Concept note for addressing adolescents’ access to electronic health records in an ethical and developmentally appropriate way

Background

Security and privacy of online medical records have or will likely become a global issue for patients of all ages. As healthcare systems transition from use of traditional written medical records to the use of electronic medical record systems, a complex set of challenges emerge [1,2]. One core challenge is the use of online systems granting continuous access to personal medical health data from electronic health records (EHRs). In countries using patient-accessible electronic health records (PAEHRs), there are wide variations in policies, regulations, and strategies intended to preserve security and privacy while also supporting patient access to health information. For example, within the European Union, there are wide variations in national policies regarding the level of access and types of restrictions in place for health care professionals and patients in accessing EHRs [3,4]. To help inform national policies, the World Health Organization (WHO) calls to develop global minimum standards for EHRs [1].

Within this context, it is important to focus on groups of patients who may have unique benefits and risks associated with medical information sharing via online medical records. Adolescent patients represent such a group. It has been raised that without affirmative action digital technologies can perpetuate disparities, and that the legal obligations that arise under the right to health framework, the same rights that are protected offline - such as non-discrimination, equality, participation, accountability, reparations and privacy - must be protected with the use of digital tools and in online spaces [5]. This shall apply to EHRs as well.

The current cohort of adolescents have been raised in environments typically associated with ready access to electronic technologies with multiple opportunities to develop skills using electronic systems. Work to understand adolescents’ perspectives on security and privacy of online medical records is under way [6].

Problem statement

It is only a matter of time before EHRs will be established across most of the globe. Policy efforts are under way to ensure that EHRs contribute to people-centered health systems, public trust in digital health technologies is strengthened, digital health literacy at the population level is fostered, and awareness of patients’ rights raised. One should not, however, assume that these efforts would automatically benefit adolescents. In fact, digital technologies can perpetuate discrimination [5], and if adolescents are not taken into consideration when electronic systems are designed there is the potential of harm [7]. The harm might be related to the violation of several rights stipulated by the Convention of the Rights of the Child [8]:

Art. 2: Non-discrimination: adolescents might be unnecessarily restricted from accessing and using the information in their EHRs on the basis of “immaturity”

Art. 3: Best interests: restricting adolescents’ right to decide who else sees their record might be harmful in the possibility of violence from the parent/guardian that might see the information about services related to sexual and reproductive health

Art. 12: Participation / Right to have one’s views expressed freely (in accordance with the age and maturity of the child): managing own health information is an important expression of the right to participation

The principles of medical ethics such as beneficence, nonmaleficence, respect (autonomy) and justice are also at risk of violation if policies in relation to adolescents’ access to EHR are not informed by science, and guided by these principles [9].

Within the wide variations in policies, regulations, and strategies that countries put in place with regards to patents’ access to EHRs, adolescents are an invisible group. Yet there are critical questions that need to be answered and that can only be answered by taking a developmental perspective to access to EHRs. Examples of such questions include:

- How and when adolescent consent to continue or not with the EHRs (which was established with the parent/legal guardian consent)? As recommended by WHO, a developmental perspective would have to take into account adolescent cognitive, emotional and social maturity, rather than age, into account, to answer this question [9].
- At which age, and under which circumstances, can adolescents have full control of their EHRs? Is age to be considered at all as a proxy for maturity, or should we opt in each case to assess the capacity for decision making [9]?
- How is a shared access between adolescent and parents/legal guardian handled?
- Does the level of access differ depending on the task involved in dealing with EHRs? The list of tasks includes but is not limited to: see and read the information; edit information; copy-paste/share information with others; having the right to enable or disable who else sees the information. Those are discrete tasks, and having the right to do one task (e.g. read the information), does not automatically means having the right to perform other tasks (e.g. copying and sharing the information)
- Does the level of access depend on the contents of the EHRs? For example, it has been reported that adolescents perceive the content related to sexual and reproductive health and mental more sensitive than the other [6].

The guidance

WHO intends to produce a guidance to countries summarizing ethical principles and developmentally appropriate approaches in putting in place policies with regards to adolescents’ access to EHRs from a human rights perspective. The aim of the guidance would be to support policy makers in adolescent health care, health care professionals, advocates, adolescent patients to advocate for, and support the implementation of, developmentally-appropriate solutions for adolescents access to EHRs.

