



ICT PSP – Empowering patients



Support USers To Access INformation and Services

Draft User Requirements Recommendations

The shift toward participatory medical recordkeeping involving healthcare professionals (HCPs) as well as patients poses indeed major challenges not only in relation to the need to integrate patient access features into already existing Electronic Health Records (EHR) that were not designed to be shared with patients and citizens at large, but also in relation to the way health information produced by HCPs is presented.

52 patients/citizens and 42 HCPs participated in the eight user requirement focus groups organised in eight countries/regions involved in the SUSTAINS consortium (Aragon, Basque Country, Central Greece, Estonia, Slovenia, South Karelia, Uppsala County, and Veneto Region (Local Health Authority 8, Asolo)) to provide their views as regards patient's access to EHR and the wide array of online services built upon this access.

Except very limited exceptions, there was large agreement among patients and HCPs who participated in the eight user requirement focus groups implemented thus far that patient-accessible EHR and associated services, if properly designed and implemented, can present a window of opportunity for improving the quality of healthcare services. Likewise, there was



large agreement on the fact that these services could make a major contribution in terms of ensuring the continuity of care through more regular contacts between patients and HCPs.

All patients and the large majority of HCPs reached out through the focus groups agree that withholding access to EHR to patients is no longer an option. The SUSTAINS services are regarded by the user representatives that participated in the eight focus groups as an important and necessary innovation in healthcare that can no longer be held over. Interestingly, no HCP explicitly reported that patients and more generally citizens at large should be fundamentally denied such access.

Overall, both patients and HCPs were largely positive towards the idea of granting access to EHR to patients and the introduction of the various online clinical and administrative services being introduced in their country/region. Patients are particularly pleased that in the near future many aspects relating to their healthcare and management of their health condition could be dealt with through the Internet through the patient portal.

Both user groups (i.e. patients and HCPs) in all eight regions put forward a number of recommendations to local developers to improve the quality and usefulness of the envisaged services, emphasising in particular the need to ensure that all relevant information is made available in EHR and can be easily retrieved through effective user-friendly built-in search functions.

It was also clear from the various focus groups that there may be at the same time some potential issues surrounding patient-accessible EHR requiring thorough attention in order to ensure acceptance across the various user groups. Making sure that the SUSTAINS services do not undermine mutual trust among their users plays a fundamental role in that respect.

Interestingly enough, these focus groups showed that HCPs were in general more worried about the downsides of online sharing of health information for patients than were the patients themselves. Drawing on the outcomes of the eight focus groups it can, however, be argued that many of these issues could be addressed through ensuring adequate flexibility in terms of usage options, involving the patients in decisions regarding this usage, and last but not least, through tailored education materials, training, and user support for both patients and HCPs.

The results of the focus groups highlight the importance of ensuring that the SUSTAINS services contribute to personalised healthcare. To that end it is crucial that users are reassured the services have been designed starting from the needs and preference of patients and not the other way around.

While the focus groups confirmed that user-centred design is crucial to fostering acceptance, another major element health authorities and service developers need to thoroughly consider is the way these services will ultimately affect patient-HCP relationship. All this suggests that findings regarding service usability, accessibility of EHR content, as well as the wide array of security-related issues discussed in the focus groups need to be thoroughly considered in the design of the SUSTAINS services.



The outcomes of the focus groups also indicate that HCPs need to be playing a key role in informing the citizens and patients about the SUSTAINS services, because citizens and patients trust their HCPs much more than advertisements. The focus groups also tell us that patient associations should also be playing a role in informing patients about the availability and benefits of the services through their bulletins, e-mails and member meetings. The involvement of patient and HCP organisations throughout the project life-span and beyond is therefore largely encouraged.

Although discussions regarding the “content” of the EHR, i.e. what types of medical and extra-medical information should be available in the EHR to the patients, are beyond the scope of the SUSTAINS project, the latter’s remit being to focus on issues around patient access to already existing records, the project team believed it was extremely important to obtain feedback from the user community regarding the information patients (as well as HCPs) should be able to access. Alongside putting in place all features required by the shift towards participatory medical recordkeeping, all SUSTAINS countries / regions are also discussing: a) what additional information needs to be included in the EHR; b) whether this information should be accessible to patients in its entirety or whether an approach whereby only relevant documentation becomes available to them should be favoured instead. Given the importance of this to user acceptance the issue discussions on the content of EHR was included as a topic for the focus groups in all country / regions.

