Needs for Open Interfaces in Personal Health Record Systems and Citizen eServices – Results from a National Survey

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Abstract

Electronic services for supporting self-care, personal wellbeing management, communication between citizens and service providers, and citizen-centric care processes are developed in many countries and initiatives. Interoperability between these services and between them and information systems for service provision is increasingly needed. Open and standardized interfaces to support such interoperability must be selected or specified according to the needs of stakeholders in each project and environment. We report the results of a national survey related to the needs of open interfaces for self-care, citizen services and personal health records. The survey was performed using a web-based questionnaire focusing on the needs for open interface specifications. Interface needs were classified in nine categories. Respondents (n=23) represented health care solution providers / vendors, health service providers and research organizations. The majority of answers regarding the interface needs were in the category "great need for open interface specifications". Most highly ranked were the interfaces for personal health record (PHR) information exchange and various needs related to identity and access management and care processes. The results are used as one basis for selecting topics for national collaboration related to open interfaces for self-care, personal health records and citizen-centric care pathways.

Keywords: consumer health information, eHealth, health information management, personal health record

Introduction

Electronic services (eServices) for self-care and supported self-care are increasingly developed to support patient or citizen empowerment and to extend the focus of health from care towards prevention and holistic well-being. In addition, health and communication needs between citizens and health service providers and service pathways are increasingly being facilitated by electronic tools and services. The development of such eServices has been proposed as a partial solution to organizational productivity issues and workforce constraints, but there is also a public demand for citizen-centric services and empowerment of citizens [1-3]. This leads to increasing needs for integration and interoperability between different electronic services, devices and systems. Self-care services and communication of citizens with service providers can be supported through interfaces between different systems and services. These interfaces should be open and standardized to increase the compatibility of solutions developed in different settings. However, the specification and agreement of open interfaces requires effort which should be directed towards the most useful features. These are features which are needed by a number of different solutions, services and products.

Despite many available standards and their implementation guides for care documentation and care processes, interfaces for personal well-being and self-care have not traditionally been the main focus area of standardization or open interfaces. Standardization efforts have mainly focused on the needs of care providers and their systems.

In this paper, we report the results from a national-level survey related to the needs of open interfaces between different services and systems related to self-care, citizen / consumer services and personal health records. The main goal of the survey was to identify the needs and the most potential candidates for the selection or development of open specifications and standards to support personal health. The scope of the survey covers citizen eServices which are provided to support electronic communication between citizens and health service providers, self-care and personal health promo-

tion. Personal Health Records (PHRs) [2] are one topic area of the survey, but also other services such as electronic booking [4] and various platform services are included in the study. There are many different components and services which have already been implemented to support self-care and communication between citizens and service providers [5]. However, most of these services have remained somewhat isolated, specific to one service provider or have been tightly coupled to systems used for the provision of services. This can be seen as an obstacle when new citizen-oriented and personalized service packages or client pathways are pursued. Thus, the results from a survey of most concrete needs related to interfaces between various components should also be useful as guidance for the specification of this emerging area.

Although interfaces and interoperability are a historically a challenging and widely studied area in the field of healthcare informatics [6-8], there have been few exploratory studies in personal health interoperability and interface requirements. We found no other surveys regarding the needs for open interfaces in this scope in Finland or internationally.

In 2010, a similar survey for health IT stakeholders in Finland which also included expert interviews. That survey was concerned with interoperability requirements related to the Integrating the Healthcare Enterprise (IHE) profiles. It did not, however, concern in the needs for interfaces from the viewpoint of this study [9].

Also in 2005 Kubicek et al have studied the interoperability in electronic government (eGovernment) and the information needs in their survey. This is also a close and interesting study but still it does not cover the issues regarding our study. [10] The early experiences with personal health records has been previously studied by Halamka et al [11]. Their study raises similar issues as our study, especially the importance of interoperability and security have been noted. Finally there are several studies highlighting the need for coordinated development in multivendor systems [12-14]. All of these studies seemed to support the need for this type of survey for open interfaces.

Methods and materials

The goals of the project were defined and refined in HL7 Finland association in 2012-2013 jointly by the authors, the board and the technical committee of the association, representing many system vendors, user organizations and authorities who have interest on standards and open interfaces. A choice was made to mainly survey the development community of solutions and services instead of the user community, since the developers and specification experts have detailed knowledge of interoperability and interfacing requirements of the solutions. We estimated that a survey-study concerning the needs for open interfaces for healthcare systems did not have any major ethical concerns at this point of research. Possible ethical and legal concerns are different in different projects and interface needs in further implementation and specification phases.

The study was designed as a descriptive survey, but in addition some open questions were included to receive qualitative results. A web-based survey questionnaire in Finnish was designed which included various different areas of integration needs. Specific candidates for integration needs were identified from several sources. These included available international standards and work products in progress by HL7 International[1], ISO TC 215[2] and IEEE[3], integration profiles from IHE (Integrating the Healthcare Enterprise) technical frameworks[4], design guidelines of Continua Alliance [13], reports and publications from five previous or adjacent projects in Finland (MyWellbeing, eKat, SAINI, FeelGood, Mind and Body), available interface documentation from PHR platforms such as Taltioni[5] and HealthVault[6], and reference architecture and documentation for citizen eServices from the national SADe programme in Finland. In addition, a functional reference architecture for citizen-centric electronic services [5] was used for the identification of additional service candidates and for supporting the grouping of different types of needs.

