



The way towards large scale deployment of eHealth: where do patients stand?

The **SUSTAINS** project Basque Country pilot

EPF e-health seminar

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Hotel Bloom, Brussels

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Sustains Project

Basque Country





SUSTAINS

Support USers To Access Information and Services

- Three-year european project
- Partially funded by the Competitiveness and Innovation framework Programme - ICT strand-Policy Support Programme (PSP)
- Participants: 16 partners from 11 European regions committed to give patients' access to Electronic Health Records (EHR) and other related web services
- http://ec.europa.eu/information society/apps/projects/factsheet/index.cfm?pr oject ref=297206
- http://sustainsproject.eu/



The Sustains Consortium includes

- 2 national bodies from Estonia and Slovenia
- 1 local-level body from Asolo Veneto Region (IT).
- 4 European-level organisations, including EPF.
- 8 regional-level bodies from the following regions:
 - Uppsala County, (SE project leader)
 - Region of South Denmark (DK)
 - Aragón (ES)
 - Scotland (UK)
 - Thessaly and Central Greece (GR)
 - South Karelia (FI)
 - Norrbotten (SE)
 - Basque Country (ES)





Main objectives

- SUSTAINS aims to measure the impact of a wide range of administrative and clinical services for patients based on patients' access to EHR on the three areas below:
 - Empowerment of patients: There is a growing tendency by patients and the public to question information from the health system, ask for a second opinion, demand respect and dignity in their treatment, expect convenience, etc.
 - Medical results: Progress in treatment especially of chronic diseases need efficient and continuous contact between the patient and the professionals in order to achieve optimal medical result.
 - Efficiency and economy: With the new treatments available, and the growing demand from patients/public, there is a need for improved efficiency and economy.





Expected impact on patients

- Empower of patients to act as more active players in the management of their health as opposed to passive receivers of healthcare services.
- Better informed patients, and users in genral, about their health and therefore they will be able to make more conscious decisions about treatment and lifestyles in collaboration with the healthcare professionals looking after them.

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Basket of Services



Administrative services

- Book or rebook a consultation/diagnostic exam
- Pay a service fee
- Change GP (when moving or similar)
- Update phone number and name of close relative
- Consult audit trail
- Access to health insurance data
- Access to the data of health services costs
- Delegation of access to family or carer
- Mask sensitive data
- Track referrals to specialist or diagniosticexamination
- Notification services (reminders, sms...)
- Consent for export of EHR data to epSOS Patient Summary

Clinical services

- Examine the EHR
- Ask a question to a physician/nurse
- Fill out a Health Declaration Form
- Print out drug and lab list before traveling
- Patient's input into EHR
- Integration of data relating to patient's self-monitoring
- Decision support





Facing new Challenges: who and where are we?

Some figures...



Population (2011): 2.183.615 inhabitants

≥65 years: 17.81%



Life expectancy at birth (2009) 78,6 for men and 85,7 for women. The Basque Country's position is one of the highest in the world, after Japan and Hong Kong.



Infant Mortality Rate (2009): 3,1 ‰

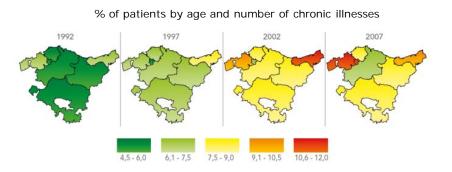


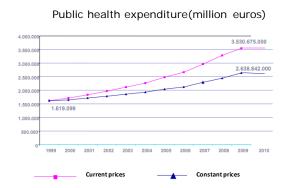




Facing new Challenges: It is time to do more with less

The total health expenditure has increased while chronic disease prevalence and complexity is growing as population ages.





New challenges undertake...

- To contain the growth of public health expenditures under strict fiscal consolidation policies while servicing an ever increasing demand.
- To address quality, safety and adequacy gaps in health services.
- Basque Country is one of European regions with the highest proportion of elderly, it also addresses an increasing incidence of chronic pathologies:
 - ✓ 80% of patient interactions with the public health system are related to chronic diseases
 - ✓ Chronic patients drive around 77% of the total Health expenditure
 - Health expenditure on current trends is expected to double by 2020.





