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self-management in cancer diseases***

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The patient's and clinical care perspective of the  
iManageCancer platform***

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# 1. Introduction

In the present document we will provide a conceptual framework for the development of the iManageCancer platform.

In the first part of the document, we assess the general state of the art on patient empowerment and self-management. In the “Patient Empowerment and Self Management” chapter, definitions of patient empowerment and self management will be reviewed, emphasizing on relevant aspects for cancer diseases. Relevant constructs in the delivery of the self-management are described and contextualized for cancer disease. Furthermore, we review eHealth based self-management intervention studies for cancer patients. Outcomes to evaluate the efficacy of Web based self-management tools and platforms are presented, derived from scientific literature and relevant theories.

In the “Review of similar platforms” sections, an overview of social platforms, tools and verified information sources for cancer patients is presented. Furthermore, the concept of personal health record (PHR) and electronic health record (EHR) is analysed, given their relevance in the design of a self-management platform. Particular relevance is given to MyHealthAvatar, which will be embedded in the iManageCancer platform.

In the second part of the document, we provide an assessment of current needs which should be taken into account in the development of the iManageCancer platform.

In the “Clinical perspective of iManageCancer platform” and “Patient’s perspective of iManageCancer platform” sections, results from interviews with healthcare providers and patients are presented and discussed. The interviews analysed the type of communication and decision-making preferences adopted by patients and healthcare providers, the difficulties encountered throughout the therapeutic path, as well as the needs and the resources in the different phases of treatment.

In the “Citizen’s perspective of iManageCancer platform”, the results of a questionnaire specifically developed for the iManageCancer project and shared among citizens are presented. The questionnaire assessed individuals’ online habits, preferences on health data sharing, opinions on prioritised proprietary features that should be available in a self-management platform as well as opinions on the use of serious games. These results will be discussed more in detail in D2.2 on Use Case Scenarios.

Finally, in the “Stakeholder’s perspective of iManageCancer platform”, the interactions with relevant associations and foundations related to oncology are reported.

## 2. Patient Empowerment and Self Management

### 2.1. *The concept of patient empowerment and self-management*

The pivotal progresses made in the early detection, diagnosis, and treatment of cancer resulted in patients being cured of their cancer or managing it as a chronic illness, which requires periodic controls and, in some cases, treatment. This demands that (1) patients and their families assume a more central role in the management of the oncologic disease, (2) healthcare professionals take a partnership with patients accepting to share responsibilities, and (3) policymakers provide adequate support to the healthcare systems in implementing new models.

In 2005, the Institute of Medicine (IOM)'s 2005 issued a report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005) characterizing different phases in the cancer care continuum: prevention, early detection, diagnosis, treatment, survivorship, and end-of-life care. This made a strong pressure for new models and approaches to arise in cancer care. In parallel, concepts as patient empowerment and self-management were emerging prominently in light of the increasing need for a general paradigm shift in healthcare, and are becoming relevant in the oncologic field now that conceiving cancer as a chronic, rather than acute disease, is becoming a reality.

Patient empowerment is a concept proxied from empowerment in social sciences which is generally described as a “social process of recognizing, promoting, and enhancing peoples’ 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). For instance, patients should be actively involved and participate in decision making on treatment, in order to promote decisions that are consistent with their values, preferences and daily life management possibilities. This shared decision making process empowers the patient because it provides him/her with the chance of making his/her own, well-discussed and well-informed, choice concerning the treatment. In other words, it is a process that helps people to be assertive in taking control over factors that affect their health. The nature of malignant disease requires patients to learn about and comprehend the illness, make difficult decisions regarding ensuing treatment, and cope with the consequences of the illness. It has been found that having relevant information not only helps cancer patients to understand the disease, but it also facilitates their decision-making and coping with the disease (Cassileth et al. 1980, Iconomou et al. 2002). However, practical

restrictions, such as tight time schedules for clinical consultations often leads physicians and other healthcare professionals to rather adopt a paternalistic approach which can override patient's preferences and considerations.

In a patient empowerment framework importance should be given to mutual participation between patient and caregiver, and in improving how well the caregiver and patient can communicate with each other. Barnato et al. (2007) noted that “in an ideal world [...] patients would come to a cancer consultation armed with sufficient knowledge, clarity about their personal value, and the ability to engage in a thoughtful discussion about the pros and cons of treatment options. Providers, in turn, would be prepared to support their patients, armed with an understanding of the patient's knowledge gaps, personal values about possible outcomes and treatment preferences.” (p.627). Therefore, it appears critical to develop tools which can increase the quality of communication, eliciting the emergence of the patient perspective as an individual, while being also time efficient and thus more easily integrated with the current clinical routine.

However, one should keep in mind that focusing on the patient's perspective and beliefs can also reveal patients who, depending on their condition and situation, cannot or do not desire to play an active role in decisions regarding their healthcare. Indeed, some patients do not even prefer a patient-centred or a patient empowerment approach (de Haes and Koedoot , 2003; Aujoulat, d'Hoore, Deccache, 2007). For instance, many patients in palliative cancer treatment have no wish to take part in decision making when their health conditions worsen (de Haes and Koedoot , 2003). Therefore patient empowerment should not come at the cost of a patient centred approach (Kvale and Bondevik, 2008), respectful of the extent to which individuals want to participate in decisions on their own health, but rather offer individuals with opportunities, skills and tools to become “empowered”.

Therefore patient empowerment demands also healthcare professionals to develop educational skills in empowering people to make informed choices about their own health (Anderson et al., 1991). Hospitals often provide patients and families with standard leaflets, which are useful in gaining more knowledge about the disease, available treatment option or side effects of treatments but this is not always enough (Holmstrom and Roing, 2010). Such actions leave empowerment to those who already have the skills to empower themselves, while leaving the others behind. If providing standard materials may seem to decrease the workload for patients' education in the hospitals, it comes at the cost of increased utilization of emergency rooms and of phone calls overloading hospitals to manage disease symptoms or treatment side effects. Healthcare professionals can teach self-management and increase patient's problem solving

skills, in order to develop patients' understanding of their situations, and consequently, eliciting actual change and leading to self-management of their disease (Bodenheimer et al., 2002).

In the context of cancer care, a difference is often drawn between self-management and supported self-management. Foster et al. (2007) described self-management as “Approaches used by the individual affected by cancer and its effects to optimise living with the illness and its effects,” while a definition of supported self-management can be found in the Co-Creating Health Project (2008) as “what health services do in order to aid and encourage people living with a long-term condition to make daily decisions that improve health-related behaviours and clinical and other outcome”. The Macmillan Cancer Support self-management work stream of the National Cancer Survivorship Initiative (NCSI, 2009) has described cancer self-management as: **“awareness and active participation by the person in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment promote survival, health and well-being.”** The work stream distinguishes self-management support as: **“What health and social care professionals, and service delivery organisations to do support self-management”**.