The majority of questions in the questionnaire were designed to focus on the needs of different interfaces instead of names of existing specifications or standards. This strategy was followed to enable responses without detailed a priori knowledge of specific standards. For example, the names of various implementation guides of HL7 CDA standard (e.g. for personal health monitoring using personal health devices, for patient summaries or for national EPR documents) were not used, but the need in question was described using generic names of informational contents or functional use of the interfaces. Interfaces between professional systems were excluded from the study. Some standards, however, can be used both for interfaces between professional systems and citizen eServices.

The resulting set of 53 questions was grouped in the following nine categories:

- Interface needs related to personal health records (PHR) information transfers,

- Interface needs related to home measurements,

- Interface needs to support platform and security functionalities such as authentication, federation and consent,

- Interface needs related to collaboration between service providers and citizens such as service directories, preliminary information delivery for appointments, virtual health checks and health surveys,

- Interface needs for electronic booking of services,

- Interface needs related to service processes such as waiting lists, status queries of case management, reminders, laboratory results, customer feedback etc.,

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[1] http://www.hl7.org/

[2] http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_tc_browse.htm?commid=54960

[3] http://standards.ieee.org/findstds/standard/healthcare_it.html

[4] http://www.ihe.net/Profiles/

[5] http://www.taltioni.fi/fi/kumppanit/kehityssivut

[6] http://msdn.microsoft.com/en-us/library/jj573975.aspx

- Interface needs related to knowledge services such as citizen decision support, risk tests and calculators, etc.,

- Standardization of functional features and requirements of PHR systems, and

- Level of interest of the respondents to participate in national or international standardization activities in the field of the survey.

Translations for all of the detailed questions can be observed in the "Results" section, and the detailed questionnaire is available in [15] in Finnish.

For each question related to the need of open interfaces, the following options were given:

1. no need for open interface specification,

2. potential need for open interface specification,

3. great need for open interface specification,

4. interface needs have already been solved,

5. cannot answer

The survey also included open questions in different categories. The questionnaire was implemented as a Google survey. Along with a cover letter, the link to the questionnaire was sent to a mailing list which consisted of 249 individual email addresses from 93 organizations. The organizations included 50 companies providing health IT services or products, 30 health service provider organizations (public, private and third sector), and 13 association, authority or research organizations. The recipients were gathered from two main sources: membership directory of HL7 Finland association (to include people and organizations with interest in open interfaces) and mailing lists of two national programs / projects dealing with electronic PHR or citizen services (to include people and organizations with interest in personal health records and citizen services). The national initiatives included were the participants of national SADe/SoTe program workshops (with permission from the National Institute of Health and Welfare) and the members of health ecosystem workstream in Mind and Body research program in which the authors participate. This set of recipients was estimated as a repre-

sentative sample of the national eHealth solutions development community. The questionnaire remained open from June to August in 2013.

The responses to the questionnaire were collected and analyzed using Excel. Summaries for all questions related to interface needs, as well as summaries of open questions were produced. The responses were analyzed for each specific integration need, in relation to group of related needs, and as a whole.

As a part of the study, available candidates for standards and specifications were also studied. This paper, however, focuses on the results of a survey which investigated the perceived needs of open interfaces in Finland for personal electronic health services.

The results of the project, including the results of the survey, were published in a summary report in Finnish in December 2013 [15]. Prior to the publication, it was ensured that no individual respondent could be identified from the published summaries or answers.

Results

We received responses to the questionnaire from 23 individuals. Two responses did not include organizational affiliation. Affiliated respondents were from 17 different organizations (some organizations had more than one respondent). Some responses and queries indicated that in some organizations the responses represented the collective view of more than one individual. Calculated response rate on individual level was 9% and on organizational level 18%, but it should be noted that in some organizations the email address of the respondent was not the same as the recipient of the questionnaire link. Eight out of 17 affiliated respondents were from companies providing IT services or systems. Eleven out of 17 were from service provider organizations (including public and private service providers). Two respondents were affiliated with research, association or national authority organizations. In the following figures 1-8, we report the summaries of responses in the main categories of the survey. Each detailed question of interface needs is included, and the

caption numbers indicate the number of question in the original questionnaire. The abbreviations for Electronic Patient Record (EPR) and Application Programming Interface (API) are used in figures. The results are discussed in the next section.

