iManageCancer

Results of a European R&D Project on Empowering Patients and Strengthening Self-Management in Cancer Diseases

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Faculty Disclosure

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EMPOWERING PATIENTS AND STRENGTHENING SELF-MANAGEMENT IN CANCER DISEASES

2/2015 – 7/2018
http://imanagecancer.eu/

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Motivation: Cancer as a chronic disease

Patient empowerment

“Social process of recognizing, promoting, and enhancing people’s abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives”

Jones and Meleis, 1993

- Cooperation
- Self-management

- Knowledge
- Re-elaboration
- Awareness

- Shared decision-making
- Participation
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Use Case scenarios

Analysis scenarios

Data Analysis and Visualization

- FORTH / BED
- eConsent
- FORTH / BED
- Access Control
  - FORTH / BED

Psycho-emotional Monitoring
  - IEO / FORTH

Life Style Monitoring
  - IBMT / Philips / BED

Familial Resilience Evaluation
  - IEO / FORTH

Health Inquiries
  - IBMT

Drug Self-Management
  - IBMT

Management Workflows
  - IBMT / USAAR

CDS
  - Philips Eindhoven

Side Effect Predictions
  - Philips UK

Decision Aid for Consultations
  - IEO / FORTH / IBMT

Game for Kids
  - SGS

Game for Adults
  - BED

Patient-Patient Interaction
  - Chat Forum
  - FORTH

Patient-Doctor Interaction
  - FORTH

Health Information Recommender
  - FORTH

Interoperability Use Case
(Semantic Layer)

PHR
  - FORTH / BED

eDiary

Patient View / Relatives View / Doctors View

Management and Decision Support

Information Communication Gaming
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Features

mHealth platform to support cancer patients and their relatives

- Cancer specific PHR and eDiary
- Drug management and drug safety
- Intelligent information services and decision aids
- Management support for pain, fatigue and psycho-emotional resilience
- Predictive models for side-effects during chemotherapy
- Serious games for kids and adults to educate and motivate
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iPHR
Intelligent personal health record and e-diary

Game for Adults
Manage your health city

Game for Kids
Kill the cancer cells with the help of your social network

iManageMyHealth
Managing drugs, drug safety, vital signs, lab values, pain and fatigue

MyHealthAvatar
Monitoring and managing lifestyle

iManageCancer Platform (1)
iManageCancer Platform (2)

Visual Analytics for patient cohorts with e-consent and de-identification tool

Care Flow Engine and Model Repository
Care flows and predictive decision support for patients and doctors

iSupportMyPatients
Data sharing with the physician and predictive patient management

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iPHR

Enabling an individual to own and manage a complete, secure, digital copy of their health information

Some of the iPHR apps (from left to right: psycho-emotional status, profiler, personal health information search engine, e-diary)
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Personal health information recommender

Smart access to cancer related content for information and education

User's search

Find a treatment for me.

Diana Allen

Disease: Breast cancer
Problem: Strep throat
Age: 40
Procedure: Biopsy
Medication: Amoxicillin

Breast Cancer
CUI:C0006142
ICD10:C50-C50.9
Malignant neoplasm, breast, unspecified

Streptococcal sore throat
CUI:C0036689
ICD9CM:034.0

Biopsy
CUI:C0005558
SNOMEDCT_US: 86273004

Amoxicillin
CUI:C0002645
RXNORM:723

Therapeutic procedure
CUI:C0087111
SNOMEDCT_US: 277132007

Personal Health Information Recommender

Search for useful information on medical topics:
Find a treatment for me.

Results are: 2 (primary disease)

1. Treating - Information and support - Macmillan Cancer Support
   http://www.macmillan.org.uk/Cancer-information/Cancer-help/Breast/treating-breasts-are-af

2. Breast Cancer: Treatment - National Cancer Institute
   http://www.cancer.gov/cancertopics/treatment/breast

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Novel questionnaire based electronic tools to empower cancer patients

- Psycho-emotional status monitoring based on extended ALGA-C questionnaire
- Family resilience evaluation tool
- Decision aid to support patient’s participation in consultations
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MyHealthAvatar

Promote healthy lifestyle and support patients in achieving their health goals

- Goal setting
- Health program and education
- Measure & detect the quality of life change
- Focus on prostate cancer and breast cancer
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iManageMyHealth App

Support patients in managing their drugs and their paper based health information

Services:

- **Drug management**
  Easy creation of a medication plan with reminders for drug intakes. Recording of outcome and side effects.

