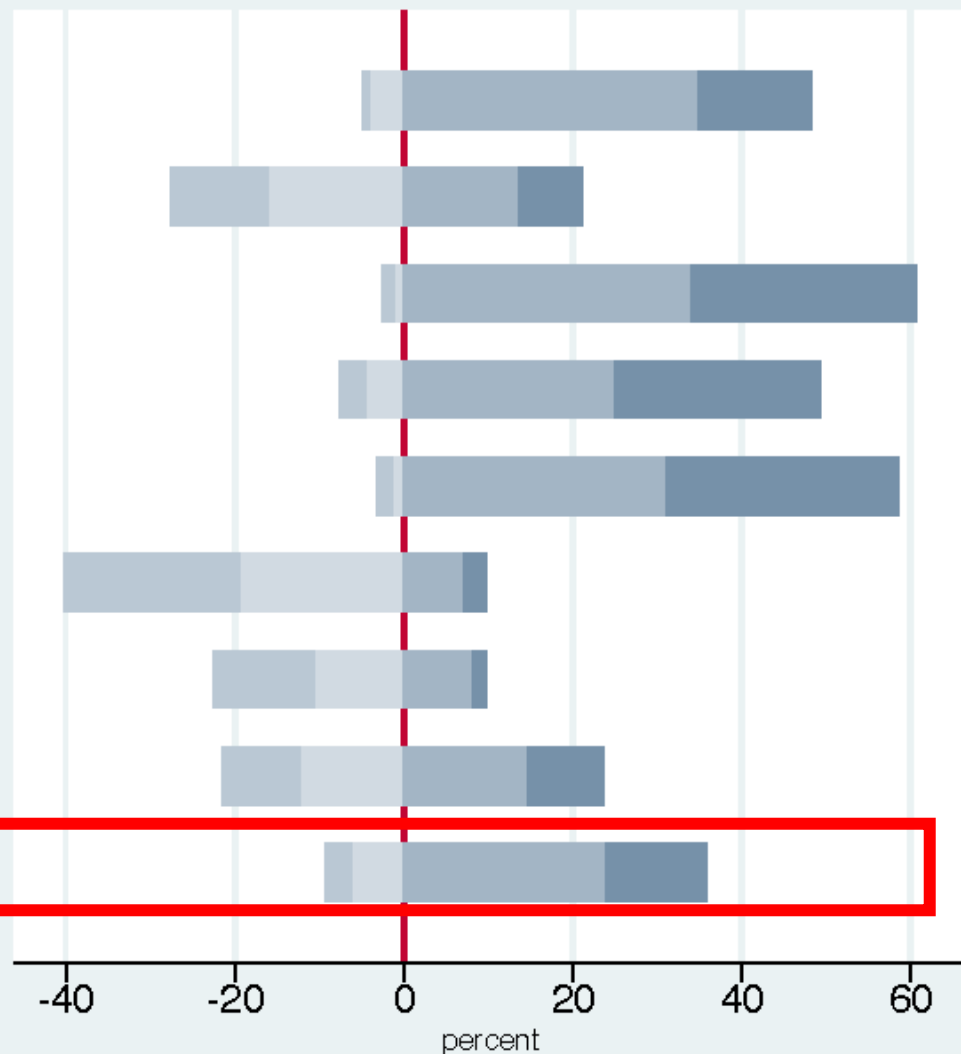
I think using my PHR would be a useful tool in managing my own-health