## **2.2. Self-management in cancer**

The prioritisation of self-management support for cancer survivors not only builds on the evidence that patients want to be involved in healthcare decisions (Coulter and Jenkinson, 2005; Hibbard and Cunningham, 2008), but it is also grounded on a shift towards a more personalised and tailored approach to care following cancer treatment. Therefore there is a greater need for planned supported self-management, so that patients are confident and informed in terms of self-management and the support available to them (Davies and Batehup, 2009). This holds in particular for those forms of cancer which can be considered more as “chronic”. Self-management support should include systematic information and education provision, regular assessment of progress and problem, progressive goal setting as well as problem-solving support and training. Notably, different theoretical frameworks emphasize different aspects which are critically involved in carrying-out this process. Cognitive-behavioural theory (Beck, 1993) provides a psychotherapeutic approach that aims to solve problems concerning dysfunctional emotions, behaviours and cognitions through a goal-oriented, systematic procedure. On the other hand, Bandura's (1986) social cognitive theory posits that portions of an individual's knowledge acquisition can be directly related to social interactions and experiences. Self-efficacy, a person's belief in their own ability to succeed at a specific goal, in our case to manage the health implications of cancer and its treatment, is an important component to social



cognitive theory and can also enhance the effectiveness of cognitive-behavioural initiatives. Self-efficacy "refers to beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995) and is indeed a core component of many supported self-management interventions. Bandura (1977) outlined four sources of information that individuals employ to judge their efficacy: performance outcomes (performance accomplishments), vicarious experiences, verbal persuasion, and physiological feedback (emotional arousal). These components help individuals determine if they believe they have the capability to accomplish specific tasks. As Williams and Williams (2010) note: "individuals with high levels of self-efficacy approach difficult tasks as challenges to master rather than as threats to be avoided". Ajzen's Theory of Planned Behaviour (TPB; Ajzen, 1991), incorporated and extended Bandura's concept of self-efficacy (as *perceived behavioural control*), and assumes that health behaviour can be analysed in terms of rational decisions. The TPB includes also the social context (*subjective norms*), which refers to the perceived social pressures towards behaving in a certain manner (e.g., self-management), and the *attitudes* of the individual toward a behaviour. The TPB was found to be a viable framework to assess health behaviours in cancer (e.g., Blanchard et al., 2002; Courneya and Friedenreich, 1996, 1999; see also Armin and Conner, 2001 for a meta-analysis on efficacy of TPB). The advantage of this approach is that the factors helps to clarify rationality in individuals' behaviour, so that they are more accessible to clinicians. However, it should be noted that emotional factors (such as anxiety) are not directly accounted in the model, despite they may dramatically influence self-management.

Davies and Batehup (2010) reviewed studies on supported self-management in cancer and established guidelines on the development of supported self-management programs.

They distinguish interventions by: (a) type, depending on whether the intervention is focused on *adjustment* (i.e., facilitating transition from an acute phase to survivorship) or on *problems* (e.g., side effects of treatment); (b) delivery, including technology-assisted interventions; (c) techniques used, which may involve information provision, self-monitoring, goal setting, action-plans and positive feedback. Furthermore, tailored support should take into account factors such as motivation, anxiety and depression, social needs and social support, symptom burden and life-style. According to Davies and Batehup (2010) the effectiveness of self-management interventions should be determined by assessing outcomes at four different levels: patient, clinician, commissioner, and policy outcomes. In particular, patients should exhibit "health literacy (i.e. to navigate the healthcare system, understand information, and access support when

needed); self-efficacy to self-manage; self-management skills development; reduced symptom burden; improved quality of life; adjustment to survivorship; satisfaction with service”.

A serious limitation which may be encountered in implementing self-management programs in cancer care may be related to the lack of structured action plans. Importantly, attitudes toward self-management both from the patient and the family shall be taken into account. Eliciting preferences regarding involvement in healthcare from patients and their families is therefore a pre-requisite to implement self-management interventions, which should be followed by actions that take into account their preferences and their abilities (McCorkle et al., 2011).

### **2.3. eHealth intervention studies on self-management in cancer**

Recently, the use of technology in clinical trials has increased, especially for what concerns web-based self-management support. In general, interactive health communication seems to be more effective than standard interventions in increasing knowledge, physical activity, smoking reduction or cessation, and result in greater perceived self-efficacy and social support (Murray et al., 2003; deVries et al., 2008).

Efforts are also being made to integrate self-management support into aftercare. Since patient-initiated aftercare is becoming more popular in theory (Davies and Batehup, 2010), integrating technological self-management support into standard follow-up will be fundamental in providing cancer survivors with the knowledge, skills, and confidence to manage the long-term implications of cancer treatment and initiate their own aftercare when necessary. eHealth technologies provide the opportunity to customize communication, rapidly extract relevant information, and to deliver different tools integrated in a single platform.

Ruland and co-workers designed a platform for self-management (Web-choice; ([www.communicaretools.org](http://www.communicaretools.org)) in cancer with the involvement of end-users (Ruland et al., 2007).

The application included an *assessment component* allowing to monitor and report symptoms and difficulties. Patients could define their priorities for support along physical, functional, and psychosocial dimensions. Patients could track the status of their disease in order to alert healthcare providers, or use the data for consultations with their physicians, or for discussion concerning treatment and care. The data could be used to obtain *tailored self-management support*, displaying possible self-management actions (including explanations, indications on how to perform the action, risk, adverse effects, level of evidence, literature reference, and indications on when the physician should be contacted) from which the patient could choose those to undertake. All actions chosen were summarised in a self-management plan according to

the individual's symptoms and difficulties. The tool also provided access to reliable *information* on tests and treatments, life-style indications, patients' rights, and support group.

A *communication section* ensured that patients could anonymously share their experiences with other patients and obtain healthcare professional support. In addition, the application provided a *diary* for patient's personal notes.

The application was tested for one year in a randomized clinical trial (Ruland et al., 2013) measuring symptom distress as the primary outcome, and depression, self-efficacy, health-related quality of life, and social support as secondary outcomes. Patients who adopted the platform exhibited significantly lower symptom distress. Furthermore, improvements in depression over time were found in the experimental group, while decrease in self-efficacy and health-related quality of life was revealed in the control group.

Sundberg and coworkers (2015) designed a symptom reporting tool for prostate cancer patients undergoing radiotherapy, which allowed communication with nurses. Problem symptoms were investigated through literature review and interviews with patients and healthcare professionals and were used to design the application. The tool allowed to report and track symptoms through standardized symptom and quality of life questionnaires. Occurrence, frequency, and distress level of bladder, bowel, and sexual dysfunctions, fatigue, pain, worries, sleep, flushing and other side effects were measured. Nurses reviewed the data on a web interface, and received alerts to contact patients triggered by a decision support engine. Alerts could have different priorities based on the occurrence, frequency, distress and type of symptom reported. At the end of the reporting period (10 days), outcomes were assessed using focus-group and interviews.