14 Strategic projects to tackle Chronicity in the Basque Country

Vision

The Strategy for chronic illnesses aspires to substantially improve the lives of patients and carers, health professionals and citizens

Policies

The Health Department of the Basque Country has defined five strategic policies:



Projects

These policies have been materialized through 14 strategic projects:







Osarean Multichannel Health Service Centre











Osarean Multichannel Health Service Centre



Actors in the Basque Country

- Department of health and consumers' affairs of the Basque country: it's the local health authority with responsibilities over policy and regulation, public health, health planning, insurance and financing of the public health system.
- Osakidetza is the public health service provider in the Basque Country, entirely financed by the Basque Government. Osakidetza runs:
 - 320 Primary Health Centers
 - 12 Acute Hospitals (4,278 beds) and 4 Chronic Care Hospitals (524 beds)
 - Mental Health: Three regional networks with 4 psychiatric hospitals, (777 beds) and 2 Contracted Long term Mental hospitals
- Osatek: is a public corporation of the Department of Health and Consumers'
 Affairs, created in 1992 with the aim of becoming a reference in the field of
 diagnostic imaging. Nowadays the main activities of Osatek are: Management,
 administration and operation of diagnostic imaging services to cutting-edge
 technology, research and teaching, development and implementation of new
 services based on ICTs.







Osarean



Mission

To set up a technological platform, based on ICTs, which allows multi-channel interaction for all the citizens of the Basque Country with the health system, enabling procedures, simplifying the life of the citizens and adding more value to the clinical work of the health professionals.

Vision

This model includes a **new vision of the roles of health professionals, citizens and patients** which consists of the **co-responsibility**, **and thus**, **the active patient** concept is inherent to the health system transformation process, where patients have **virtual spaces and social networks** of knowledge and interaction.

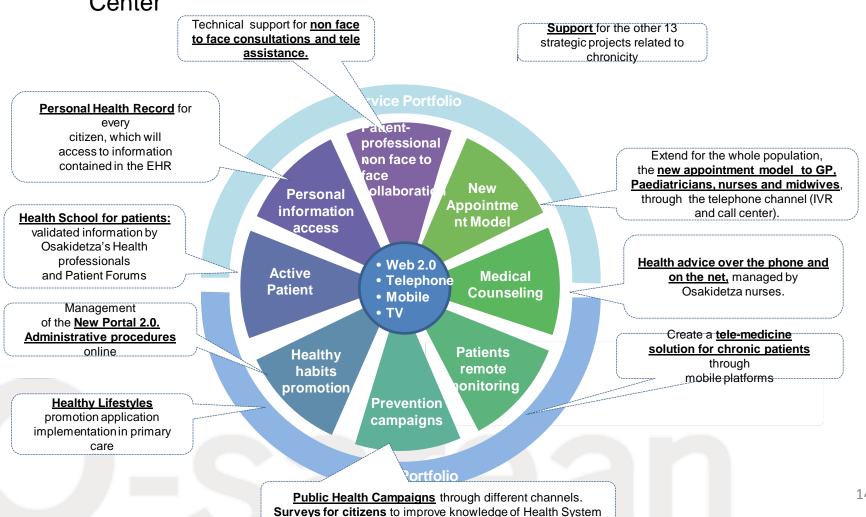
Objectives

- 1 To improve quality of life of the whole populations on the whole and of the patient particularly
- To turn citizens into active agents of the Basque public health system
- 3 To improve the quality of health care delivered and to motivate health professionals
- 4 To improve the efficiency of the Basque Public Health System
- 5 To contribute to the **equity** in the Basque Public Health System