On the basis of the outcomes of the focus groups a total of 44 general recommendations have been formulated. These are addressed to the countries / regions participating in the SUSTAINS projects as well as to any other country / region considering opening up the EHR to the citizens.

On top of that 284 context-specific user requirement-related recommendations have been collected through the eight focus groups.

General user-requirement recommendations on patient accessible EHR

Recommendation 1

Pay thorough attention to ensuring that services and interfaces effectively respond to the different requirements and constraints of targeted users in order to eliminate barriers to use. Specific attention needs to be paid to the needs and constraints of older people, people with physical and/or sensory disabilities, or people with little familiarity with new technology, Internet, and on-line applications.

Recommendation 2

Take into account the changing needs of patients who are losing capacities due to aging or worsening of their health condition.

Recommendation 3



Ensure the availability of easy to use filters to enable users to easily and quickly retrieve information they need from the EHR. Retrieval of information should be quick and intuitive, including to people who will not use the services regularly or may have limited capacity of remembering how to perform tasks within the system.

Recommendation 4

Set up a help desk available to provide technical assistance to all users in using the portal whenever they encounter problems or need support to perform actions within the system.

Recommendation 5

Produce and update regularly user manuals and videos explaining and showing citizens and patients how to use the services and navigate through the system.

Recommendation 6

Provide ways for individual users to flag up usability issues relating to navigation, retrieval of information, layout and design, contrast, font size, and colour of background and text and ensure these are followed through accordingly, through either available user support or improvement of the portal whenever needed.

Recommendation 7

Streamline the user account activation process and put in place different channels for opening a new account when it is not possible to do so on-line.

Recommendation 8

Ensure that user identification and authentication processes are as easy and user-friendly as possible.

Recommendation 9

Regularly involve users, including old people and people with reduced sensorial capacities and low health and/or IT skills, to seek feedback on service usability and improve available services accordingly.

Recommendation 10

Ensure that medical documents available in the EHR are compiled according to standards but with a language and a terminology that is as clear as possible in order to prevent bad interpretations or imprudent self-diagnoses made by the patient.

Recommendation 11



Establish information points consisting of “health educators” who are available to explain the content of medical reports or other type of health information available in the EHR to patients.

Recommendation 12

Provide ways for individual users to flag up issues relating to EHR content accessibility and ensure these are followed through accordingly.

Recommendation 13

Embed links to credible health educational sites in the patient portal and/or create and regularly update a glossary providing lay-man friendly explanation of medical terms.

Recommendation 14

Provide training for HCPs on how to maintain medical records in a participatory record-keeping environment.

Recommendation 15

Regularly involve patients, including those with low health literacy levels, to assess accessibility of information available in the EHR.

Recommendation 16

The citizen shall be in control over who should be able to access his/her EHR.

Recommendation 17

Ensure that procedures for granting consent are simple, clear, and transparent and make sure the citizen finds it easy to: a) check who he/she has granted access to their records; b) make changes regarding HCPs who will or will no longer be granted such access.

Recommendation 18

The citizen shall have the possibility to withhold consent for certain HCPs to access EHR or a portion of EHR.

Recommendation 19

Health information falling within the category of personal health data as defined by national legislation shall be generated as masked information. Only the citizen shall be able to decide whether to unmask this information to one or more HCPs.

Recommendation 20



The citizens shall have the possibility to mask information other than sensitive data to either individual or all HCPs.

Recommendation 21

Patients and citizens shall be educated about the consequences of HCPs' not having access to vital information about the health status of an individual. Information about risks of masking data other than sensitive personal data shall be provided in the user interface. HCPs should also play a major role in informing citizens and patients about such risks.

Recommendation 22

Make sure the system warns the patients any time he/she tries to mask certain information other than sensitive data from the EHR to one or more HCPs about risks involving in performing this action e.g. through a pop-up message. It is recommended that a standard message is agreed by the SUSTAINS consortium to be translated and used in all eleven countries / regions participating in the project.

Recommendation 23

For the sake of patient safety, in case of emergency any HCP should be able to access EHR. In those cases it is recommended that emergency services be granted access to an edited version of the EHR with restricted access to highly sensitive content (e.g. sexual health, abuse of alcohol or other substances, mental health, or termination of pregnancy) and ensure such access is notified and properly justified to the citizen.