The feasibility study included a sample of ten patients, treated in two university hospitals in Sweden, and eight nurses (four for each treatment centre). Patients reported the tool to be acceptable and user-friendly, despite their old age and very limited knowledge of smartphone prior to the study. Symptom report gave patients a sense of security and reassurance, and made them feel more prepared to consultation with physicians. Problems in the use of application concerned words meaning and scaling of symptoms. Most of the patients accessed the self-care advice tool, and found it useful. Nurses reported that patients concerns during scheduled appointments decreased compared to their standard. They experienced that patients' distress over symptoms was reduced. Worries concerned the possibility of increased workload using the application. The alert system was activated on various occasions and patients described that the interaction with nurses gave them a sense of involvement and collaboration.

Wheelock et al. (2015) implemented a remote follow-up program (System for Individualized Survivorship care, SYS.NET) for breast cancer survivors in TNM stage I, II, or III, who

completed acute treatment. The program consisted in a set of online questionnaires including the 36-Item Short Form Health Survey (SF-36), the 8-item Personal Health Questionnaire Depression Scale (PHQ-8), and self-reports on medical conditions, family history of disease, and symptoms experienced. Furthermore, patients could write in a free text area to ask questions or report concerns to the physicians. The assessment generated a clinical report with patient's symptoms, and identification of those above threshold for clinical concern. Based on patient responses, the tool also redirected to support resources.

Patients in the experimental group were compared with patients in standard care. The primary endpoint was the time elapsed between symptom reporting and remote evaluation of the symptom by a nurse practitioner. The secondary endpoint was the use of health care resources over a period of 18 months. Patients in the SYS.NET group were more prone to report new symptoms or changes in symptoms compared to controls, which were reviewed by the nurse within 3 days. No difference was found on secondary endpoint measures.

In view of the increasing number of cancer survivors and the potential role that interactive Web-based interventions could play in stimulating patient empowerment, it is important to individuate factors that make a web-based intervention an efficient and valid self-management tool. A recent review (Kuijpers, Groen, Aaronson, et al., 2013) on such tools identified 7 elements that are the most common for the majority of interventions: education, self-monitoring, feedback/tailored information, self-management training, personal exercise program and communication (see table below).

Elements of Web-based intervention	Recommendations for survivorship care	
	Long-term follow-up/surveillance	Management of (late) effects
Education	Information about reasons for surveillance	Information about possible late effects of cancer treatment
Self-monitoring	Recommendations for self-screening	Upload of relevant vital signs (eg, pain scores, blood values)
	Reporting results of self-screening	
Feedback/Tailored information	A personal follow-up schedule with frequency and type of screening	Advice for managing (late) effects as identified by self-monitoring data
Self-management training	Feedback on reported self-screening	Training to learn to cope with late effects of cancer treatment
	Training aimed at performing regular self-screening	
Personal exercise program	X	Individual exercise advice to prevent or reduce (late) effects, taking into account a survivor's specific needs and preferences
Communication with health care provider	Possibility to ask questions about follow-up and self-screening	Possibility to ask questions about symptoms and how to deal with them
Communication with fellow patients	X	Share experiences and tips about managing (late) effects

<sup>a</sup>X=application not relevant

*Figure 1: Most recommended elements in web-based interventions for cancer survivors (source: Kuijpers, Groen, Aaronson, et al., 2013).*

However, the majority of studies that actually compared web-based intervention with usual intervention reported mixed results in patient empowerment.

The problem could be the absence of adequate control groups and in any case patients also in the control group receive some kind of intervention characterized by a continue evolving (even though not web-based). Another difficulty in finding the efficacy of the intervention might be due to the fact that the considered elements were used in different combinations and adapted to specific patient populations, making it difficult to evaluate the outcome of each single element. Furthermore, most of the studies did not prescribe an intervention schedule, leading to a heterogeneity in frequency, intensity and length of use of the web-based intervention that makes difficult evaluating the outcomes.

Another important issue of web-based interventions is the high dropout rate (Eysenbach, 2005), especially due to a loss of interest (Bennett, Glasgow, 2009). A possible explanation can be found also in the perceived barriers typically related to technical aspects, such as problems with “Internet connection, slow loading of website, security concerns, discomfort with using the computer or Internet, and problems with related hardware” (Kuijpers, Groen, Aaronson, et al., 2013). To solve this criticism peer support, counsellor support, email and phone contact, frequent website updates, record keeping, and individualized feedback can help sustain intervention use (Brouwer, Kroeze, Crutzen et al., 2011; Schubart, Stuckey, Ganeshamoorthy et al., 2011). In order to implement a valid and efficient web-based intervention, it is crucial to consider not only patients who adhere to the intervention but also those patients that drop-out, using statistical analyses on an intention-to-treat basis (as opposed to only analyzing the participants who completed the intervention). Coherently, most recent studies on technology-based self-management interventions in cancer took into account patients’ perspectives with interviews and focus groups, and adopted an iterative software development technique (e.g., Lubberding et al., 2015; Wolpin et al., 2015).

Review of outcomes from previous technology-based interventions suggested that the effect of these platforms may be “dose-dependent” i.e., the greater use of the platform, the better the outcomes (Moore et al., 2008). Importantly, certain groups of cancer patients may require more intensive support (Fenlon and Foster, 2009; Addington-Hall et al., 2010; Davies and Bateup, 2010): this is the case of survivors experiencing depressive symptoms or psychological difficulties (e.g., survivors of gynaecological cancer), individuals at greater risk of treatment-related sexual dysfunction (e.g., prostate and gynaecological cancer survivors), low literacy groups, ethnic minorities, individuals who are single, socially isolated, or lacking social support,

older cancer survivors and others with co-morbidities or mobility problems, individuals requiring behaviour change or lifestyle change interventions (e.g., overweight or obese survivors).

Furthermore, it should be taken into account that supportive self-management should be supported by face-to-face contact, where the platform is conceived as part of a patient-healthcare provider relationship and as an adjunct to other types of supported self-management delivery (e.g., Campbell et al., 2007). This partnership was often one of the most important factors in boosting self-efficacy among participants (Cimprich et al., 2005). In addition, adoption of the platform is expected to facilitate changes in life-style and self-management only when the individual is ready to acknowledge that a change is required (Stages of Change model; Prochaska and DiClemente, 1983). Patients should first be aware of the benefits of self-management, before they can contemplate making any changes towards this method of dealing with the consequences of cancer and its treatment. This highlights the importance of health literacy in creating a patient-centred healthcare system (Coulter and Ellins, 2006), and demands for a tailored intervention that takes into account patients' preferences and state of activation.

### **3. Review of existing similar web based platforms**

In the following sections, we present further examples of online tools and platforms available to cancer patients and highlight their characteristics. Further information on the state-of-art will be given in deliverable 3.1 'Initial iManageCancer Architecture Document' in the context of Work Package 3 'System Design and Integration'.

#### **3.1. Social media platforms for patients**

People often join support groups online when they find themselves in stressful circumstances, such as having a serious health condition. van Uden-Kraan et al.(2008) reported about the outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. The analysis of the authors of 32 interviewed participants of online support groups revealed the following empowering processes: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. Disempowering processes were mentioned far less often. Empowerment outcomes mentioned were: being better informed; feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; enhanced self-esteem and social well-being; and collective action.