Figure 1 presents the results of the survey from the category *Interface needs related to personal health records (PHR) information transfers*. The results from this category show that especially the *Information transfer from EPR to PHR, Information transfer from PHR to EPR, Single sign-on interface for services on PHR platform* and *"Download my data" interface for citizen's personal data from provider interfaces* were seen as necessary.
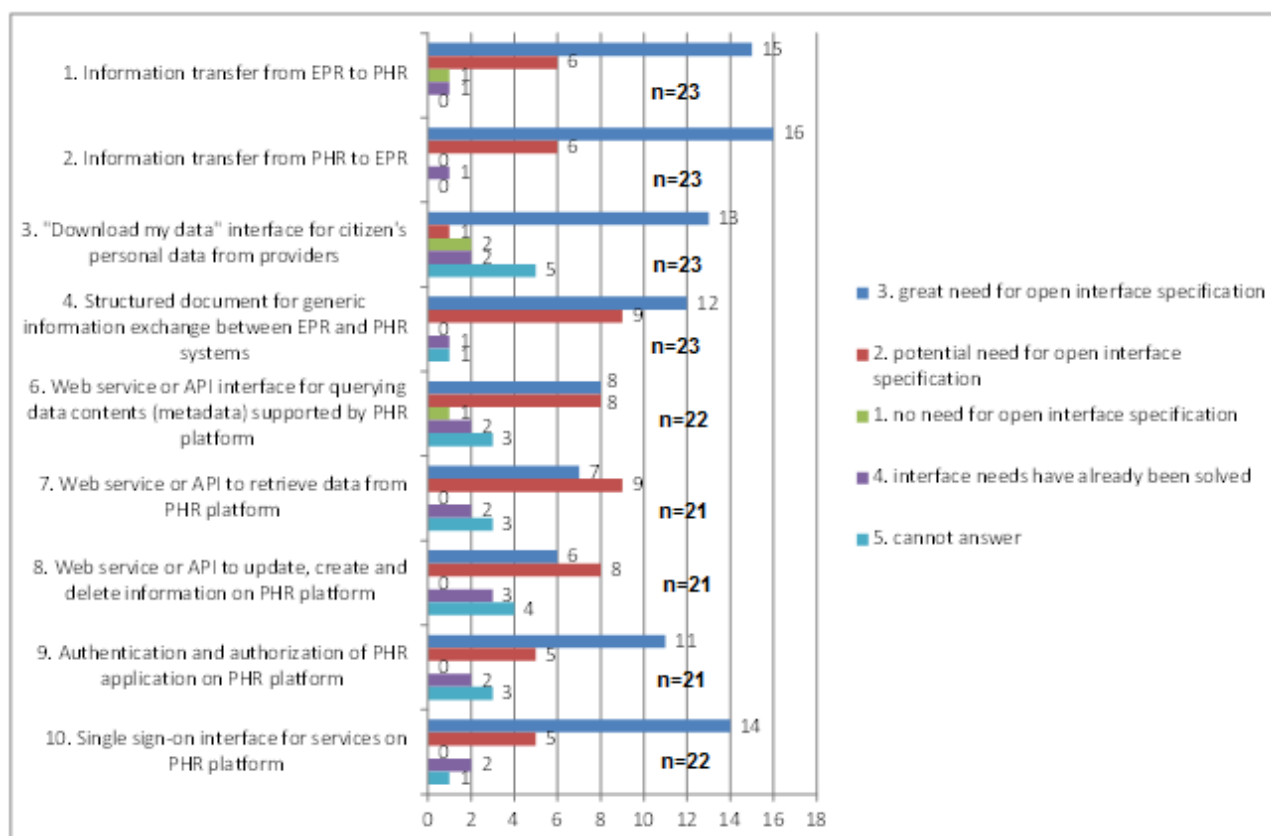
Figure 1. Interface needs related to personal health records (PHR) information transfers.

Figure 2 presents the results of the survey from the category *interface needs related to home measurements*. The results from this category show that especially the *Personal (manual) data entry interface to EPR system* and *Home measurement device interface to EPR system* were seen as necessary, but also other needs were seen almost as important.

Figure 3 presents the results related to the interface *needs to support platform and security functionalities*.

