Sharing patient data through Integrated Personal Health Records

PhD in Digital Media, UT Austin | Portugal
Inês Rodolfo, Dr. Nuno Correia
Research context
Medical records are now digital and pervasive

Source: “Alert Life Sciences Computing”, in Alert-online.com/pt
Fragmented and incomplete patient data:
Electronic medical records do not communicate with each other
We live in an aging society
2 billion in 2050
People with long-term conditions and senior people are considered to be the most vulnerable to the decentralization of health information, caused by the facilities non communication (or non-interoperable systems).
New Paradigm in Healthcare industry: Patient centered care

- People own their healthcare data: Patient’s health control & centered care

- Healthcare providers and patients team based care: Participatory Medicine

- Healthcare Reforms around the world: Integrated healthcare networks

- Human measurement-based medicine: Self-tracking tools: help providers to make care choices; engage people to make life choices
Integrated Personal Health Record
a transition model

Integrated PHR

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
Research work
Research goal

Explore the potential and design strategy of Integrated Personal Health Records

Contribute with our findings to case studies with application in real life
## Research work plan

### First Stage
- Design model of an Integrated PHR
- Proposal for the National Patient Portal redesign
- Participatory Expert Review
- PHRs Scoping Review
- Card Sorting
- Stakeholders Interviews
- Backasting
- Web analytics

### Second Stage
- Senior Health module
- Proposal of an online complementary channel for a telemedicine program
- Senior Interviews
- Physicians & Nurses Interviews
- Integration workflows
- Integrated Senior Health Assessment Dev.
- Satisfaction survey

---

**National Patient Portal**

**National Health 24 Senior line**

**Final implementation / Usability testing**
Portuguese National Health Data Platform
a cross-channel healthcare experience

Citizen / Patient Portal
9 million habitants
over 990,000 users

Health Professional Portal
More than 565 healthcare facilities

Institutional + International Portal

Any Portuguese citizen registered in the Portuguese National Health Service (NHS) can access the citizen platform with their unique patient identifier number.
Design strategy for a National Integrated PHR

User Experience - Participatory Expert Review

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
Design strategy for a National Integrated PHR

User Experience - Participatory Expert Review

92 usability problems

Results:

• 92 usability problems;
• 70 were critical;
• Technical, clinical, functional, structural, interaction and visual problems

Design strategy for a National Integrated PHR

**Literature Review**

**Used terms:** "Personal Health Records" OR "patient portal" OR "Personally Controlled Health Records” OR “electronic patient record” OR “patient health record”.

- PubMed, Embase, Web of Knowledge e ACM Digital
- 1047 articles
- Screening by title & abstract
- 946 articles excluded
- 101 articles
- Full articles read
- 19 duplicated
- 82 articles included

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
Design strategy for a National Integrated PHR

Literature Review Functionality Gathering

Total of 61 functionalities

- Healthcare services and information exchange (17)
- Healthcare education and other sources of support (6)
- Health data collection (4)
- Self-management and patient decision support (11)
- Information sharing (10)
- System functions (13)
Design strategy for a National Integrated PHR

Functional Analysis

Total de 55 functionalities

- Cross-sectional areas of the app
- Personal data
- My health
- Healthcare monitoring
- Health management
- Agenda (-)
- Health education
- Information sharing