**PatientsLikeMe**<sup>3</sup> represents the most prominent and commercial online patient platform with more than 250.000 members and 2000 reported health conditions including all kinds of cancer diseases. PatientsLikeMe allows patients to input data on their conditions, treatment history, side effects, hospitalizations, symptoms, disease-specific functional scores, weight, mood, quality of life and more resulting in a patient record with assessment tools for patients to gain insight in their disease and that they share with the community and they provide for research. The data-sharing platform is designed to help patients find other patients with the same conditions, and allowing them to place their experiences in context and see what treatments have helped other patients like them. One can search patients with similar conditions, symptoms and treatments and can follow their case or even contact them in a chat. A forum offers the possibility to start a discussion on a specific topic or to search for topics. Further services available to patients are a clinical trial finder, the compilation of a doctor visit sheet from the record and to connect the Fitbit activity tracker with the record. In addition, the platform allows the patient to invite his caregivers to share his record or to connect with other patients and create his social network. The business model behind the platform focus on the sale of aggregated, alleged de-identified data to commercial partners, including pharmaceutical companies and medical device makers.

Many research papers were published on the benefit of this platform for clinical research. Some of them also investigate the ways in which patients respond to the shared use of personal health data (Frost and Massagli, 2008). Frost and Massagli (2008) conclude from their research on health data sharing in PatientsLikeMe the need to design innovations that promote data-centered patient conversation since many patients refer personal health data in their comments.

**CancerConnect.Com** is a platform for cancer patients that offer them a forum with different target groups for discussions and experience exchange on their cancer case, but also various information sources about cancer diseases ranging from screening and testing to treatment and the management of side effects including videos and recorded and live chats with experts. In opposite to PatientsLikeMe, CancerConnect does not include a personal health record. CancerConnect is a specialisation of OMNIConnect, a US private label social media application for clinics and hospitals to support their patients, create community, and extend their brand for patients, caregivers, and their family.

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<sup>3</sup> [www.patientslikeme.com](http://www.patientslikeme.com)

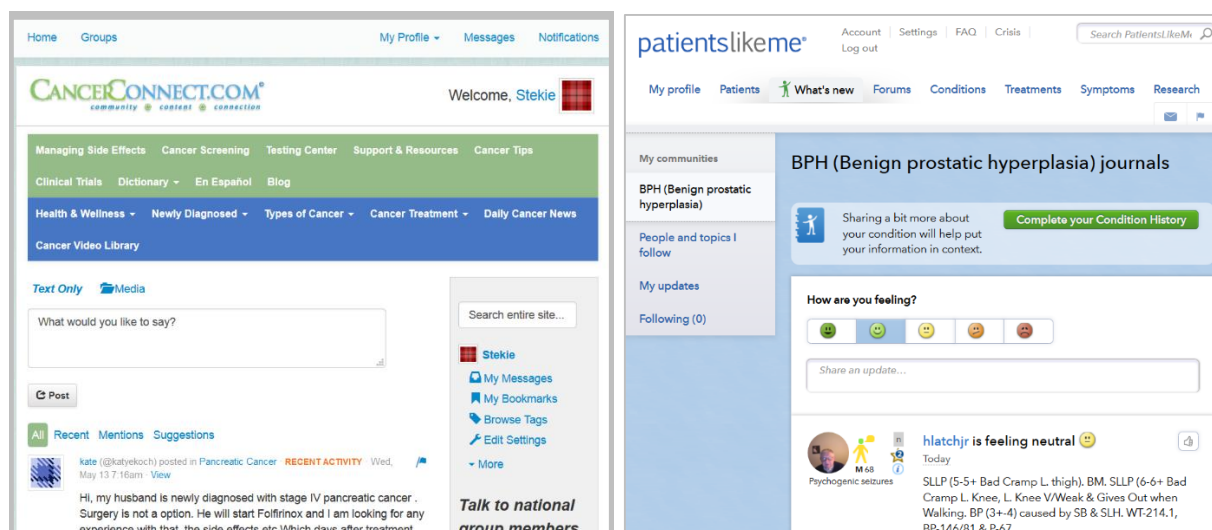


Figure 2: Personal home page of patient platforms PatientsLikeMe and CancerConnect.Com.

The Patient Empowerment Network is another example of a social media platform that aims at information provision through video based content and web meetings.