These results show that especially *Delivery of consent given by the citizen, Interface for acquiring authorization information of delegates acting on behalf of the citizen* and *federated authentication and identification between citizen services* were seen as necessary.
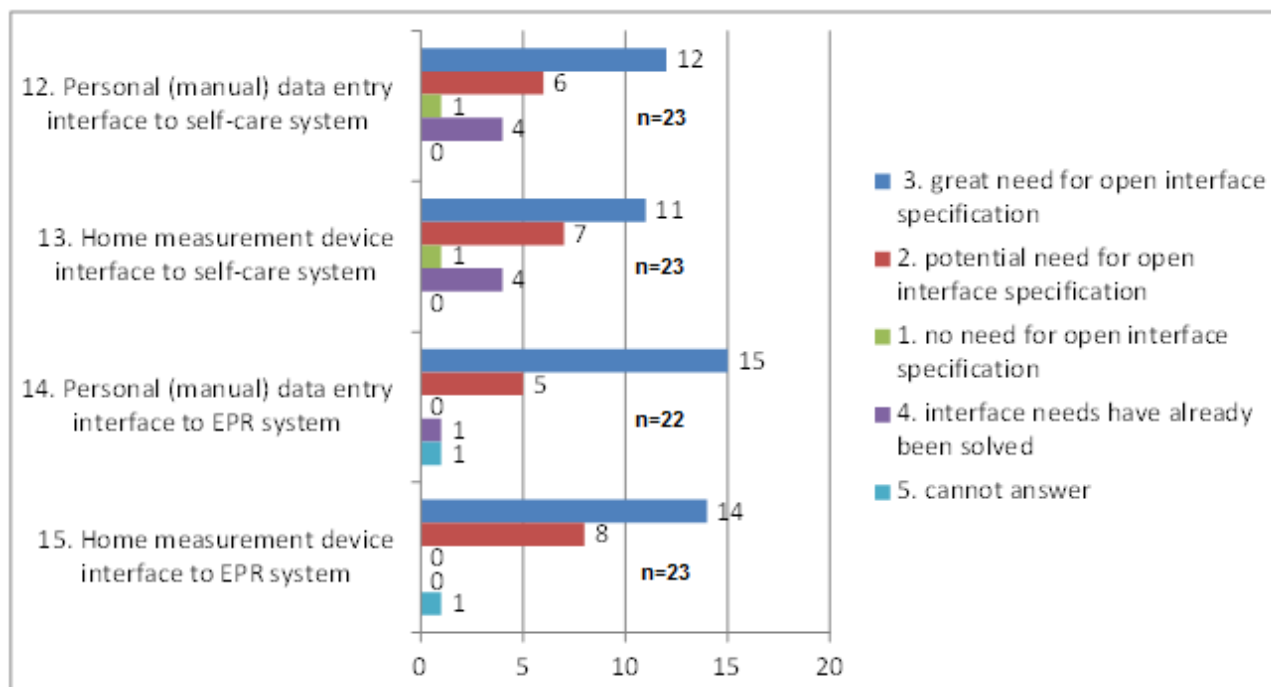
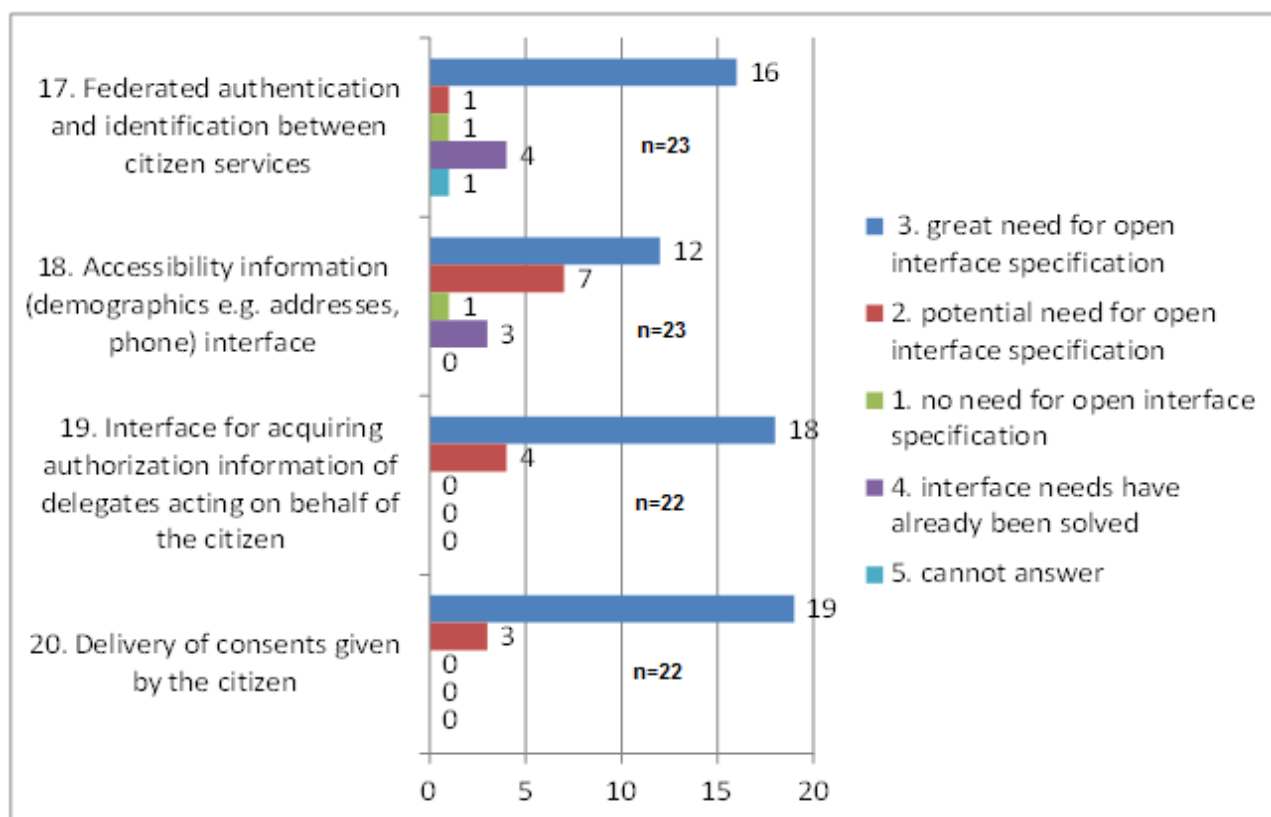**Figure 2.** Interface needs related to home measurements.

Figure 3. Interface needs to support platform and security functionalities.

Figure 4 presents the results of the survey from the *interface needs related to collaboration between service providers and citizens* category. The results show that especially *the interface for acquisition of preliminary information for encounters* and *service directory query interface* were seen as necessary.

Figure 5 presents the results of the survey from the *interface needs for electronic booking of services* category. The results show that especially *the interface for delivery of appointment booking information / confirmation to the citizen* was seen as necessary, but also other interface needs received lots of "great need" responses.

Figure 6 presents the results of the survey from the *interface needs related to service processes* category.

These results show that especially the first three interfaces were seen as necessary.