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
<table>
<thead>
<tr>
<th>Personal data</th>
<th>My Health</th>
<th>Healthcare System</th>
</tr>
</thead>
<tbody>
<tr>
<td>General data</td>
<td>Allergies</td>
<td>Summary care record</td>
</tr>
<tr>
<td>Family situation</td>
<td>Problems</td>
<td>My unit care center</td>
</tr>
<tr>
<td>Social situation</td>
<td>Vaccines</td>
<td>Healthcare providers</td>
</tr>
<tr>
<td>Contacts</td>
<td>Lab and image exams</td>
<td>Surgery waiting list</td>
</tr>
<tr>
<td>Emergency contacts</td>
<td>Family history</td>
<td>Advanced directives</td>
</tr>
<tr>
<td>Family doctor</td>
<td>Inpatient episodes</td>
<td>Healthcare insurance</td>
</tr>
<tr>
<td></td>
<td>Procedures</td>
<td>Healthcare expenses</td>
</tr>
<tr>
<td>My identification in</td>
<td>Past appointments</td>
<td></td>
</tr>
<tr>
<td>the patient national</td>
<td>Blood transfusions</td>
<td></td>
</tr>
<tr>
<td>records</td>
<td>Other therapeutic modalities</td>
<td></td>
</tr>
<tr>
<td>Health Management</td>
<td></td>
<td>Information Sharing</td>
</tr>
<tr>
<td>Health programs</td>
<td></td>
<td>Access history</td>
</tr>
<tr>
<td>Health diaries</td>
<td>Health library</td>
<td>Manage accesses</td>
</tr>
<tr>
<td>Health assessments</td>
<td>Health glossary</td>
<td>My emergency profile</td>
</tr>
<tr>
<td>Measurements</td>
<td>Health news</td>
<td>Send health information</td>
</tr>
<tr>
<td>Reminders</td>
<td>Healthcare support groups</td>
<td>Print health information</td>
</tr>
<tr>
<td>Health Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health diaries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health assessments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measurements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reminders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Sharing</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Design strategy for a National Integrated PHR

UX Design - Information Architecture > Card sorting

Total of 73 participants

Senior group
Total of 11 participants > 64 years old average
10 Female
1 Male
3 Healthcare providers
3 People already heard about the Portal (none ever used it)

Younger people
Total of 62 participants > 33 years old average
54.1% Female (33 people)
45.9% Male (28 people)
37.1% Healthcare providers (23 people)
55.5% People already heard about the Portal (35 people)
14.5% Already had used the portal (9 people)
Information Architecture > Card sorting online > Initial draft

Personal data
- General data
- Family situation
- Social situation
- Contacts
- Emergency contacts
- Family doctor
- My identification in the patient national records

My Health
- Allergies
- Problems
- Vaccines
- Lab and image exams
- Family history
- Inpatient episodes
- Procedures
- Past appointments
- Blood transfusions
- Other therapeutic modalities

My unit care center
- Summary care record
- Healthcare providers
- Surgery waiting list
- Advanced directives
- Healthcare insurance
- Healthcare expenses

Health Management
- Health programs
- Health diaries
- Health assessments
- Measurements
- Reminders

Health Education
- Health library
- Health glossary
- Health news
- Healthcare support groups

Information Sharing
- Access history
- Manage accesses
- My emergency profile
- Send health information
- Print health information
I suggest that an additional division should be created such as Health History. My Health ends up receiving excessive content, harming the navigation experience.

Male, 31 years old
Adicionar problema

1. Selecione o problema
2. Especifique o problema

Selecione o seu problema a partir da lista de problemas do ICPC-2:

Respiratório

Nome do problema | Descrição
--- | ---
Abcesso da córnea | Lorem ipsum dolor sit amet ullam forensibus an usu Fabellas eleifend neglecentur
Abcesso da glândula de Bartholin | Lorem ipsum dolor sit amet ullam forensibus an usu Fabellas eleifend neglecentur
Abcesso da pápèbra | Lorem ipsum dolor sit amet ullam forensibus an usu Fabellas eleifend neglecentur
Abcesso da uretra | Lorem ipsum dolor sit amet ullam forensibus an usu Fabellas eleifend neglecentur

Caso não encontre o que procura na lista, registe aqui o seu problema:

Problema: 

Cancelar

Continuar
Filipa Martins

Estado actual da saúde

Problemas

Diabetes, nível I
Início a 27-04-1002
Dor no Peito, muito intensa (8)
Início a 27-04-1992