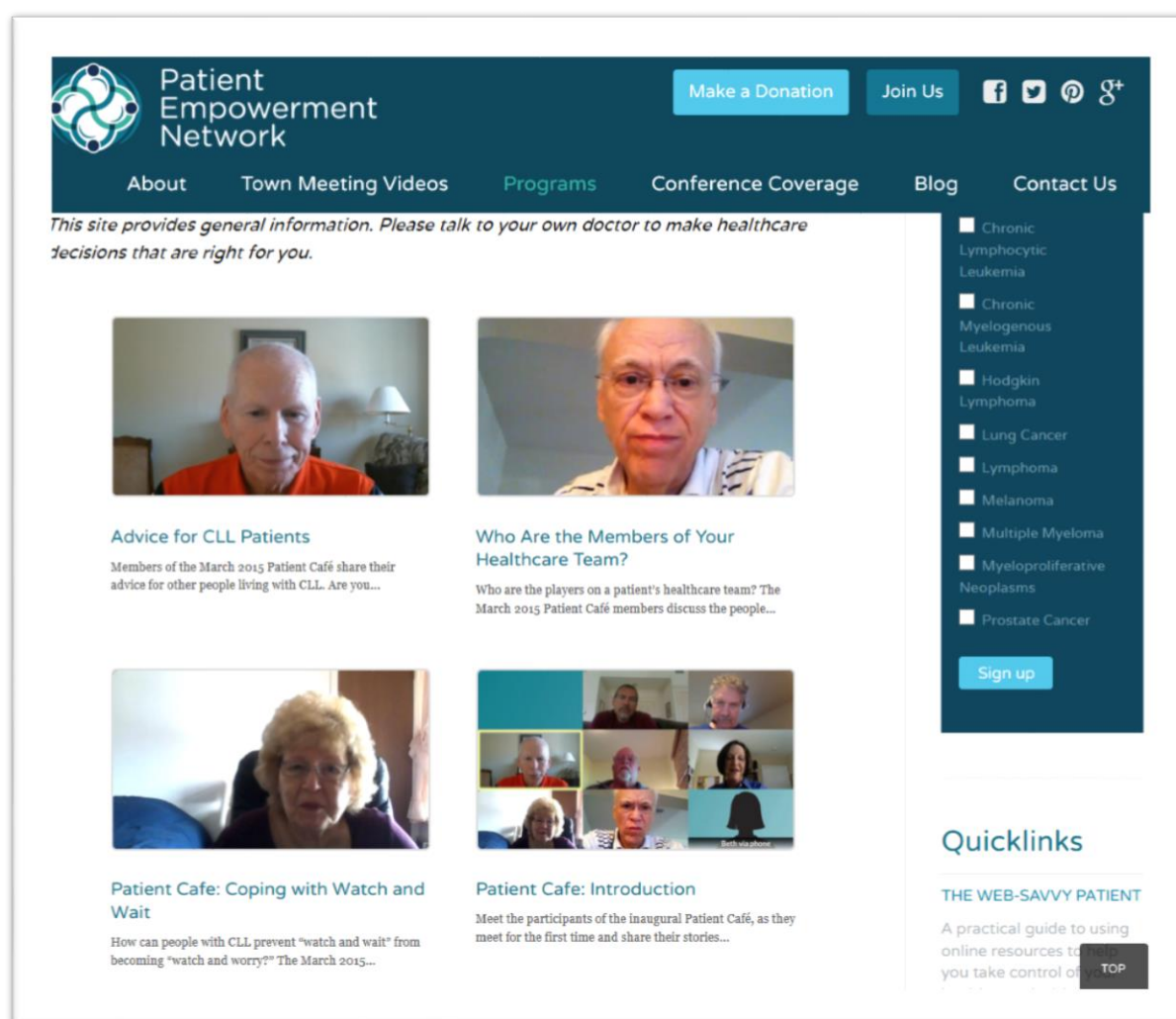


Figure 3: Virtual patient cafe of the platform Patient Empowerment Network.



### 3.2. Online information resources for cancer patients

Access to understandable high quality information on cancer medicine plays a fundamental role in the empowerment of patients.

Davies and Thomas (2007) assessed in a review paper information needs of cancer patients and their satisfaction with the information they have on their cancer condition. According to Davies and Thomas, adequately informed patients, who share decision-making with their medical team, have been shown to have greater autonomy and physical well-being within randomized and prospective observational studies. Patients offered higher levels of information also tend to have improved compliance, and significantly reduced anxiety and depression. If they are not adequately informed the anger and frustration associated with an inability to understand their treatment options can lead to anxiety, depression, poor compliance and cooperation with strategies to reduce treatment related side-effects. Information is especially important in the area of lifestyle, since published evidence has highlighted that patients who decide to improve their lifestyle will have major benefits in terms of quality of life and physical outcomes.

Various national and international websites exist that provide relevant information to cancer patients on their disease and only a few examples are listed here. They are usually offered by national comprehensive cancer centres, cancer charities and patient organisations.

The above mentioned platform **CancerConnect** represents both an information portal as well as an online community. There is also some evidence that cancer patients learn more from educational videos compared to text based training resources (McGregor, 2003). In consequence, the European website **eCancerPatient**<sup>4</sup> provides only educational videos for various medical aspects of cancer diseases. **Cancer.Net**<sup>5</sup> is the patient portal of the American Society of Clinical Oncology. The **Patient Empowerment Network**<sup>6</sup> is an information platform with video resources, a blog and interactive online events such as the patient café. For children with cancer an important resource is the website provided by the **German Society of Paediatric Oncology**<sup>7</sup> (GPOH) including information about cancer types and all related issues to parents of affected children.

Since iManageCancer also intends to provide personalised information to patients in Europe an index of good quality national health information resources on cancer need to be built for the

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<sup>4</sup> <http://ecancerpatient.org/>

<sup>5</sup> <http://www.cancer.net>

<sup>6</sup> <http://www.powerfulpatients.org>

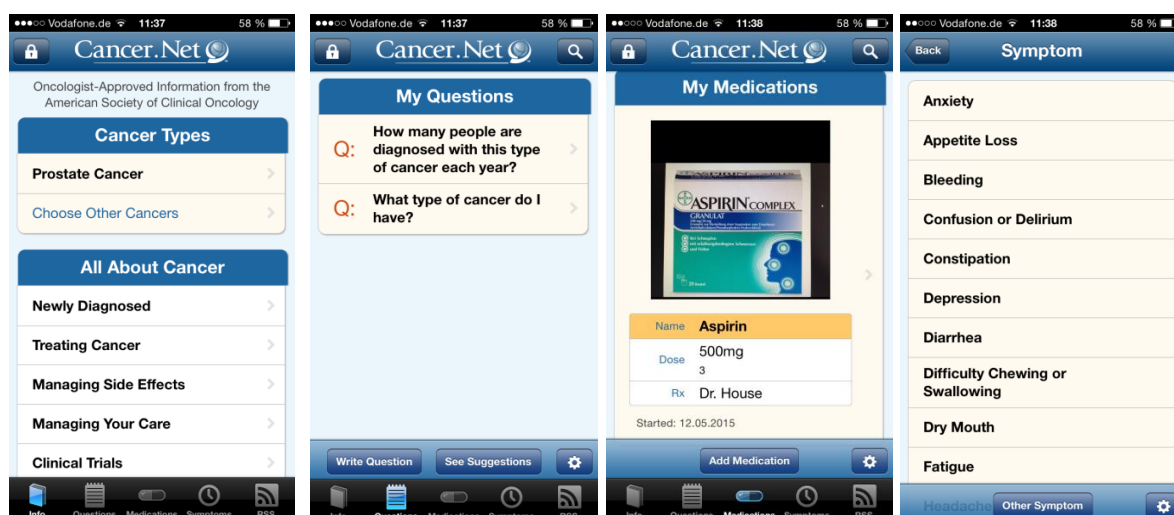
<sup>7</sup> [http://www.kinderkrebsinfo.de/patients/index\\_eng.html](http://www.kinderkrebsinfo.de/patients/index_eng.html)

target pilot countries. In Germany, the website of the **Deutsche Krebshilfe**<sup>8</sup>, the **Deutsche Kinderkrebsstiftung**<sup>9</sup>, and the **Krebsinformationsdienst of Deutsches Krebsforschungszentrum**<sup>10</sup> and the **Deutsche Gesellschaft für Kinderonkologie**<sup>11</sup> are such examples. Relevant websites in Italy represent **Associazione Italiana per la Ricerca sul Cancro**<sup>12</sup> with very helpful and good structured information about cancer diseases and **Associazione Italiana Malati di Cancro**<sup>13</sup>, an information portal for patients and their relatives.

### 3.3. Cancer specific apps for patients

Various health apps for cancer patients can be found in the app stores of Google and Apple. They cover multiple aspects of the disease and their management. Some of those apps with English user interface are exemplified in this section to illustrate the spectrum of available support.

**Cancer.Net Mobile** is a free app for iOS and Android of the American Society of Clinical Oncology. It guides through targeted information on all types of cancer, contains an interactive tool to keep track of questions to ask healthcare providers and record voice answers, allows to save information about prescribed medications, including photos of labels, tracks symptoms to record the time and the severity of symptoms and side effects and features videos, podcasts, and articles.



