A Reference Architecture for Personal Health Record Ecosystems

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The personal health record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider. (AHIMA)

Besides clinical health information, the PHR may include other information related to maintaining good health (sports, activities, nutrition, lifestyle, ...)
Business Ecosystem

An economic community supported by a foundation of interacting organizations and individuals - the organisms of the business world. This economic community produces goods and services of value to customers, who are themselves members of the ecosystem. The member organizations also include suppliers, lead producers, competitors, and other stakeholders. Over time, they co-evolve their capabilities and roles, and tend to align themselves with the directions set by one or more central companies. Those companies holding leadership roles may change over time, but the function of ecosystem leader is valued by the community because it enables members to move toward shared visions to align their investments and to find mutually supportive roles. 

PHR ecosystem stakeholders and business aspects

- **Consumers** - PHR users
  - Wellness device manufacturers: increasing product value
  - Employers: PHR utilisation for occupational health
  - Insurance companies: PHR as a tool for cut-down of reimbursements
  - Banks: authentication service provision
  - Policy makers, regulation, reimbursement: responsibility for public health
  - Health service providers: PHR utilisation in service provision
  - Public health infrastructure provider: EHR archive services
  - IT service providers: PHR service provider
  - Content providers: health information content provision
  - Software providers: PHR solution vendor
  - Content providers: health information content provision

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**Health service provider**

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FeelGood -project

• Objectives
  — Identify and start implementation of actions that are needed to create an internationally competitive PHR-based service market in Finland

• Results
  — Action plan / Roadmap, Implementation plans

• Approach & Timing
  — Phase 1: Creating the Action Plan through common workshops (Oct ’08 → Mar ’09)
  — Phase 2: Implementation (Mar ’09 → Dec ’09)

Participants
IT industry & service providers
- Avain Technologies
- Codeator
- Elisa
- Fujitsu
- Innofactor
- Itella Information
- Logica
- Mawell

Content providers
- MediWare
- Microsoft
- Nokia
- ProWellness
- Pfizer
- TietoEnator
- Vivago

Insurance companies
- Duodecim
- Finnish Broadcasting Company

Employers (HR)
- Ilmarinen
- Pohjola

Public Health Service Providers
- Etelä-Karjala Social and Health Services District
- Helsinki Uusimaa Hospital District
- Turku City

Other public bodies
- The Social Insurance Institution of Finland
- Ministry of Social Affairs and Health
- Finnish Funding Agency for Technology and Innovation (Tekes)
- Sitra, VTT

http://feelgood.vtt.fi
Preliminary conclusions by FeelGood workshops

• Target: free, business-based evolution of competing and complementing PHR solutions

• Standards, open interfaces and common terminology are needed in order to achieve interoperability between PHR services and supporting service components (→ interoperable PHR *)

• A PHR ecosystem reference architecture is needed for providing a common framework for technology considerations

* CITL (Center for information technology leadership): "The Value of Personal Health Records"
## Existing PHR standards and specifications *

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Standard/specification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functionality</td>
<td>What does a PHR do?</td>
<td>HL7 PHR-S Functional Model</td>
</tr>
<tr>
<td>Content</td>
<td>What information does a PHR contain?</td>
<td>HL7 CCD/CDA, IHE XPHR, DICOM IODs, ASTM CCR</td>
</tr>
<tr>
<td>Vocabulary and coding</td>
<td>How the information is coded?</td>
<td>SNOMED-CT, LOINC, ICD 9/10, CPT 4/5</td>
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<tr>
<td>Information exchange</td>
<td>How information is exchanged between systems?</td>
<td>HL7 V2&amp;V3, IHE XDS, NCPD (X12N), DICOM</td>
</tr>
<tr>
<td>On-line forms</td>
<td>How information is captured and exchanged via forms?</td>
<td>XForms, IHE RFD Profile, OASIS Open Document Format</td>
</tr>
<tr>
<td>Personal health devices</td>
<td>How information is captured from devices?</td>
<td>IEEE PHR, Continua Health Alliance Guideline 1.0</td>
</tr>
<tr>
<td>Portable media</td>
<td>How is information exchanged using portable media?</td>
<td>USB key, CD-ROM, smart card, IHE XDM, IHE XDR</td>
</tr>
<tr>
<td>Web Services</td>
<td>What is needed for a web services based PHR system?</td>
<td>SOAP, WSDL, WS-I Basic Profile</td>
</tr>
</tbody>
</table>

Existing PHR ecosystems (Microsoft Health Vault, Google Health) *

User organisations:
- health providers
- farmacies
- insurance companies

Technology and service providers:
- software providers
- web service providers
- device manufacturers

PHR service platform

- PHR provider specific interfaces
  -- Google Health Data API
  -- HealthVault Class Library
- content description standards (CCD, CCR, ...)