Alergias

Pólen
Início a 27-04-1992
Pêlo de gato
Início a 27-04-1992

Medicação

Brufen 300, 2 vezes ao dia durante 1 semana
Início a 27-04-1992

Últimas medições

Peso e IMC

65 kg  | Normal
26,6 IMC  | Normal

Glicemia

15 mg/dl  | Normal

Tensão arterial

120 mmHg  | Normal

Notícias dos media

Dieta mediterrânea é boa para a memória
29-05-2013

Destaque da sua biblioteca

Sobre diabetes

Próximos eventos

Dia 30 de Abril às 15:00
Centro de Saúde
<table>
<thead>
<tr>
<th>Problema</th>
<th>Ver: todos</th>
<th>intermitentes</th>
<th>passados</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>actual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inicio a 27-04-1992</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosticado por Dr. João Sequeira, Hospital da Luz</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dor no peito</td>
<td>intermitente</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inicio a 27-04-1992</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terminado a 27-05-2000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosticado por Dr. João Sequeira, Hospital da Luz</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alergias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ver: todas, a medicamentos, a outras substâncias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pólen</td>
<td>a outras substâncias</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inicio a 27-04-1992</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosticado por Dr. João Sequeira, Hospital da Luz</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicação</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ver: toda, activa, passada</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brufen 400 - &quot;comprimido cor de rosa&quot;</td>
<td>intermitente</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Adicionar medicação

1. Selecione o medicamento

Medicamento selecionado: Brufen 400

Dosagem / Composição: 3 Comprimido(s)

Data de início:* 02-05-2013

Frequência:* Diariamente Frequência diária:* 1 vez por dia

Duração:* Medicação crónica Data de fim: 

Medicação prescrita pelo médico? Sim Não

Prescrito por: João Sequeira Adicionar outro prestador

Na instituição: Hospital da Luz Adicionar outra instituição

Comentários:

Informação avançada

Nome alternativo:

Foto do medicamento: Importar foto... Tirar foto...

Nome pelo qual está acostumado a chamar o medicamento (por ex: "medicamento azul")

A foto pode ajudá-lo a identificar o seu medicamento (por ex: durante uma consulta médica)

Cancelar Anterior Adicionar
Understanding the Users of a Nation-wide Patient Portal with an Integrated PHR
Backcasting Portal do Utente
Período de tempo: 6 meses
Backcasting: looking back from the future

1. Unique cross-channel experience
2. Meaningful content
3. User engagement
4. Inclusive Portal
Sharing Patient Data through Integrated PHRs

Use case - National Patient Portal

User Experience > Stakeholders Interviews

User experience, benefits, hurdles and project directions

Highlights customer support
(consumers understanding of online health information)

• Users wish to have an easiest way to access their clinical data
• Frequently ask to enable their medical exams
• Are interested on contacting directly their providers

• Major concern is regarding privacy control: users expect
• their data only to be accessed during appointments or clinical episodes or have a clear way of being notified when, by whom and under which circumstances are their records accessed.
Sharing Patient Data through Integrated PHRs
Use case - National Patient Portal

User Experience > Statistics & Web analytics

Highlights

- The portal has about **990,000 users**, 10% of the total National population
- An average on 5000 visits per day
- Consumer habits: largest accesses performed on sundays
- Largest cities
- The most typical users are women between 30 and 39 years old

Demographic distribution of registered users by age and gender

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
Sharing Patient Data through Integrated PHRs
Use case - National Patient Portal

User Experience > Mixed User Research

Highlights

*During 2014* the main used functionality has been the request for scheduling appointments; The most used PHR functionality has been habits followed by medication. Users report overall PHR functionality limited behavior.

High low spent time in the portal (36,4% - stayed no longer than 1 min): due to usability problems at login and registration (42% abandoned pages) - confirmed by users. Nevertheless, analytics show the portal has been attracting a large amount of new users.

Findability: the portal needs to gain impact and visibility among citizens.