<sup>8</sup> <http://www.krebshilfe.de/nc/startseite.html>

<sup>9</sup> <http://www.kinderkrebsstiftung.de/>

<sup>10</sup> <https://www.krebsinformationsdienst.de>

<sup>11</sup> [http://www.kinderkrebsinfo.de/index\\_eng.html](http://www.kinderkrebsinfo.de/index_eng.html)

<sup>12</sup> <http://www.airc.it>

<sup>13</sup> <http://www.aimac.it/>

Figure 4: App Cancer.Net Mobile.

**Cancer Coach** is a free app (iOS, Android) for breast and colon cancer patients who can access information about personalized cancer treatment options and use tools such as a calendar, note-taking and audio-recording functions, a list of questions to ask the doctor, a glossary of terms and links to additional resources (Developed by Breastcancer.org, Fight Colorectal Cancer, and Genomic Health, Inc.).

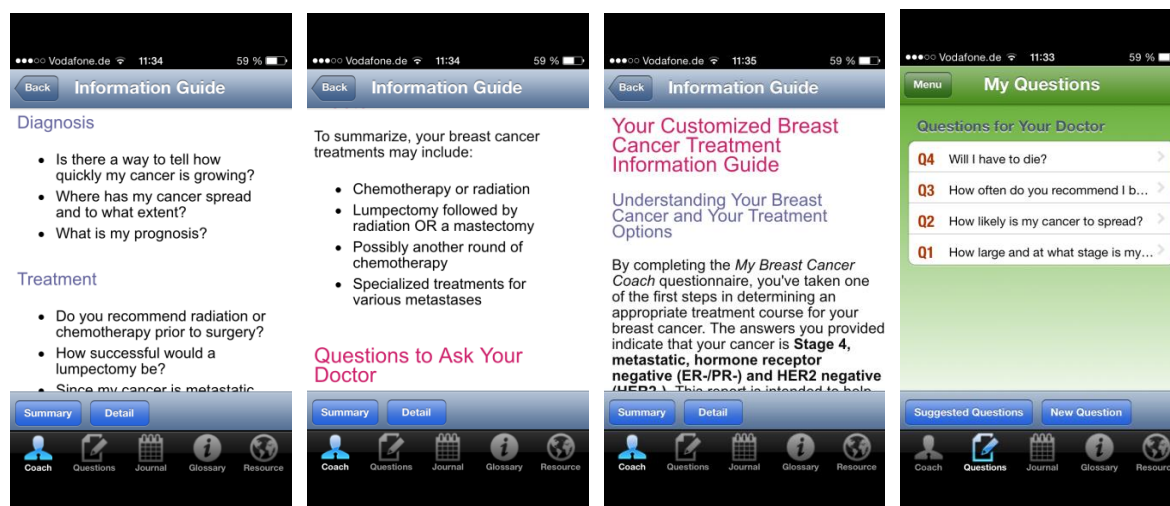


Figure 5: App Cancer Coach.

**Breast Cancer Diagnosis Guide** is a free app that walks patients through their breast cancer pathology report and other tests and information in order to help to decide which treatments are right for a patient. (Developed by Breastcancer.org)

**Breast Cancer Diary** is a commercial app for breast cancer patients to keep a record of all medical information on the cancer case. The diary allows users to document pain, symptoms, mood and pain management, to record thoughts, notes, reminders, To-Do lists and questions and answers. It assists in keeping track of appointments, biopsies, test results, surgeries and procedures and in recording therapy details. Further to this, patients can record breast exam screenings and breast cancer prevention lifestyle changes including tracking weight, diet, exercise, vital statistics, medications and side-effects.

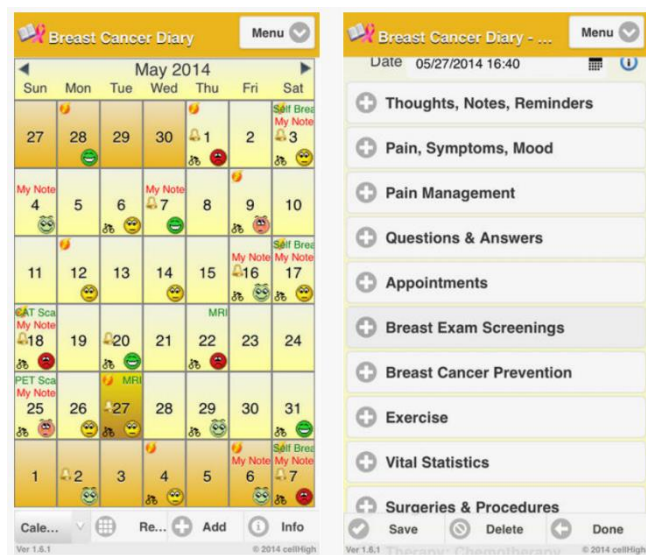


Figure 6: App Breast Cancer Diary.

**My Cancer Manager** (iPhone) allows patients tracking for common physical and emotional concerns such as fatigue, sleep, sadness, anxiety and pain and links to related cancer information. In addition, the user can keep track on potential life worries such as family, work, money and nutrition. It contains a personal journal to record thoughts and questions, and links to a Cancer Support Community nearby. (Provided by Cancer Support Community)



Figure 7: App My Cancer Manager.

**iCANCer** (iPhone) is a commercial app designed to help patients, caregivers, and cancer survivors manage their medical information. iCANCer seeks to help store personal medical information including cancer treatments, medications, medical issues, appointment information, and medical contacts. (Developed by Naomi Bartley)

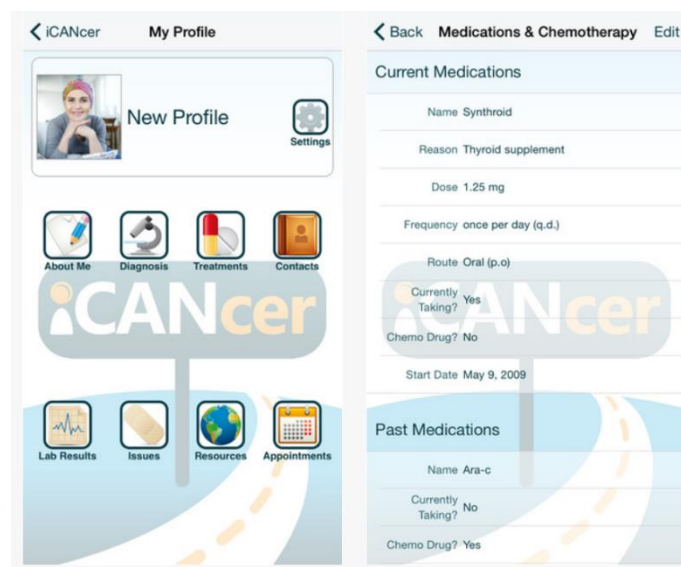


Figure 8: App iCANcer.