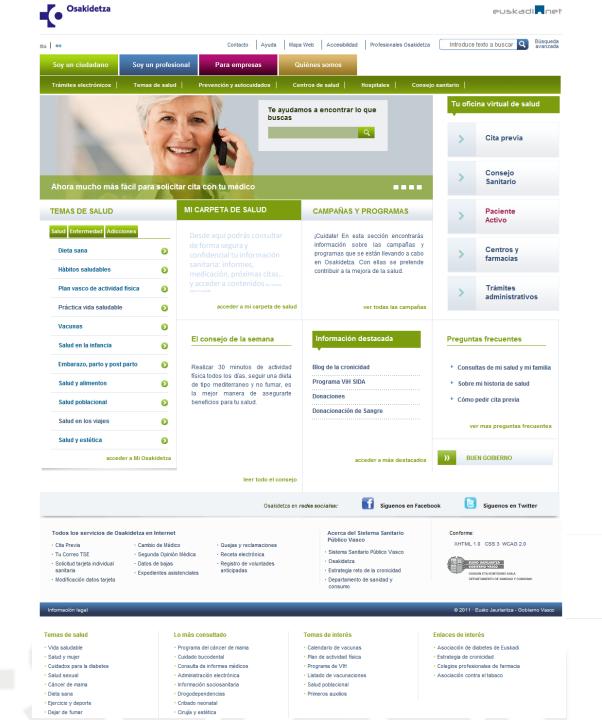
Service portfolio for the Multi-channel Health Service Center



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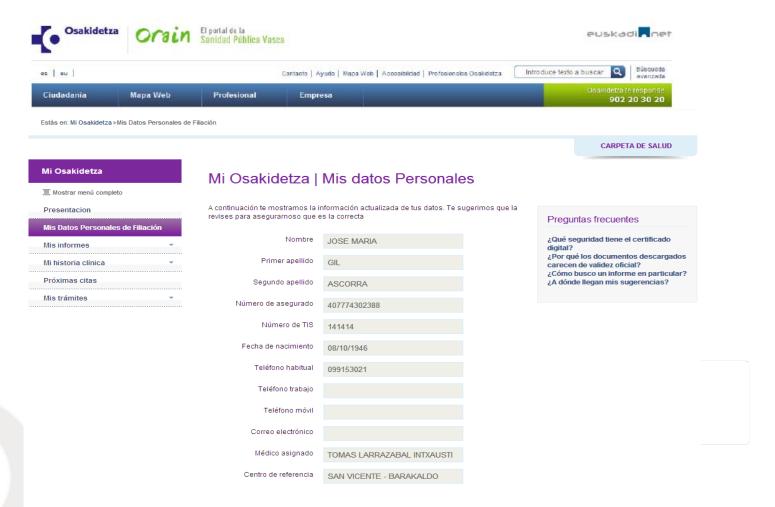
Accessing to my Personal health folder