Figure 7 presents the results of the survey from the *interface needs related to knowledge services* category. These results show that there were no major differences between interface needs in this category: all were seen as necessary.

The figure 8 presents the results of the survey from the *standardization need of functional features and requirements of PHR systems* category. These results show that both interfaces in question were seen almost equally important, but these specifications did not receive as high expressions of needs in general as many interface specifications.
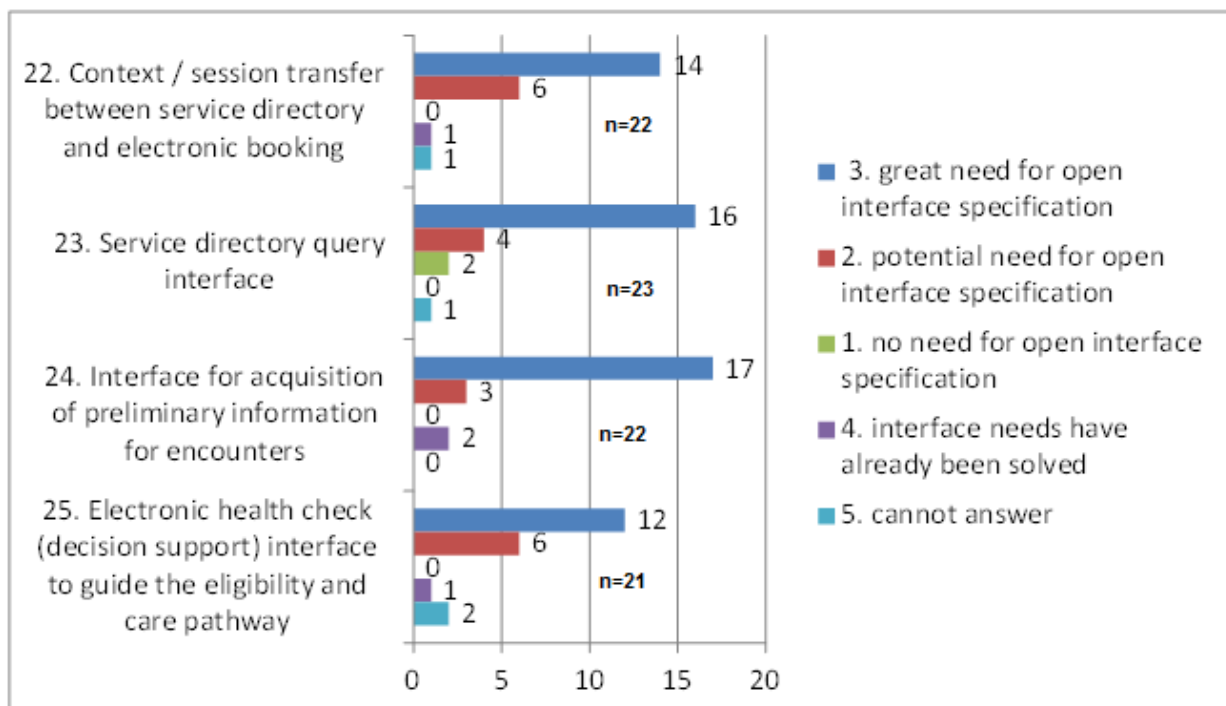