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
Sharing Patient Data through Integrated PHRs
Use case - National Patient Portal

User Experience > Mixed User Research > User groups > Current users

**General public:** Search health topics.
*Main goal health information. Interested / First-time use*

**Active adults:** Search for quick online health services.
*Main goal eHealth services. Regular use*

**People with long-term conditions:** Renewing medication, monitor their problem.
*Main goal eHealth services and PHR features. Regular or Passionate Use*

**Householders:** Parents looking for the children’s health record eBook - NHS program
*Main goal eHealth services and PHR features. Regular or Passionate Use*

**Senior people:** Scheduling appointments or renewing medication. + self-tracking tools
*Main goal eHealth services and PHR features. Regular or Passionate Use*

**Children and grandchildren:** help their parents to schedule appointments
*Main goal eHealth services. Regular Use*
Sharing Patient Data through Integrated PHRs
Use case - National Patient Portal

User Experience > Mixed User Research > User groups > Portential users

**Underrepresented population:** low digital literacy level, unemployed or isolated elderly people. Need help to perform some tasks related to eHealth services.
*Main goal eHealth Services. Unaware.*

**Foreigners:** Search for the general functioning of the NHS. Need multi-language.
*Main goal eHealth services. Unaware / Interested / First-time use.*

**Wellness group:** Wellness activities, health prevention, healthy life. Integrate with third party apps.
*Main goal PHR features. Regular or Passionate Use*
Personas
Visualize a sua informação de saúde e a da sua família de forma integrada

Sobre o Portal do Utente
A sua integração na Plataforma de Dados de Saúde

Assum tritani alienum mei id, ut vim iudicabit conceptam. Ex sonet consetetur eum. Tamquam feugait detraxit sit ex, pri falli dicam tritani no. Nisl mentitum eu pri, eu alia alterum democritum mel, malis facer ex pri.

An liber scaevola adipiscing eam, aliquid adipiscing eu sit. In duo solet nostrum consequuntur, usu justo laoreet nostrum at. Altera liberavisse eu sed, rebum brute dissentium ius cu, probo alterum nec ad. Mei ei falli aliquip aliquam, et nec gubergren aliquando, zril exerci habemus eu sit. Ne hinc reque accommodare per.
Login

Aceder através do cartão de cidadão

O cartão de cidadão permite acessar à sua informação clínica de saúde, registada pelos prestadores de cuidados do Serviço Nacional de Saúde, de forma confidencial e segura. Saiba como aderir

Coloque o cartão de cidadão no leitor de cartões e clique no botão para efectuar a sua leitura e entrar.

OU

Aceder através do número de utente

Número de utente

Password

Esqueceu-se da password?

Lembrar-me

Entrar

Ainda não se registou?

Criar registo
2nd anniversary of the National Health Data Sharing Platform
1 October 2014
Current and expected results
Sharing Patient Data through Integrated PHRs

CONFERENCES


NordiCHI 2014 Helsinki, Finland

Inês Rodolfo, Ph.D fellow in UT - Austin | Portugal Program
What’s next in eHealth?
Health tracking devices: mobile, tablet, web & wear

Health, an entirely new way to use your health and fitness information

You are in charge of your data

Wear what you want

Apple

Google Fit

Android Wear

UT Austin | Portugal
Health tracking devices: mobile, tablet, web & wear

Stay connected
Live healthier
Be more productive

Microsoft smartband
The future of eHealth: how to integrate all system platform and device healthcare sources and deal with Big Data?

Estimated 50 petabytes of data in the healthcare realm today.

**Biometric data** are predicted to grow by a factor of 50, to 25,000 petabytes by 2020.

(source: healthcare consultancy drbonnie360)
The future of eHealth
Big Data & the Internet of Things

Big Data
Wellness devices
Healthcare system

Fitness
Well-being
Relaxation
Prevention

Integrated
PHR

EHR

Wellness devices
Healthcare system
Live healthier. Live longer.

Inês Rodolfo: imsrodolfo@gmail.com