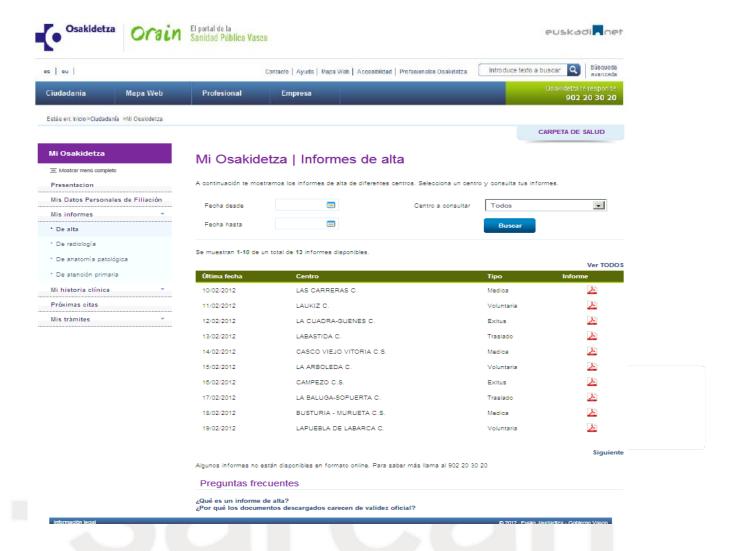
Checking my personal data







Taking a look at my Hospital Discharge Clinical Reports

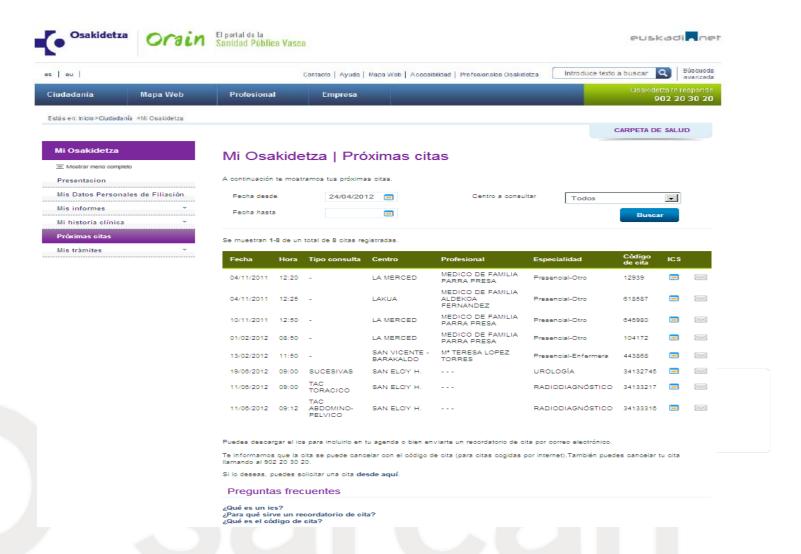






Browsing into My Personal Health Folder

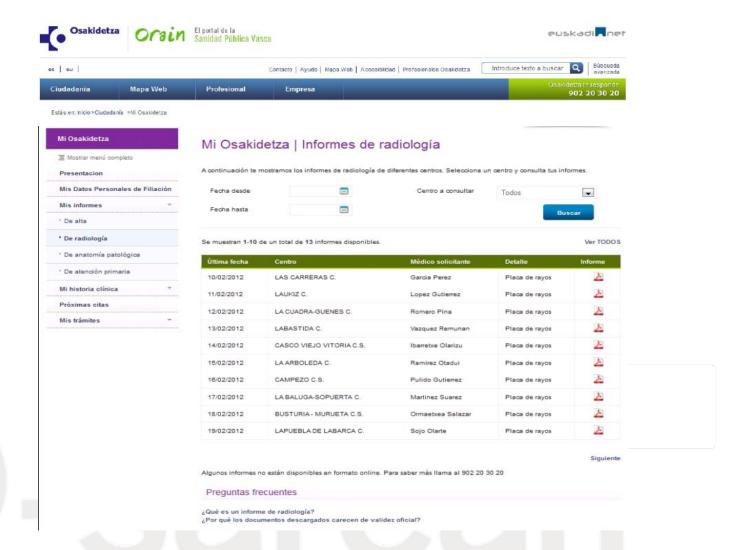
Reviewing my next appointments







Looking and Downloading a RX report





Medir mis parámetros



362ED21C69F16B8DCA6865EB3014392F Bienvenido EUGENIA MONASTERIO OMAETXEBARRIA Inicio Ayuda Accesibilidad Cerrar sesión eu Estás en: Inicio » Mis Datos Personales de Filiación CARPETA DE SALUD Mi Osakidetza Mi Carpeta de Salud Gestión de Crónicos Mostrar menú completo Presentacion En la Hora de Medición debes añadir la hora exacta a la que te realizaste la medición. Si tienes cualquier duda, Mis Datos Personales de Filiación por favor, contacta con tu enfermero/a Mis informes Mi historial clínica Intervalo Medición Hora Medición Parámetro Unidad Valor Próximas citas Gestión de Crónicos Enviar>> Registro de Parámetros y 5,45 [Hora Desde] - [Hora limite] Insulina 15:30 mg cuestionarios Histórico de parámetros Enviar>> °C Próximas citas Temperatura 37.5 [Hora Desde] - [Hora limite] 17:45 Mis trámites



Sat. de Oxígeno

En el caso de enviar por error datos incorrectos, ya sean parámetros o cuestionarios, no podrá modificarlos a través del aplicativo de registro ,deberá ponerse en contacto telefónico con su enfermero/a para modificar los valores erróneos

[Hora Desde] - [Hora limite]

20:00

Envía los datos al

gestor.

