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Citizens' Access to Online Health Information – An International Survey of IMIA Member Countries

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Background

Citizens’ access to their personal health information and data online, is important for several reasons:

1. From a democratic perspective, every citizen has a right to have access to their data.
2. Digital healthcare systems need to be accessible and based on a foundation that promotes equity in healthcare.
3. The active or participatory patient needs access to their health data to aid in self-management, health decisions, and treatment.

Research Question

To what extent are citizens able to access their personal health data online in the IMIA member countries?

Methods

- 98 International Medical Informatics Association (IMIA) representatives invited to participate
- Questionnaire available – January – February, 2021, online administration, ~ 4 minutes to complete
- Data were analyzed using SPSS and MS Excel
- Descriptive statistics and cross-tabulations were used to provide overviews of associations between countries, healthcare settings and information types

Questions

1. What type(s) of information do citizens in your country have online access to from **a) all / b) some hospitals** in a public health care system?
2. What type(s) of information do citizens in your country have online access to from **c) all / d) some ambulatory care settings** in a public health care system?
3. What type(s) of information do citizens in your country have online access to from **e) private hospitals** or Health Maintenance Organizations (HMOs) hospitals **f) private ambulatory care settings**?

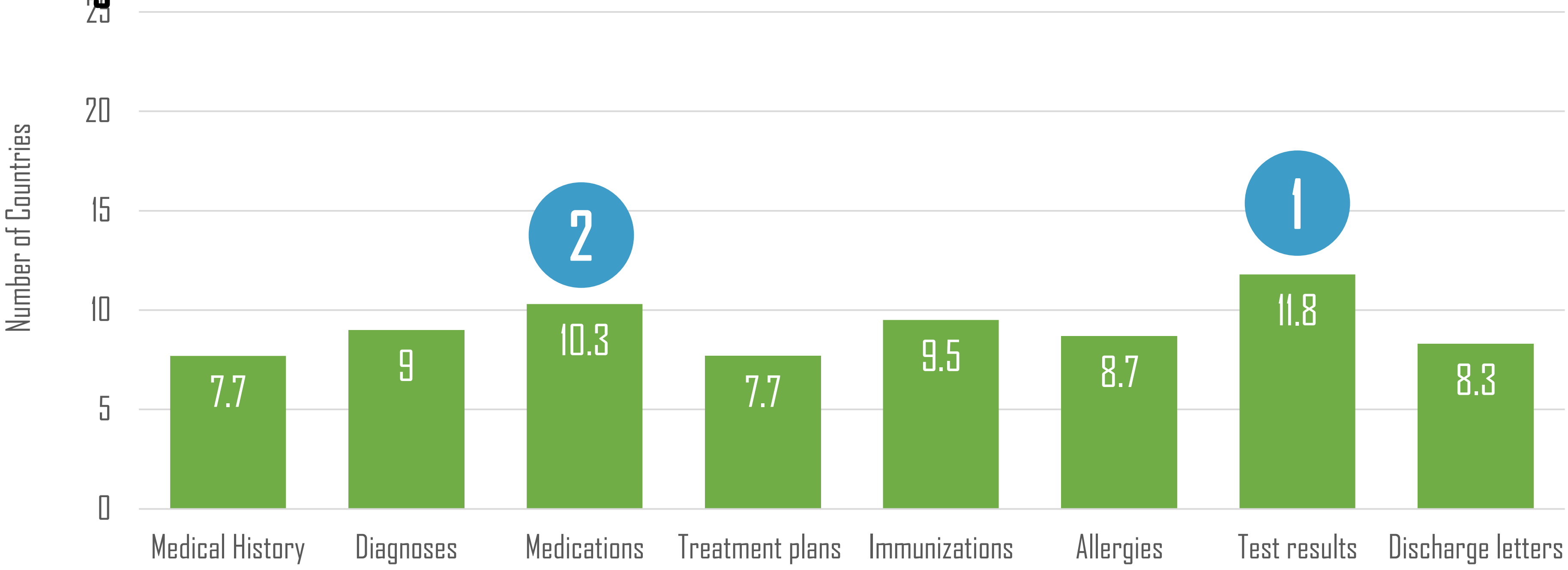
Results

Response rate: 29 out of 98 country representatives = 28%

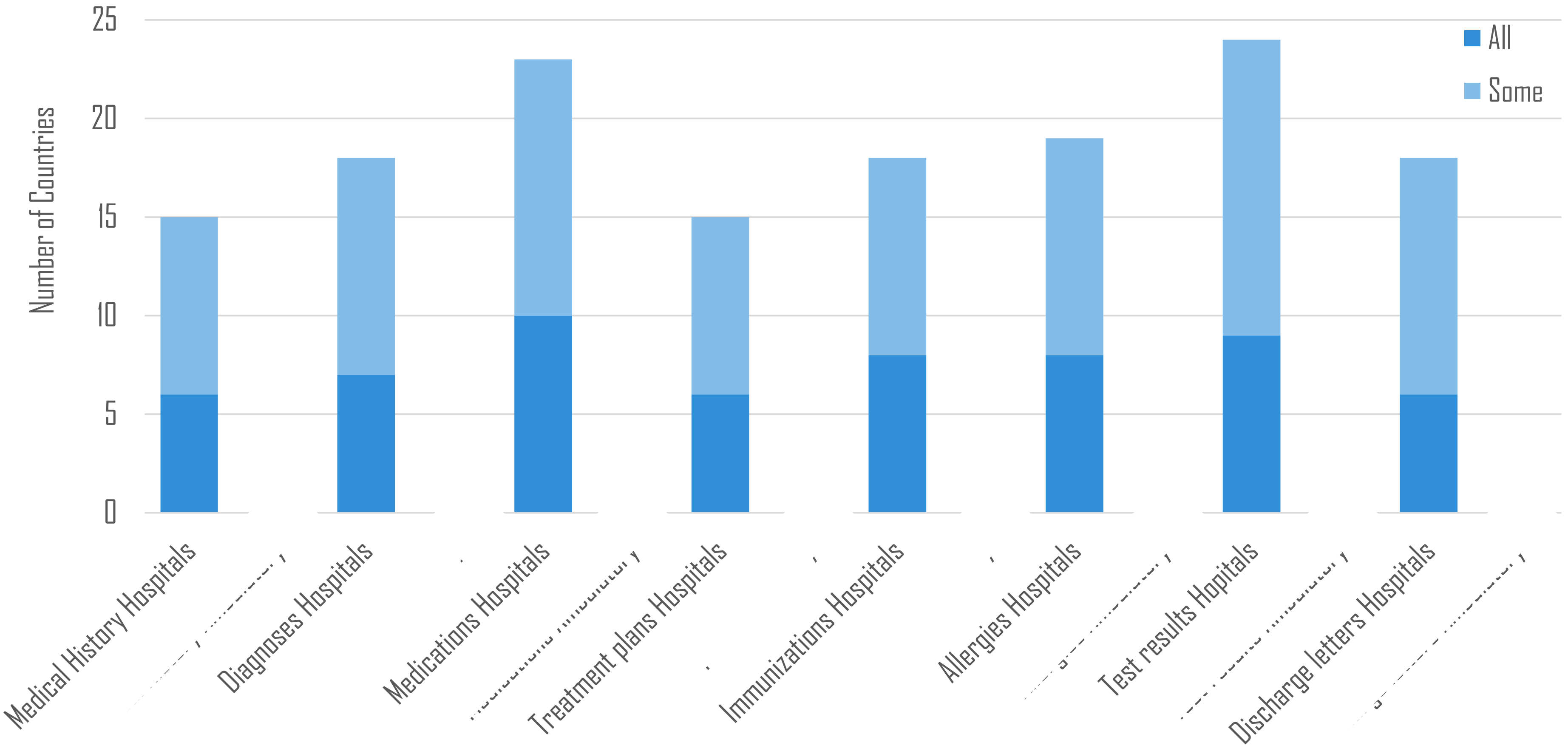
The following countries participated:

Austria, Brazil, Burkina Faso, Canada, Croatia, Democratic Republic of Congo, Denmark, Finland, France, Germany, Hong Kong, Ireland, Kuwait, Korea, Norway, New Zealand, Peru, Philippines, Spain, South Africa, Sweden, Singapore, The Netherlands, Turkey, Taiwan, Tanzania, USA, United Kingdom, Venezuela