* http://www.healthvault.com/
  http://www.google.com/health
Preliminary PHR ecosystem reference architecture

iPHR: exchange PHR content

iCo: get information about PHR services

iArp: get PHR content from centralized health archive (eArchive)

iCo, iPAN, iXHR, iWAN: transfer health data from devices (covered by Continua Alliance guidelines)

iCS: proprietary interface

iAr, iAu, iPo: existing standards
# Examples of needed web service operations

<table>
<thead>
<tr>
<th>Operations</th>
<th>Interface</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>RegisterPHRService</td>
<td>iCo</td>
<td>Register (or unregister) a PHR service</td>
</tr>
<tr>
<td>SetPHRServiceInfo</td>
<td>iCo</td>
<td>Set PHR service information (of a registered PHR service)</td>
</tr>
<tr>
<td>EnumeratePHRServices</td>
<td>iCo</td>
<td>Listing of registered PHR services</td>
</tr>
<tr>
<td>GetPHRServiceInfo</td>
<td>iCo</td>
<td>Get published PHR service information, e.g. access and security policies, supported standards etc.</td>
</tr>
<tr>
<td>GetPHRServiceAttributes</td>
<td>iPHR, iArp</td>
<td>Get service attributes e.g.: PHR service type, access and security attributes etc.</td>
</tr>
<tr>
<td>EnumerateData</td>
<td>iPHR, iArp</td>
<td>Listing of PHR content of a specific subject (= customer).</td>
</tr>
<tr>
<td>GetContent</td>
<td>iPHR, iArp</td>
<td>Get PHR content of a specific subject</td>
</tr>
<tr>
<td>SendContent</td>
<td>iPHR</td>
<td>Send PHR content of a specific subject</td>
</tr>
</tbody>
</table>
Simplified sequence diagram for user-initiated transfer of data between two PHR services

1. Request PHR data transfer
2. Display PHR services
3. Select data transfer from PHR service 2
4. GetPHRServiceInfo (request)
5. GetPHRServiceInfo (response)
6. GetPHRServiceAttributes (request)
7. GetPHRServiceAttributes (response)
8. GetContent (request)
9. GetContent (response)
10. Transfer PHR2 -> PHR1 OK
Security considerations for iPHR interface

• Trust between the parties exchanging PHR data
  —pre-condition: agreement between parties has to exist

• Transport-level security → usage of SSL protocol (https)

• Message-level security
  —message authentication, integrity, confidentiality and non-repudiation → WS-Security specification (OASIS)

• Mechanism needed for indicating users' consent concerning information disclosure between service providers
  → e.g. SAML assertion (OASIS)
Message-level security for SOAP

SOAP Message

SOAP Header
- Security tokens, e.g.: X509 certificate, Kerberos ticket, SAML, XrML
- XML signature
- XML encryption

SOAP Body
- Message (e.g. "GetContent-request")
SAML\(^1\) token structure

\(<\text{Assertion ID="_a75adf55-01d7-40cc-929f-dbd8372ebdfe"}\
\>\text{IssueInstant="2003-04-17T00:46:02Z" Version="2.0"}\
\text{xmlns="urn:oasis:names:tc:SAML:2.0:assertion">}\
\text{<Issuer>example.com}\
\text{</Issuer>}\
\text{<ds:Signature> ....</ds:Signature>}\
\text{<Subject>}\
\text{<NameID Format="urn:oasis:names:tc:SAML:1.1:nameid-format:emailAddress">Alice@example.com</NameID}>\
\text{<SubjectConfirmation Method="urn:oasis:names:tc:SAML:2.0:cm:sender-vouches"/>}\
\text{</Subject>}\
\text{<Conditions NotBefore="2003-04-17T00:46:02Z" NotOnOrAfter="2003-04-17T00:51:02Z">}\
\text{<AudienceRestriction>}\
\text{<Audience>example2.com</Audience>}\
\text{</Audience>}\
\text{</AudienceRestriction>}\
\text{</Conditions>}\
\text{<AuthenticationStatement> .... </AuthenticationStatement>}\
\text{<AuthorizationStatement> .... </AuthorizationStatement>}\
\text{<AttributeStatement> .... </AttributeStatement>}\
\text{</Assertion>}

\(^1\) Security Assertion Markup Language, OASIS
Conveying health information in a SOAP message

SOAP Message

  SOAP Header
    security tokens, signatures ...

  SOAP Body
    Message (e.g. "GetContent -response")
      CCD / CCR document
        Header
        Body

Content standards are oriented for clinical health care, not for "wellness applications"!
Enterprise architecture view (e.g. PHR service provider)

USER
- citizen/patient
- health professional

PROCESS
- managing chronic conditions
- health coaching
- sports community
- ...

APPLICATIONS
- own data management
- device interaction
- peer group interaction
- subscription management
- ...

SERVICE COMPONENTS
- CRM
- internal PHR
- external PHR
- health info resource
- EHR archive
- service directory
- ...

INFORMATION SYSTEMS
- internal components
- external components
Towards interoperable Personal Health Records – next steps

- Definition of the PHR ecosystem reference architecture
- Definition of interface specifications
- Development of a semantic model and vocabulary for "wellness information"
- Open source reference implementations for
  - demonstration and promotion of interoperability
  - supporting commercial service development

- All this can not be covered by the FeelGood community alone. Co-operation at national and international levels are needed, e.g.:
  - National projects, e.g. eKat and OHV
  - Continua Health Alliance
  - HL7
  - Indivo community
  - ...
More information

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FeelGood web: http://feelgood.vtt.fi
VTT creates business from technology