While the primary focus of the guidance will be on adolescents, we will envisage to extend the scope of the guidance to younger children. This will be decided at a later stage after deliberations between the members of the Technical Working Group (see below).

As part of this project we want to establish a global Technical Working Group (TWG) that will support WHO during the process.

<u>The process will involve the following steps:</u>

1. Establish a global Technical Working Group (TWG) including adolescents/youth, researchers, policy makers with expertise in EHRs and digital transformation, technical experts in human rights, ethics and adolescent psychology, health and development.

2. First virtual meeting of the members of the TWG to (i) establish the group (ii) plan the process and research necessary to be conducted to inform the guidance (iii) finalize the terms of reference of the group, and (iv) review the project’ timelines

3. Evidence review.

3.1- Conduct systematic review(s), and summarize results, on current practices of how access to EHRS is dealt with, including sub-analyses (i) specific considerations for adolescents; (ii) considerations in function of the task involved (e.g. viewing the information, sharing the information, deciding on who else access the information, etc.).

a. Peer reviewed literature

b. National policy documents and other grey literature

c. Regional policy frameworks (e.g. EU/EC directives on digital health) and recommendations from professional associations

d. Human rights instruments and relevant treaties

e. key technological features of EHR that may interfere with the future recommendations regarding sharing, editing, locking an unlocking the information

f. Global guidance for digital health (including by WHO, ITU and other relevant agencies),

3.2 - Global survey with adolescents around their views on security, privacy and other aspects of online record access

A background report summarizing the results of the evidence review and global consultation with adolescents will be prepared ahead of the second meeting of the TWG (step 4). The background report will be prepared by a subgroup of members of the TWG

4. Second meeting of the TWG (Face-to-face) to (i) discuss the background report, (ii) recommend developmentally appropriate approaches to policies regarding adolescent' access to EHRs (iii) develop an annotated outline for the guidance

5. Synthesis of current practices and recommendations by the TWG in the report from the meeting.

6. Iterative drafting and finalization of the guidance, write-up of the manuscript(s)

7. Translation in WHO official languages and dissemination:

   a. publishing manuscripts resulting from the scientific output of the project

   b. engaging with relevant communities for dissemination and policy influencing

   c. dissemination at high profile events and scientific fora

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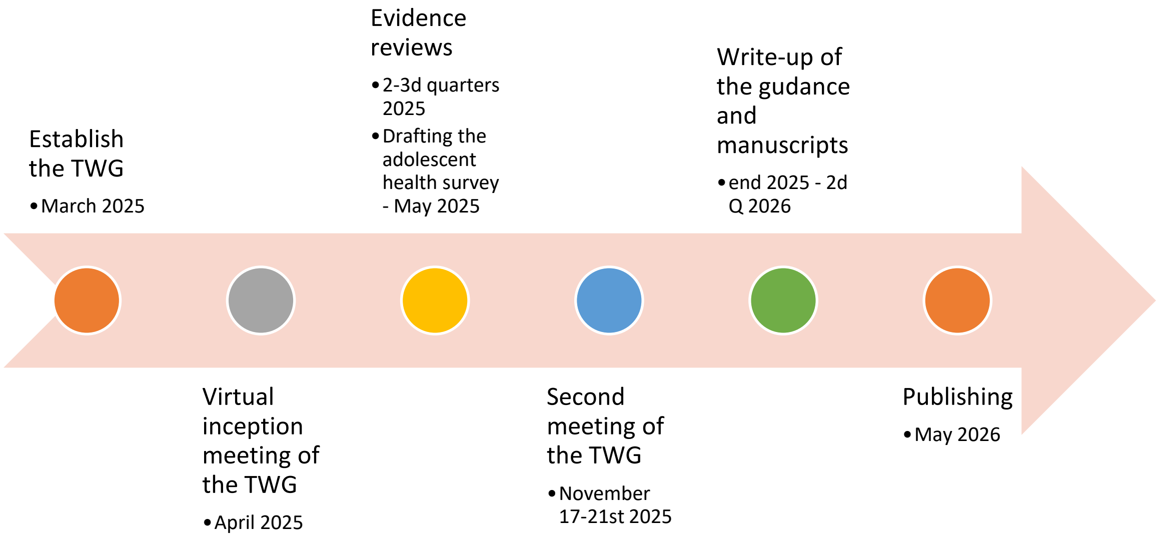
Timelines



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