Figure 4. Interface needs related to collaboration between service providers and citizens.
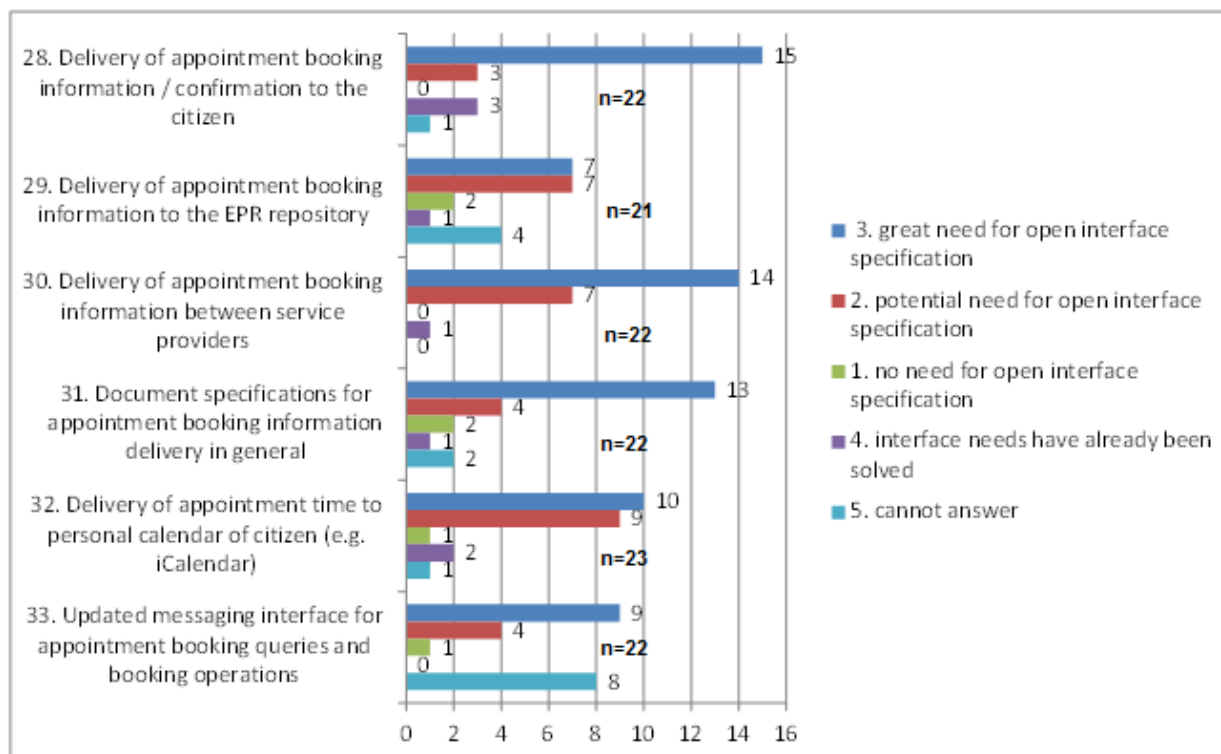
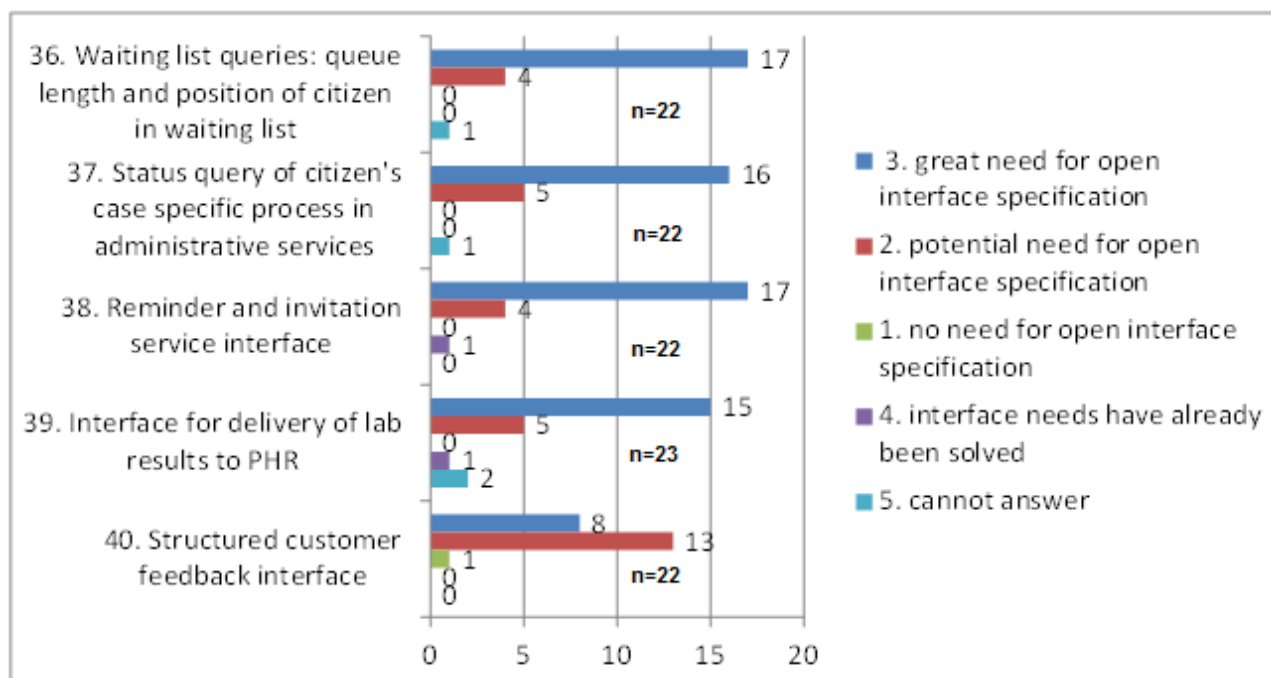**Figure 5.** Interface needs for electronic booking of services.

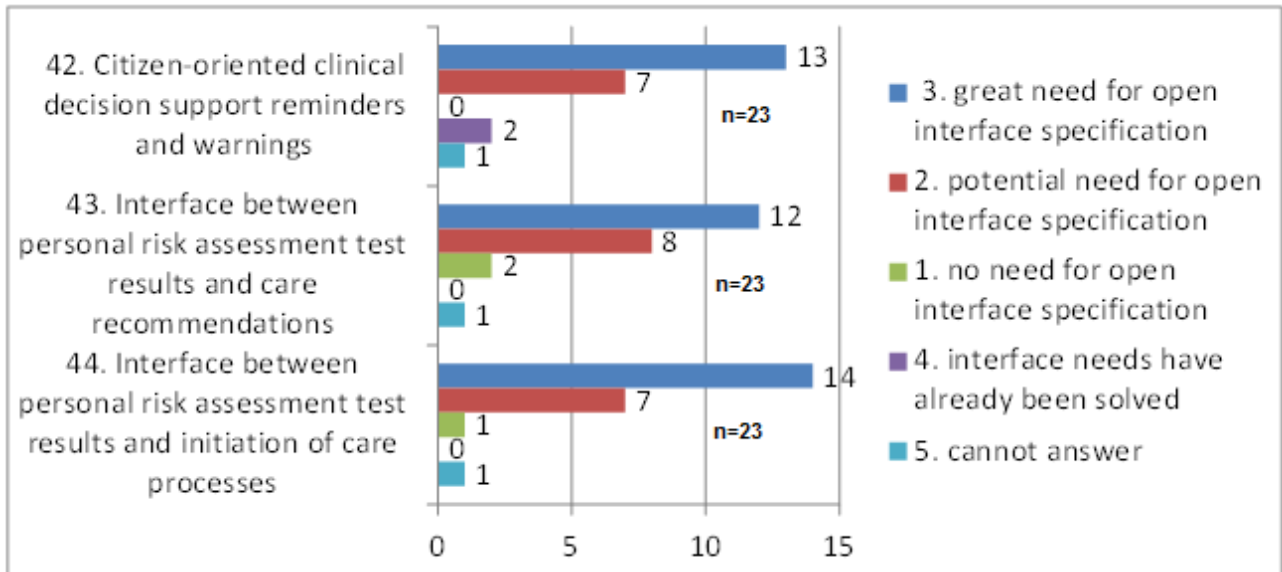**Figure 6.** Interface needs related to service processes.