Enviar>>

Atrás

200

mmHg





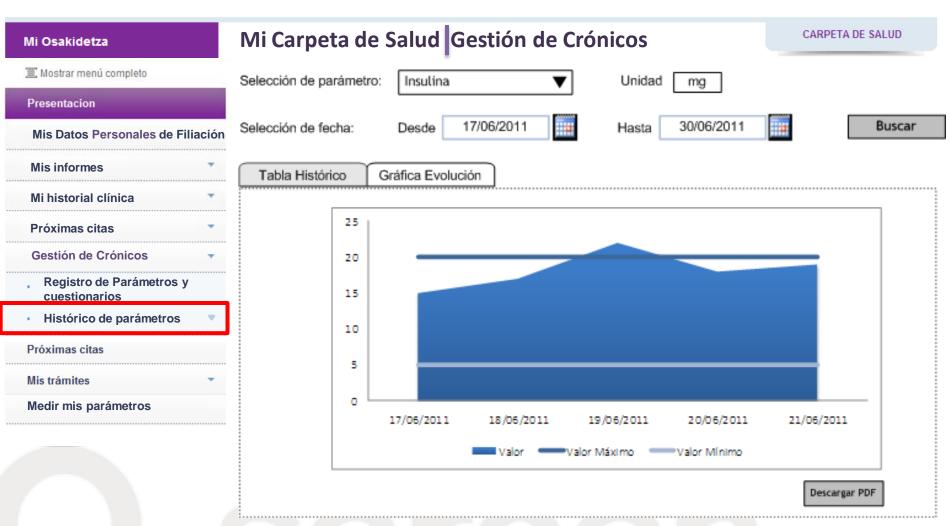
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Estás en: Inicio » Mis Datos Personales de Filiación







Main user involvement actions carried out

- Social Research: FARAPI (2010)
- Focus Group: SUSTAINS (2011)
- Stakeholders meetings, actors maps and user usability tests: ERGOLAB (2012)
- On-line Courses for users
- Disemination actions



Social Research: FARAPI 2010



MAIN OBJECTIVE

Identify the needs of potential web users and the and specify web contents

Specific objectives

- Identify the issues that are the subject of doubts and questions by both,
 the user- and health professionals of the region of Bilbao
- Provide a classification of possible demands to give criteria for web design.
- Identify the functions that must contain the web (inform, assist, advise,
- etc ...)
- Identify obstacles and constraints to implementation and use of the website.





Individual interviews:

- > Caregiver (Basic use of ICT)
- > Blind and health professional (no use of ICT)
- > Professional (active 2.0 user)
- > Professionals (Basic use of ICT)
- > Chronic patient (Discouraged about ICT)
- Elderly man and woman (not active user of ICT)
- > Seniors Couple
- Cancer patient's husband





Group Discussions:

- Group 01: patients and family associations.
 Neighborhood associations.
- GROUP 02: citizenship. Carers, people with chronic diseases
- GROUP 03: Osakidetza professionals with different profiles



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Observational studies (onsite observation +interview):

Primary care centers in Bilbao

- > Basurto / Altamira
- > Indautxu
- > Old Town





Barriers and constraints found in the study

Mistrust

Chronic patient: "Just want to get rid of us, as they lack infrastructure take you where they want"

Fear of dehumanization, loss of personal contact

 Representative of the association neighborhood of Altamira, group associations: "I see the web page complicated. What people demand is personal attention, not through a computer. Might be good for appointment, for general information for existing services...There are many pages... but for the time of care...the treatment must be personal

Lack of interest

- Individual interview: "I like it a lot but for me it has come too late... I'm lazy... I have no patience, has come late. Neither course or anything, I step, I step
- Man 84 years old "All new technologies are a breakthrough for me, for my age ... I have no interest... but it would not cost for me, isn't it?
- Personal interview:"I do not need it..."
- Elderly person: "All that is better is great but we do not use, just know exist but ... We use the mobile and it's not too complicated. The elderly do not have way to do that"