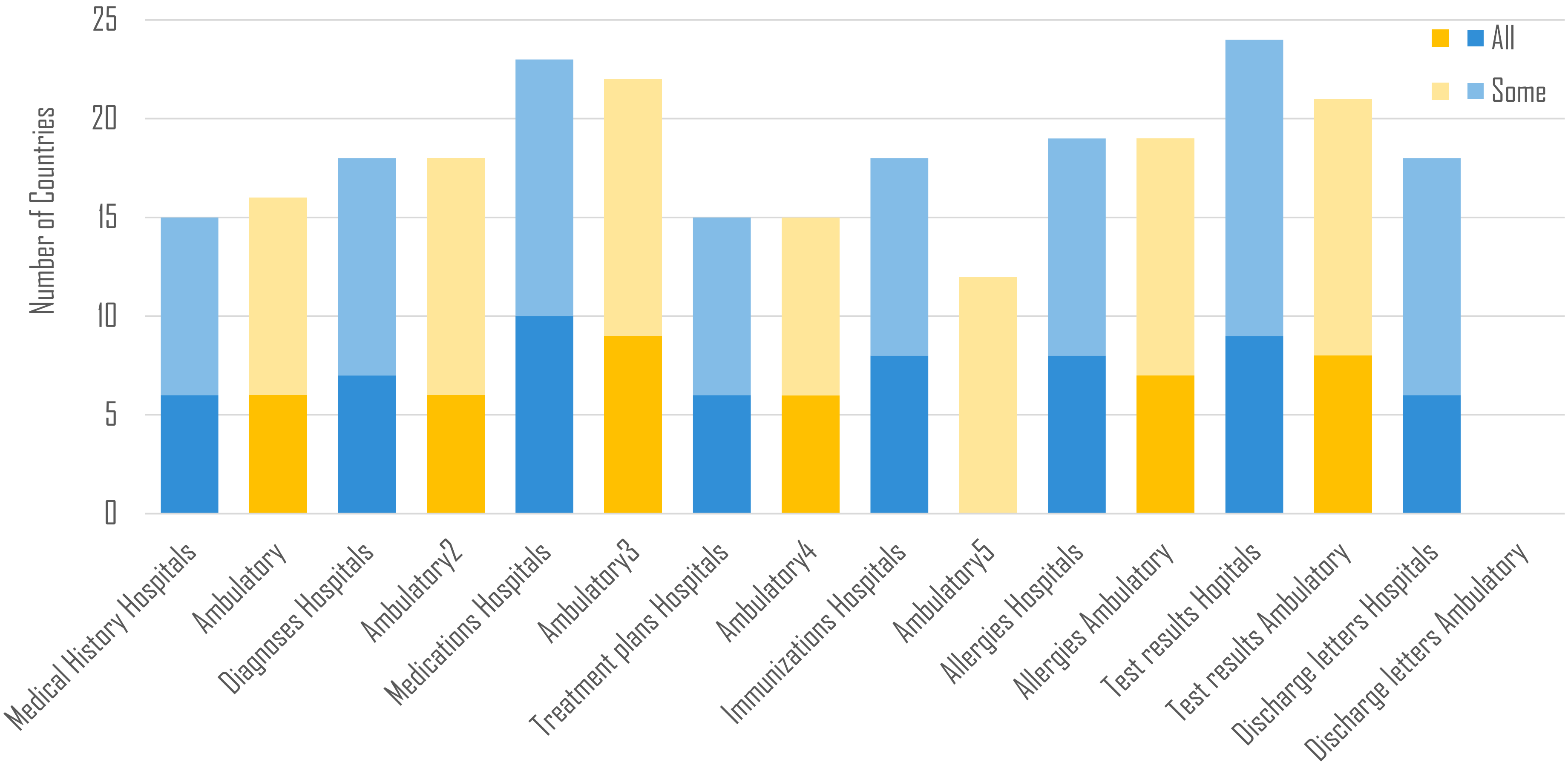
Average Number of Countries with Access to Health Data Types Across All Health Care Settings



Access to Health Data Types in Hospitals



Access to Health Data Types in Hospitals



Country Leaders – *Some Hospitals*

- Access to the maximum types of information (8) in *some hospitals* is possible in
    - The Netherlands
    - Finland
    - Denmark
    - Sweden
    - USA, and
    - Canada

Country Leaders – *Private hospitals/HMOs*

- Access to the maximum types of information (8) in *Private hospitals/HMOs* is possible in
  - Finland
  - USA
  - Taiwan, and
  - South Africa

Country Leaders – *Some Ambulatory Care*

- The maximum amount of information types (6) *in some ambulatory care settings* is possible in
  - The Netherlands
  - Finland
  - Denmark
  - Sweden
  - United Kingdom
  - USA
  - Canada, and
  - New Zealand

International Comparison

- Only **Finland** and the **USA** have the maximum amount of information accessible across the public/private sector and hospital/ambulatory settings
- In The Netherlands, United Kingdom, Denmark, Sweden and Canada, online health information is particularly accessible through **public** services
- Whereas, in Taiwan and South Africa information is primarily accessible through **private** providers

Discussion

- Access to online health information varies across, countries, healthcare systems, healthcare settings, and information types
    - Some differences in access might also be explained by regional variations characterized by the organization of health systems and cultural differences
- In 10 of 29 countries, citizens can access the maximum amount (6 to 8) of health information types explored in this study

Discussion

- *The IMIA Code of Ethics for Health Information Professionals stresses:*
    - The principle of autonomy: all persons have a fundamental right to self-determination
    - The principle of equality and justice: all persons are equal as persons and have a right to be treated accordingly
- IMIA members should help emphasize the importance of and encourage access to personal health information

Conclusion

- Access to personal health information varies globally but we expect it will continue to increase with time
- COVID-19 may have been a catalyst for offering new information types to citizens
- Adequate levels of health literacy and digital literacy are also required to achieve a patient-centred health system

Thank you!