

# Citizens and Health Data

## – what about digital health literacy by all?

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**Abstract:** Citizen themselves is the least utilized resource in contemporary health care. Digital tools are vital for providing citizens the best possible care as they support collaboration and information sharing between healthcare providers, and with patients and their family caregivers. For this workshop we will introduce and engage a discussion on active use of accumulated personal health information from multiple sources, and what it takes to ensure digital health literacy to comprehend and use the information. Supported by novel functionality and interoperability standards we anticipate tremendous potential to accelerate health care transformation and personalize care across Europe and internationally.

**Keywords:** Citizens; Health Data; Digital health literacy; Transformation

### Introduction

The starting point for this proposed WG is that “the citizen themselves is the least utilized resource in contemporary health care”, as pointed out by one of the health informatics pioneers, Dr. Slack, in 1978. Today, several decades later most information exchange is still about a patient and less in collaboration with or for the patient and their significant other, as citizens. Despite the recent EU General Data Protection Regulation on Data Portability (GDPR)<sup>1</sup> gives European citizens the right to a digital copy of all personal information. We cannot collect, compile, curate and interpret, or control health data from multiple institutions, and systems, nor get a good overview and understanding of its implications.

We witness an gradually complex information and communication reality in contemporary health care. Increasingly, citizens are granted access to personal health information, for example by patient portals and subset of the EHR like patient summaries, medication and ePrescription. We use IoT type gadgets and devices to keep track of selected parameters for activity, exercise, diet etc., and secure video-conferencing has opened convenient channels for new forms of citizen – provider interactions. Furthermore, citizens keep track of selected personal observations (ODL – Observation of Daily Living) and care outcomes (PROM – Patient Reported Outcome Measure). To ripe the full benefit, the citizens should be an active resource in their personal health and information management. They deserve the appropriate tools and services.

Recently, the EFMI Council accepted our proposal for the WG “Citizens and Health Data”, and we invite to discussions to leverage and converge activities where use of

personal health data support sense-making, empowerment, engagement, independence and thrive. Digital health literacy is a premise for these activities.

### **1. The focus of this workshop**

For this workshop, we will zoom in on Digital Health literacy, and in particular engage in a discussion of experiences and strategies to ensure capacity to interpret, comprehend, make sense of personal health data. Our hypothesis is that citizens wish to engage if novel functionality that help comprehend and ease their personal health concerns is available. If supported by digital health literacy efforts and interoperability standards there is tremendous potential to accelerate health care transformation and personalize care across Europe and internationally.

We will invite the ICIMTH community to discuss if and how opening up for active use of accumulated personal health information from multiple sources, will mobilize the citizens in personal prevention and early interventions, increase adherence to suggested treatment and overall engage and empower us all.

### **2. Organization of the workshop.**

We will give a 30-minute section to introduce core concerns for discussion in the workshop; digital health literacy, citizens engagement, opportunity to collect, curate and control personal health information and examples of efforts to open up for citizens' active use of available information. Then there will be a 45-minute discussion with the ICIMTH community on the potentialities in citizens engagement and in particular how to approach and build capacity to increase digital health literacy. The workshop will end with a 15 – minute sum up of the discussion and suggest next steps for digital health literacy for all.

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<sup>i</sup> EU (2016): REGULATION (EU) 2016/679 on processing of personal data and on the free movement of such data.