**Pocket Cancer Care App** (iPhone) lets patients browse questions to ask their doctor based on their diagnosis, build a list of questions, and record and play back doctors' answers. (Developed by the US National Coalition for Cancer Survivorship)

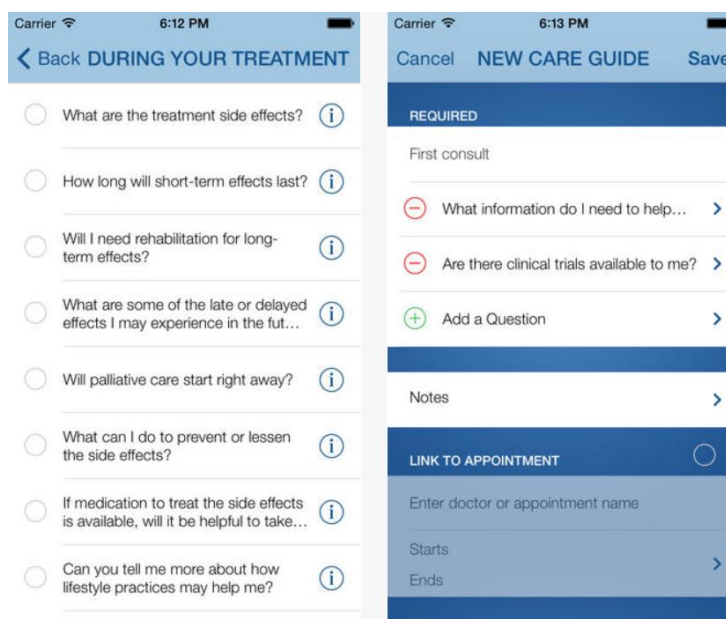


Figure 9: Pocket Cancer Care App.

**Cancer Blockade** (iPhone) is a free serious shooter game to prevent cancer cells to invade the body. (Developed by Dirk Fried Karnath & Gisa Borchers GbR for BodyXQ)





Figure 10: Cancer Blockade Game.

### 3.4. Personal Health Record Systems

The advancements in healthcare practice, the limitations of the traditional healthcare processes and the need for flexible access to health information, create a continuing demand for electronic health systems (e-health systems) everywhere. E-health (Eysenbach, et al., 2001; Griskewicz, 2002) systems encompass a wide range of services that engage computer science and healthcare in an unprecedented, innovative way to support the healthcare delivery.

In the field of e-health, electronic health record services are considered critical to aid management and maintenance of patient health-related information. For years, the basic mean of maintaining patient information has been the paper-based record. However, paper-based patient records bring many drawbacks (Chen et al., 2012; Lovis et al., 1998) such as accessibility, readability and conservation limitations. The drawbacks of paper-based records led to the evolution of electronic health record systems (EHR systems or EHR-S) in order to be able to maintain and manage patient health-related information electronically. An EHR is defined as the continuing, systematic and longitudinal collection of an individual patient's health information in digital form (HIMMS, 2006). The information may come from different healthcare environments, is presented uniformly, is accessible from different locations and is shared to healthcare facilities and devices, through various network technologies.

The concept of EHR is often confused with the concept of electronic medical record (EMR) and personal health record (PHR) (Garrett et al., 2011; Tang et al., 2006; Garets and Davis, 2006; Nagle, 2007; Charters, 2009). For clarification purposes we provide our working definition of a PHR system, in line with the definition given in “Personal Health Records and Personal Health Record Systems: A Report Recommendation from the National Committee on Vital and Health Statistics” (2006).

*“The term “record” in “personal health record” may itself be limiting, as it suggests a singular static repository of personal data. The Committee found that a critical success factor for PHRs*

*is the provision of software tools that help consumers and patients participate in the management of their own health conditions. A “personal health record system” provides these additional software tools. The Committee proposes adopting the term “personal health record” to refer to the collection of information about an individual’s health and health care, stored in electronic format. The term “personal health record system” refers to the addition of computerized tools that help an individual understand and manage the information contained in a PHR. These terms are analogous to the terms “electronic health record” and “electronic health record systems” that have been adopted by the standards development organization HL7, which is leading the standards activity in this area. The PHR and the PHR system are intended for use by consumers, patients or their informal caregivers, in contrast with EHR systems that are intended for use by healthcare providers.”*

It is therefore obvious that the concept of EHR is more generic and encompasses the PHR and EMR concepts. Essentially, the term describes the systematic collection of health information about an individual patient that is provided by healthcare professionals or the patient himself and can be shared across multiple healthcare environments when it is required, through various network technologies (Katehakis and Tsinakis, 2006). Thus, a PHR and an EMR can serve as data sources to an EHR (interconnected systems) or can be identified as integral parts of it (tethered systems), in specific EHR system implementations. Users of an EHR may be both patients and health professionals, while different levels of data accessibility and information control can be applied to them according to their role.

The PHR concept is patient centric in the sense that the management of a personal health record is primarily the responsibility of the patient. The advantages of personal health records are numerous (Endsley et al., 2006; Kaelber and Pan, 2008). PHRs provide a complete summary of patients' health history, enhance accurate clinical diagnosis and empower patients to take more active role in their own health and make informed decisions. The potential of personal health records to improve healthcare delivery and reduce costs has been recognized in many countries worldwide. In recent years many regional and national healthcare networks based on PHRs have been established in Europe (Dogac, 2012) and America (Carrion et al., 2011). At the same time PHR research, development and adoption efforts have received significant funding. Due to this global interest and support of electronic personal health records, emerging PHR systems and their associated tools are evolving constantly.

The continuing growth of electronic personal health record systems leads to an ongoing research into their evaluation from different viewpoints (Kaelber et al., 2008). Several such studies have been recently reported (Haggstrom et al., 2011; Halamka et al., 2011; Kim and Johnson, 2002;

Liu and Hayes, 2010; Liu et al., 2011; Mykkänen et al., 2010; Peters et al., 2009; Raisinghani and Young, 2008; Segall et al., 2011; Sunyaev et al., 2010). The studies reported in (Haggstrom et al., 2011, Liu and Hayes, 2010; Peters et al., 2009; Segall et al., 2011) focus on the evaluation of the usability of PHR systems and the provision of generic design recommendations. Research reported in (Halamka et al., 2011; Liu et al., 2011; Raisinghani and Young, 2008; Kahn et al., 2009) identified various problems from the adoption of PHR systems while studies in (Kim and Johnson, 2002; Mykkänen et al., 2010; Sunyaev et al., 2010) attempt to define requirements that should be met by effective PHR systems and which can be used for analysis and comparison purposes.

Two recent reviews by FORTH (Genitsaridi et al., 2013, 2015), evaluated 25 PHR systems which are shown in Table 1 and the results of the technical evaluation will be also reported in D3.1. Among the conclusions are that only a small percentage of existing PHRS implementations satisfies the specified requirements, while most analyzed personal health record systems have functional limitations. In addition, PHR systems do not adhere to well-known accessibility standards for people with disability and elderly people and thus, impose barriers to their adoption. Our study revealed the need to analyse the quality of health data in a personal health record system that may be generated by non-professionals such as patients and wellness providers.