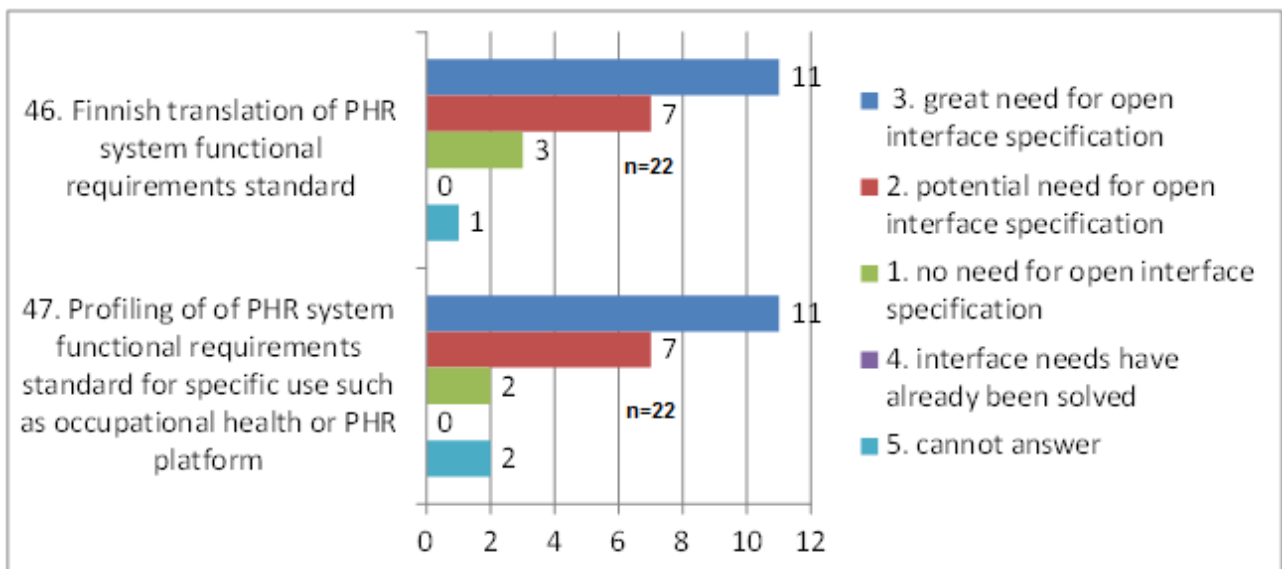**Figure 7.** Interface needs related to knowledge services.

Figure 8. Standardization needs of functional features and requirements of PHR systems.

In addition to the questions related to detailed needs of different types of interfaces and standards, the survey included questions on architectural choices for PHR integration and the level of interest of the respondents to participate in national or international standardization activities. In addition, open questions in end of each category provided valuable additional information on issues faced in relation to the integration needs. Ten out of 23 respondents were interested in national

standardization. Twelve respondents were interested in following the international standardization activities in the domain of the survey. The respondents also provided feedback to the survey through an open question, indicating needs to avoid overlapping integration activities, currently heterogeneous status of interfaces, and supporting generic idea of open standards and regional collaboration.

Discussion

The number of responses or respondent organizations, as was expected, was not very large. Only a subset of all the recipients of the questionnaire are actively involved in personal health record or citizen eService projects. Thus, care should be taken when interpreting the results. The number of responses for the survey does not satisfy statistical requirements, although response rates were moderate. The results, however, seem to strengthen the overall background hypothesis of the study: there are various needs for open interfaces in relation to electronic personal health and wellbeing services. To attract respondents we used open mailing list for the promotion of the survey. We can only guess why the number of respondents was not higher and also we cannot estimate how the persons not responding could have affected the results, thus in this study we did not evaluate the range of error.

Another limitation of the study is related to the selection of respondents: it can be argued that the selection of development community instead of user community only indirectly reflects the end user requirements despite the fact that many respondents were representatives of user organizations. However, the goal of the survey was to clarify and prioritize somewhat detailed needs for interfaces which requires understanding of solution architectures and interfacing efforts. Such knowledge cannot be expected from end users and clinicians in general, as successful integration solutions are often "invisible" to the users. In addition, the focus of questions on the functional requirements instead of technical specifications should also relieve this concern, and we believe the relative prioritization performed by the respondents genuinely reflects the requirements of users in various projects and organizations.