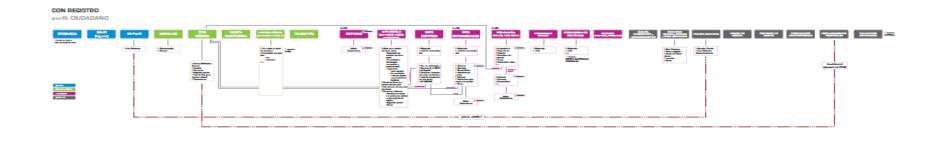
Insecurity

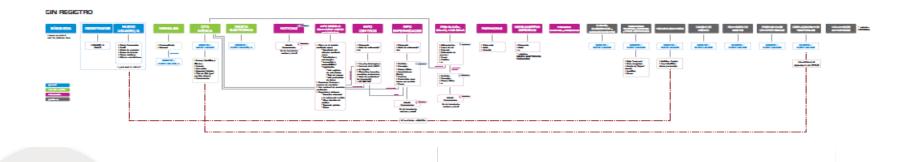
 Individual interview, outsider: "But the doctor would receive the mail? Does she have time? ... I do not know. A doctor who wants to answer by email I see he has no time. In addition, I have it very close and I prefer to approach



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Focus Group Basque Country

General information

Date of the focus group: 2nd May 2012

Place of the focus group: Bilbao, Basque Country

Moderators: 2 researchers of Tecnalia with experience in the application of user involvement techniques (focus group, brainstorming, interviews...)

Recruitment methodology: contacts per e-mail and personal interviews, starting point were members of Bioef and contact network

Total number of participants: 14

Patients/citizens focus group: 7

- Patients: 4
- Citizens:2
- Informal carers:1

Health professionals focus group: 7

- Doctors:4
- Nurses:2
- Pharmacists:1





Focus Group Basque Country

General Conclusions

- Services considered useful/very useful (ease of accessing "your" personal data, also when you are not at your region)
- Efficiency of health professionals will increase (they will be discharged from administrative tasks with no added value)
- Regarding accessibility, perception is that a high percentage of elderly people won't benefit directly from this services
- Regarding usability, must be improved (too many letters on the screen, many access points to the same place and several services are difficult to find
- EHR should not include subjective assessment of health profesionals and information on all acute diseases (cold, flu...)
- Reports and information containing bad news should be available at the EHR once the patient has been informed by the health professional, in any case before





Focus Group Basque Country

Expectations, perceived benefits and risks

- Main foreseen risks: Lack of security and confidentiality
- Relationship between patients and professionals
 - (patients) will be better, even though there is a risk to lose the face-to-face consultations
 - (health professionals) relationship won't change so much (not at least in the next few years and in the case of chronic patients)
- Accessibility to health professionals will increase, as a consequence, quality of healthcare will be increased
- Availability of these services will make possible the patient empowerment and to take shared decisions between patients and health professionals.







Usability assesment in ICT projects

Objective:

- Design systems that can understand the expectations and needs of users and technologists.
- Transfer some personalized and useful information to business and system developers agents, so it can help to make the right decisions for functional improvement and information system usability.
- Promote the information society by developing actions which can promote citizen participation to co-create, define, design, develop joint solutions.



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Stakeholders meetings

Actors Maps

Focus Groups

- Number of Focus Groups conducted: 15
- Number of people attending the focus groups: 162 (102 women, 60 men)
- Questionnaires filled out: 162
- **User tests:** This is a test conducted in 'laboratory', trying to reproduce as faithfully as the context of a user's actual use. Besides individual interviews were conducted with each of the users as well as type Test SUS (System Usability Scale) for each of the users in order to measure the user experience of the Personal Health Folder both qualitatively and quantitatively.
- Number of user tests conducted: 13
- Number of interviews: 13
- Number of Test SUS (System Usability Scale) made: 13

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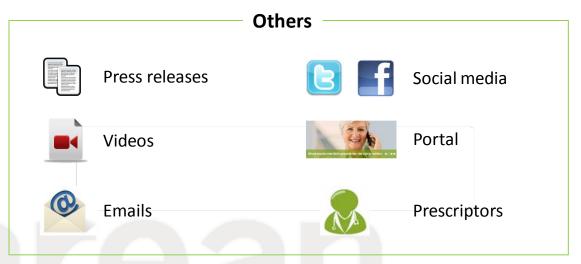
Communication Actions

Acciones de comunicación realizadas













Bottlenecks and barriers

REGARDING USERS

- Insufficient extension of health promotion and prevention
- Present obligations, future benefits!
- Reluctance to loose face to face contact
- Lack of digital skills
- Little power in decision making
- Slow growth of Active Patients numbers





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