I feel nervous about using my PHR

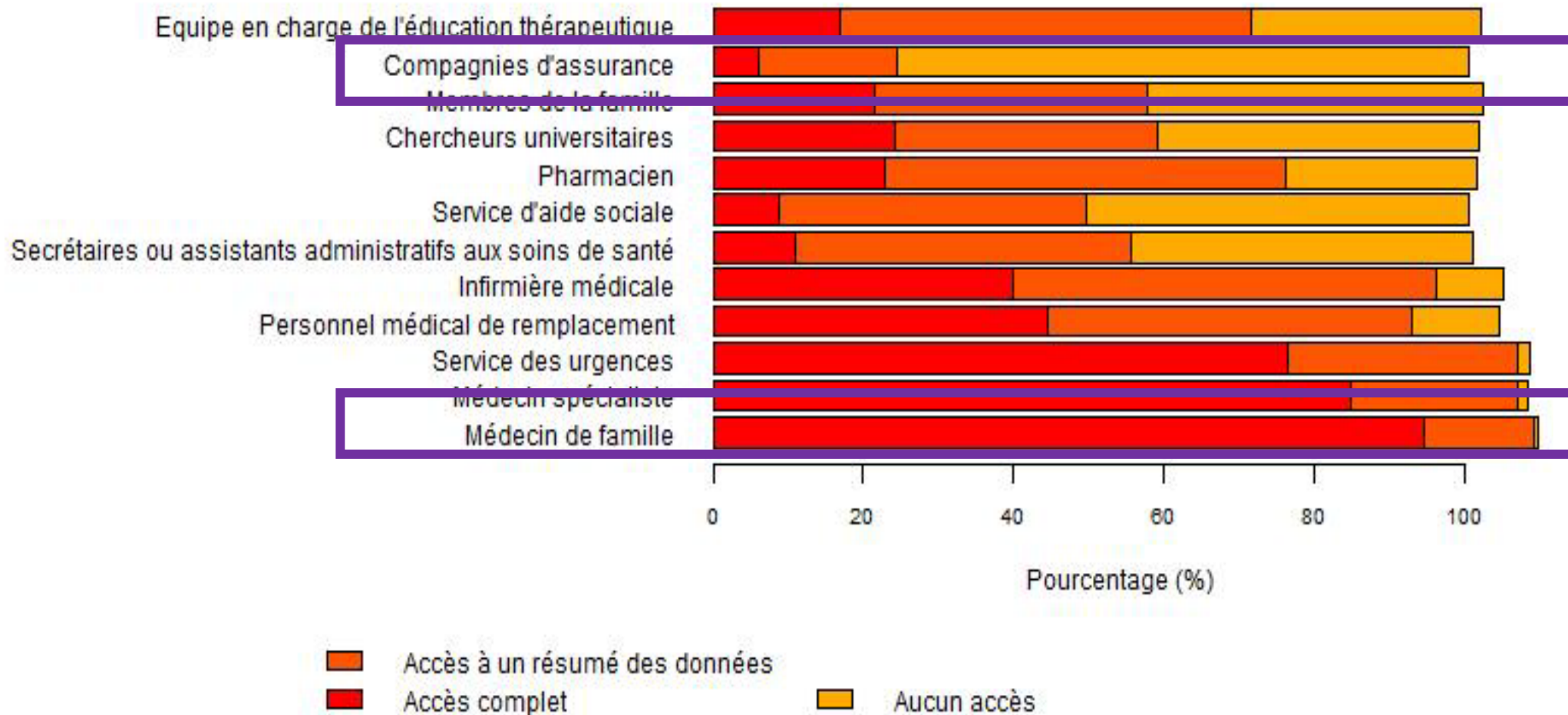
My family and friends are using PHR

I have someone to explain to me how to use my PHR

I intend to use my PHR on a regular basis



# Safety considerations – who should have access?



# Safety considerations – Data protection

## DMP – Dossier médical partagé

Mes données personnelles sur la santé sont protégées par la législation européenne en vigueur

J'ai l'intention d'utiliser le DMP sur une base régulière

Je suis stressé à l'idée d'utiliser le DMP

J'hésite à utiliser le DMP de peur de rendre publiques mes informations médicales