- **Drug safety**
  Check for contra indications and drug-drug interactions

- **Document management**

- **Vital sign monitoring**

- **Specific management services**
  Pain, fatigue, …
Serious games to fight cancer

Game for children:
- Shooter game where the child fight against its own cancer cells
- Support from friends and relatives through a strong social component

Main objectives
- Aid with psycho-emotional support
- Let the child focus on the right enemy, the cancer cells
- Let the child learn about its disease
- Raises the child’s acceptance of the treatment
- Measure & detect the quality of life change
Serious games to fight cancer

Game for adults:

► A lifestyle management game
The user will balance available activities in order to increase their avatars happiness while managing symptoms and treatments. The game’s purpose is education in healthcare.

► Gameplay is based on achieving goals using a mobile device’s click and drag interface. The user will play through a number of scenarios containing management challenges, completing challenges will allow progression to the next scenario and earn rewards.

► The users can draw parallels between their avatars improvements and their own real life.
Decision Support Framework

Care Flow Engine and Model Repository
Care flows and predictive decision support for patients and doctors

iSupportMyPatients
Data sharing with the physician and predictive patient management

iManageMyHealth
Managing drugs, drug safety, vital signs, lab values, pain and fatigue

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Guidance to manage side effects and therapy with patient pathway models

► Care Flow Engine analyses recorded data, detects health problems and provides individualized support.

► Care Flow Engine executes workflows (processes) within the system that involve patients and doctors.

► Clinical expert can design a formal management workflow for a specific therapy related problem (i.e. fatigue management, pain management) that the system will execute.

► Models for side effect prediction (i.e. neutropenia) can be included in the management workflows at decision points.
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Decision support for chemotherapy monitoring

Focus: Febrile Neutropenia
Pilot for children

Parental Distress Questionnaire (Dietrich et al 2014):
https://obtima.org/alga-c/kids

No healthcare professionals involved!
Faced obstacles

**Parents** had the following problems and concerns:

- Further stress with using such an IT tool
- Complaints that data need to be deleted after the end of the project
- They do not want that their children spend too much time with playing online games
- Fear that the game will cause stress for the children. They may feel that they are responsible if treatment fails because they don’t play well enough or long enough
- Number of friends supporting their kids might be lower than in other children

**Children** showed the following problems:

- Under chemotherapy they just want to sleep in the hospital
- At home they want to play with their friends and not to think about their disease
- After a while the game loses attractiveness
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**Pilot for adults**

**eHI (N=64)**
- Use of iManageCancer platform
  - Breast cancer patients (N=32)
  - Prostate cancer patients (N=32)

**IM (N=64)**
- Informative Material on a paper format
  - Breast cancer patients (N=32)
  - Prostate cancer patients (N=32)

No health professionals involved!

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**Baseline**
- Patient Health Engagement Scale (main endpoint)
- Resilience Scale for Adults
  - Mini – Mental Adjustment to Cancer
  - Profile of Mood States

**6-8 weeks**
- eHI > use of the platform
- **IM > standard care**

**T1**
- Patient Health Engagement Scale (main endpoint)
  - Resilience Scale for Adults
  - Mini – Mental Adjustment to Cancer
  - Profile of Mood States
  - Usability assessment (only for eHI group)

**T2**
- Patient satisfaction questionnaire
- Costs assessment

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No health professionals involved!
Intermediate results and issues faced

- Recruitment rate 46.5%
- Difficulties using the apps (bugs, technological literacy)
- Lack of time and interest in the apps
- Stress
- Lack of indication on how much time to dedicate
- Perceived usefulness of the platform is low in prostate cancer patients
- Women found the monitoring features useful (exercise, sleep, mood, etc) as well as the post surgical physiotherapy exercises.
- Patients appreciated search engine: provision of reliable information
Conclusions and lessons learned

- Comprehensive mobile platform for cancer patients provided
- Usability is a major key to success. KIS principle.
- ‘One-size-fits-all’-approach does not work for cancer
- Readiness of patients to use health apps
- The value of the tools is much higher if the clinicians are in the loop
- Standardized clinical guidelines required to advice patients how to cope with monitored findings
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