It should be noted that majority of questions related to concrete interface needs received many replies in option "great need for open interface specifications". Thus, it is difficult to draw any conclusive differences between many individual interface needs based on the results.

The "top ten list" of all questions related to interface needs reflects the heterogeneous nature of the needs. Ten questions which received most answers in option "great need for open interface specifications" include:

• three interfaces related to PHR information transfer needs,

• consent management,

• authorization of delegates to act on behalf of the citizen,

• reminder and invitation service interfaces,

• acquisition of preliminary information for encounters,

• status query for administrative case management (needed in many social services),

• service directory interfaces, and

• federation of identity between electronic services.

To some extent, this list may also reflect an organizational bias of respondents: several of these needs are seemingly related to provider-oriented or administration-oriented objectives of electronic services (such as securing the processing of personal data or streamlining the service provision process of a given provider) in comparison to citizen-oriented objectives (empowerment, personalization and personal wellbeing, coordination of processes across various service providers). This is reinforced by the following observation: the information needs of service providers ("getting information for the provider from the patient") received more acute needs than the opposite direction ("getting information for the citizen from the providers"). Differences, however, are not conclusive. The majority of questionnaire recipients' organizations provide social and health services or IT solutions / services to support the service provision and the needs of professionals. Only few concentrate on consumer products or services. However, the authors had no access to contact lists which comprehensively collect stakeholders related to the citizen or consumer viewpoint instead of service provision.

There are many existing standards and specifications which could be utilized in relation to the stated interfacing needs. Indeed, these specifications were an important starting point for the survey and the grouping of questions. Utilization or localization of any of these specifications, however, requires more detailed evaluation in relation to the regional or national requirements before the selection of a standard can be made. International standardization bodies and collaboratives increasingly consider personal health records and support for self-care and citizen communication in service provision. Conversely, there are several areas in which some models or specifications which have already been (or are currently) considered or specified in Finland could be used as a basis for international standards or specifications which have remained underdeveloped so far. These include eBooking, some personal health record interfaces / subsets of data, and care coordination.

The survey presented in this paper focused on "functional" needs related to various interfaces. Detailed semantic aspects such as data types, data structures, terminologies, vocabularies and code sets were not included as separate questions or areas. These aspects are, without doubt, of crucial importance for all interfacing needs and standards. We justify their omission in this study based on the fact that according to good design conventions of systems design and enterprise architectures, details of data representation (and information architecture) should follow the functional needs of the users (and business architecture), and not vice versa. Utilization of national and international standards in these aspects would increase compatibility with existing solutions, reduce overlapping work and increase the quality of specifications. The same rationale can be applied to use of standards in general, despite the fact that many countries rely on national terminologies and code sets which must be incorporated in the local implementation guides of international standards.

Some results of the survey can be discussed in relation to some international studies and recommendations. In many aspects the results of these studies support the findings of this survey. Halamka et al [11] have presented important issues from early experiences with per-

sonal health records and their research also shows many features which are also seen important in our results. Their study raises issues such as secure messaging, authentication, security issues but also specific sets of patient data such as medication, allergy list and problem list, diagnostic test result sharing or information exchange between citizens and care organizations. In addition, several studies have noted the importance of interoperability and security issues which were emphasized in the results. In addition to interoperability considerations of this study, issues which need to be addressed include privacy, reliability, and usability but also non-technical aspects such as consumer confidence and trust, lack of technology training and resistance to change. In a multivendor system the importance of coordinated development must not be underrated [12-14].

The report by Kubicek et al [10] studies the same issues as our study from a more general viewpoint, however they do not discuss the issues on detailed level. Our perspective aims to directly support the design and development of personal health interfaces in Finnish context. Naturally, when building and designing interfaces, we must see beyond the borders and also take the international points and existing models into account. Earlier interoperability requirements survey on IHE profiles [9] have not covered personal health issues, but it can be noted that also several IHE profiles are potential candidates for personal health interoperability needs.

As far as the utilization of results and further activities are concerned, many high-ranking interface needs of the survey are included in high-level plans or roadmaps related to national programs or consortia. The HL7 Finland Association, along with its various member organizations, has planned to provide a forum for discussion and collaboration on open interfaces through a special interest group (SIG) dedicated to personal health and eServices in 2014. An existing voting and reconciliation (standardization) process of the association can be utilized to ensure fair and open collaborative specification. The further possible standardization and collaboration activities, however, depend on the willingness and timing of active projects, service pro-

viders and companies which have current activities and needs related to interoperability and interfacing solutions. Regardless of these activities, it is expected that standardization and collaborative efforts related to electronic solutions for personal health will increase both on international and national levels.

Conclusions

The survey questionnaire sufficed to create some basis which is needed for informed decisions for the selection or specification of open interfaces and standards related to personal health records and citizen eServices in Finland. Several candidates for the most urgent or important open interfaces were received. The increased demand and drive towards solutions which increasingly empower citizens and emphasize wellness and prevention instead of sickness and care are likely to increase the standardization and collaboration activities for personal eHealth solutions. These trends and drivers can be identified both in healthcare services provision and in different consumer markets. Open and standardized interfaces are also a prerequisite for ecosystems which involve several different service providers.

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