J'ai quelqu'un pour m'expliquer comment utiliser mon DMP

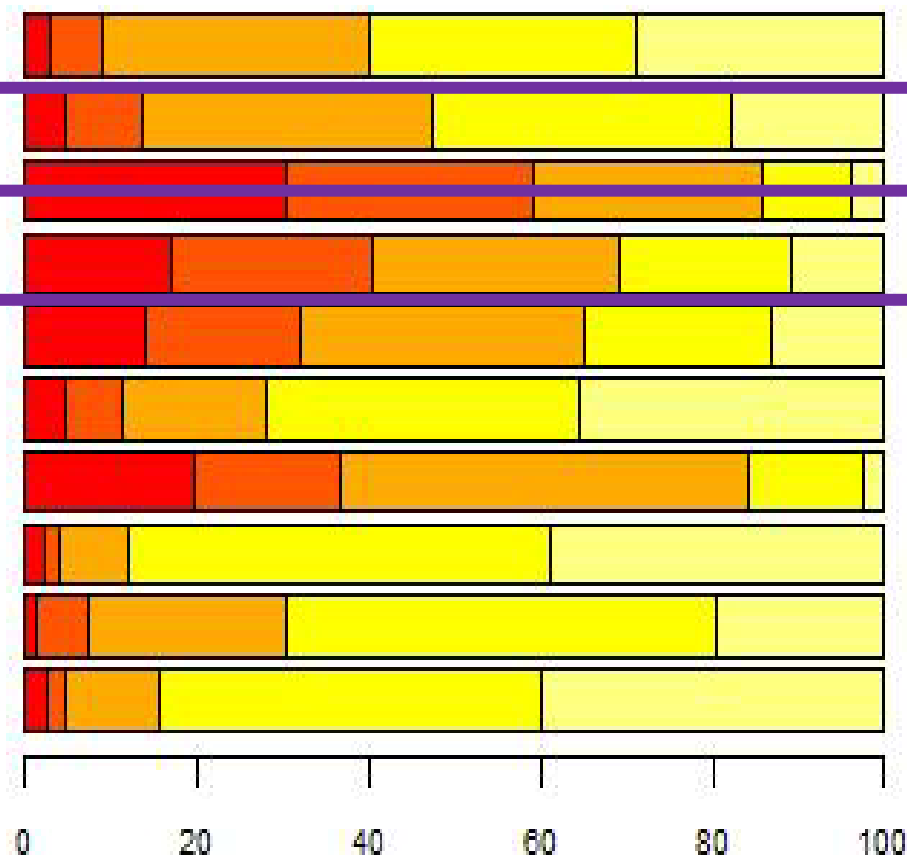
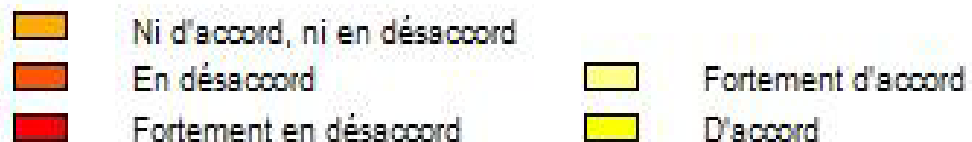
J'ai les connaissances numériques nécessaires pour utiliser mon DMP

Ma famille et mes amis utilisent leur DMP

Je pense que l'utilisation de mon DMP est une bonne idée

Je pense qu'il me sera facile d'utiliser mon DMP

Je pense que mon DMP serait un outil utile pour gérer ma propre santé



Pourcentage (%)



# Socioeconomic determinants of PHR use – Availability doesn't mean uptake

Some populations have physical access to the electronic health portals and their PHRs, but uptake among certain socio-economic and ethnic minorities has been rather slow and socially patterned (Denton 2001; Chiesa et al. 2019; Lin et al. 2019; Walker et al. 2019)

PHR are used more frequently by those who are already healthier and socioeconomically more advantaged (Anthony and Campos-Castillo 2015; Ancker et al. 2017)



# Research questions

- Which socio-demographic and socio-economic factors determine whether people have access, wish to access, and intend to use their PHR regularly?
- What behavioral factors from **Unified Theory of Acceptance and Use of Technology (UTAUT)** are associated with the intention to regularly use PHR, and are these moderated by the socio-economic characteristics of the individual?

# Measures

## Outcome measures:

- Having physical access to PHR (“Do you currently have access to your Personal Health Record?”)
- Desire to access PHR (“Would you like to have access to your Personal Health Record?”)
- Intention to regularly use their PHR (“I intend to use my PHR on a regular basis”); five-point Likert scale from “strongly disagree” to “strongly agree”

## Determinants

- Education, perceived comfort living on present income, migrant status
- Factors of UTAUT: PHR useful and easy; social support; lack of anxiety

## Covariates

- Age, gender, employment, partnership status, chronic diseases, social network, country



# Summary of findings

- There is a clear gradient in the **desire to access** and **physical access** to PHRs, with those more educated and living comfortably on present income showing a stronger desire to obtain access to their PHR, and a greater intention to use their PHR regularly.
- People aged 65+ years, and migrants with lower comfort living on present income, reported lower desire to access their PHR.
- About one third of those with desire to access intended to use their PHR regularly.
- Perceived usefulness and ease of use (UTAUT) were the strongest predictors of intention to use the PHR regularly, followed by social support and lack of anxiety using the technology.

# Recommendations

- Regional actors, health professionals, policy makers need to take into consideration each stage of PHR use: **physical access, desire to use, and intention to regularly use PHR.**
- Provide universal PHR access on an opt-out basis, with a possibility to close or permanently delete the data at any time.
- Special attention needs to be paid to those who are not motivated or who do not wish to have access to their PHR: people aged 65+, migrants from less advantaged socioeconomic backgrounds
- Once uptake is satisfactory: Ensure PHR are accessed regularly
- Otherwise risk to exacerbate existing health inequalities

# The APPS équipe



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