Recommendation 24

Establish clear rules on access for HCPs who do not have a direct therapeutic relationship with the patient.

Recommendation 25

Ensure that privacy policy and confidentiality measures are fully understood by the user upon opening a new account and make sure the citizen has the always possibility to request and obtain clarifications in a timely manner regarding such measures.

Recommendation 26

Educate users, especially people with little or no familiarity with online services, on how to preserve the privacy of their EHR account, paying particular attention to how safely sign off from the portal and the importance of not sharing passwords. It is highly recommended that security-related information and support be easily available to users.

Recommendation 27

Upon creating a new account always ask the citizen if he/she wants to be notified every time a HCP access his/her records.



Recommendation 28

In case of access by unauthorised users in circumstances other than emergency, in which cases exceptional access right is automatically granted by the system, both the citizen and the entity responsible for managing and supervising the system must be notified immediately.

Recommendation 29

No matter the solution implemented the citizen shall always have the possibility to request who accesses his/her records.

Recommendation 30

Define clear rules regarding access of minor's EHR by parents. Local service developers are strongly encouraged to seek advice from local legal authorities and ethical committees regarding how these situations should be handled.

Recommendation 31

Given the importance of users' perception on the effectiveness of security measures for large scale up-take and acceptance of patient-accessible EHR, authorities in charge of developing and supervising the SUSTAINS services are strongly recommended to thoroughly assess how confidentiality-related aspects in online sharing of health records are perceived by citizens and HCPs at the end of the project.

Recommendation 32

Upon creation of a new account ask the citizen how he/she wants the information to be handled, i.e. whether he/she wants to wait to have any information from the HCP first or to have it immediately available in the EHR.

Recommendation 33

When it comes to abnormal results the citizen shall always receive this information from a HCP first unless he/she explicitly requested to have any information, including "bad news", immediately available in the EHR. In the latter case always make sure the person is aware that it is highly recommended that abnormal results be first reviewed and discussed with a HCP.

Recommendation 34

It is recommended that a scale for assessing the seriousness of a diagnosis / lab test results is developed to help determine whether this information can be made available to the patient in the EHR without prior consultation with a HCP. It is however highly recommended that the treating physician decides whether a medical report a consultation with the patient is needed before the latter becomes available to the patient in the EHR.



Recommendation 35

A HCP should always be able to “temporary screen” information in the EHR he/she believes must be communicated to the patient by him/herself or another HCP on his/her behalf.

Recommendation 36

Regardless of the approach, it is highly recommended that diagnoses as well as tests results once available in the EHR include thorough explanations in a layman-friendly language.

Recommendation 37

Local authorities in charge of the services are invited to further discuss with user representatives how best to ensure that patient entries contribute to the quality and completeness of the EHR.

Recommendation 38

Provide clear guidance for citizens regarding uploading of medical reports and laboratory test results done in other institutions, paying particular attention to how and where to locate new files within the EHR.

Recommendation 39

Make sure the system includes features allowing the citizen to report any error he/she spots in the EHR requesting such errors be rectified in a timely manner.

Recommendation 40

Envisage the introduction of features allowing the citizen to report comments and personal opinions in the EHR. Since there still are concerns among HCPs regarding the effectiveness of this feature it is recommended that this type of patient entries be piloted and assessed before making it available to all users.

Recommendation 41

The citizen should have the right to decide which information they wish to see in the patient portal.

Recommendation 42

Thoroughly assess the impact of patient accessible EHR on patient-HCP relationship at the end of the project in order to ensure that mutual trust is not undermined as a result of online sharing of health records.

Recommendation 43

With specific reference to the service offering citizens the possibility to ask questions online to their treating physicians and nurses it is strongly recommended to define protocols to



ensure that this service is used properly by the citizens, but also to ensure that the latter have instant access to the relevant HCP in case the matter is urgent.

Recommendation 44

Give HCPs the possibility to add and screen complementary notes in the EHR.

Recommendation 45

Authorities responsible for the SUSTAINS services are invited to carefully assess the impact of patient-accessible EHR on access to healthcare in order to ensure that existing health inequalities are not ultimately exacerbated by the introduction of these services.