In summary, the field of personal health record systems is a new and constantly evolving area, with great potential for patient-centred care and various future research directions. The benefits are yet to be realized, although it is clear that they provide a tremendous opportunity, for engaging patients more broadly in their own health and healthcare, indicating a generally growing interest in PHR use, but there is much more to be done in tailoring PHRs for intelligent patient health self-management and sustainability. There is also some evidence for the inclusion of certain functionalities in PHR systems, especially from the patient perspective, as gleaned from the utilities they use most. However, the clinical effectiveness and cost effectiveness of PHR interventions has not been adequately confirmed, and this remains an important topic for future research within iManageCancer.



Table 1. Evaluated Personal Health Record systems.

PHR System	URL
1. Microsoft HealthVault	<a href="http://www.microsoft.com/en-gb/healthvault/default.aspx">http://www.microsoft.com/en-gb/healthvault/default.aspx</a>
2. Web MD Health Manager	<a href="http://www.webmd.com/health-manager">http://www.webmd.com/health-manager</a>
3. NoMoreClipboard	<a href="http://www.nomoreclipboard.com/">http://www.nomoreclipboard.com/</a>
4. PatientsLikeMe	<a href="http://www.patientslikeme.com/">http://www.patientslikeme.com/</a>
5. Patient Ally	<a href="https://www.patientally.com/Main">https://www.patientally.com/Main</a>
6. Patient Fusion	<a href="http://www.practicefusion.com/pages/phr.html">http://www.practicefusion.com/pages/phr.html</a>
7. MyOscar	<a href="http://myoscar.org/">http://myoscar.org/</a>
8. myMediConnect PHR	<a href="http://www.passportmd.com/">http://www.passportmd.com/</a>
9. eclinicalWorks Patient Portal	<a href="http://www.eclinicalworks.com/products-patient-portal.htm">http://www.eclinicalworks.com/products-patient-portal.htm</a>
10. MedHelp PHR	<a href="http://www.medhelp.org/">http://www.medhelp.org/</a>
11. MyALERT	<a href="http://www.alert-online.com/myalert">http://www.alert-online.com/myalert</a>
12. CareZone PHR	<a href="https://carezone.com/">https://carezone.com/</a>
13. Indivo-X	<a href="http://indivohealth.org/">http://indivohealth.org/</a>
14. Epic MyChart	<a href="http://www.epic.com/software-phr.php">http://www.epic.com/software-phr.php</a>
15. 911 Medical ID	<a href="http://www.911medicalid.com/">http://www.911medicalid.com/</a>
16. zweena PHR	<a href="http://www.zweenahealth.com/">http://www.zweenahealth.com/</a>
17. MedicAlert	<a href="http://www.medicalert.org/">http://www.medicalert.org/</a>
18. Tolven	<a href="http://www.tolven.org/">http://www.tolven.org/</a>
19. HealtheTracks	<a href="http://www.healthetracks.com/">http://www.healthetracks.com/</a>
20. LifeLedger	<a href="http://www.elderissues.com/">http://www.elderissues.com/</a>
21. OpenMRS	<a href="http://openmrs.org/">http://openmrs.org/</a>
22. KIS PHR	<a href="http://kismedicalrecords.com/">http://kismedicalrecords.com/</a>
23. MedicKey PHR	<a href="http://medickey.com/">http://medickey.com/</a>
24. Dossia	<a href="http://www.dossia.org/">http://www.dossia.org/</a>
25. Minerva Health Manager	<a href="http://www.myminerva.com/">http://www.myminerva.com/</a>

### 3.5. MyHealthAvatar

The MyHealthAvatar project<sup>14</sup> is a research and demonstration action, through which the feasibility of an innovative representation of the health status of citizens through a 4D MyHealthAvatar is studied. A 4D avatar is a unique interface that allows data access, collection, sharing and analysis by utilizing modern ICT technology, overcoming the shortcomings of the existing resources in Europe, which is highly fragmented. It is the citizen's lifelong companion, providing long-term and consistent health status information of the individual citizen along a timeline representing the citizen's life, starting from birth. The avatar is equipped with a toolbox to facilitate clinical data analysis and knowledge discovery.

The system will be presented here in more detail since it will be adapted to the needs of cancer patients and embedded in the iManageCancer platform.

As a proof of concept, the system features the following properties:

1. Information collection and access. The 4D avatar functions as an interface to support the collection of, and access to, the complete medical information relating to individual citizen's health status, gathered from different sources, including medical data, documents, lifestyle and other personal information, represented along a timeline. Also, it is an interface to access integrated predictive computer simulation models which foresee the growth of the disease and the effect of treatment. The system has:

- Internal data repositories to store individual data for the avatars
- An internal model repository to store models commonly used by all the avatars.
- Links to external sources, such as hospitals' Electronic Health Records (EHRs) and other data and model repositories.
- A range of modern ICT techniques will facilitate the data collection and information access, including: Information extraction from the web and data collection using mobile apps; Semantics and linked data to support the data/model searching and reasoning.

2. Data management, which is controlled by the individual citizens. They will decide how the data is shared by stakeholders. MyHealthAvatar is a tool that allows highly self-motivated data management and user-centred data collection, supported by the necessary data integrity measures. These are supported by the underlying ICT architecture, which have adequate measures to ensure data reliability and integrity.

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<sup>14</sup> <http://www.myhealthavatar.eu/>

3. Information analysis using an integrated ICT toolbox, which is a vehicle by which medical professionals can augment their clinical knowledge with heterogeneous information from the avatar for clinical decision making and knowledge exploration. It offers significant assistance to doctors by:

- displaying related information in a body-centric view around the avatar.
- allowing simulation via access to the model repositories supported by the computing resource provided by the architecture.
- performing visually assisted data analysis (i.e. visual analytics) to extract clinically meaningful information from the heterogeneous data of individual/shared avatars, such as the patterns of symptoms, experience of treatments, medicines, self care guidelines, risk factors etc.

In MyHealthAvatar the most important stakeholders are:

- Patients/Citizens. In MyHealthAvatar where personalized provision of health and patient empowerment services are to be delivered, patients represent a prominent type of stakeholders.
- Researchers/Medical personnel expert domain users. These can be further classified in bioinformaticians, clinicians, users of clinical trials management systems, etc.
- .

### 3.5.1. Project Information

Duration: March 2013 – Feb 2016, 36 months

Total Cost: 3,364,588.00 €

Project Funding (EU Funding): 2,447,000.00 €

Programme: 7<sup>th</sup> Framework Programme of European Commission – ICT (FP7-ICT-2011-9)

### 3.5.2. MyHealthAvatar Platform

The current platform of MyHealthAvatar can be accessed via (invitation only):

<https://www.myhealthavatar.org/mha/>

The platform places emphasis on patient empowerment, encouraging them to stay in a healthy lifestyle by logging & monitoring their own lifestyle data. The development of the platform is going through a few stages:

## 1) Initial stage (completed in July 2014):

- a) Location and activity data collection using Fitbit device (<https://www.fitbit.com/>) and Moves mobile app (<http://www.moves-app.com/>). The users are also manually log their activities through textbox.
- b) The users are able to view their actives on a calendar-based online diary – see the screenshot below

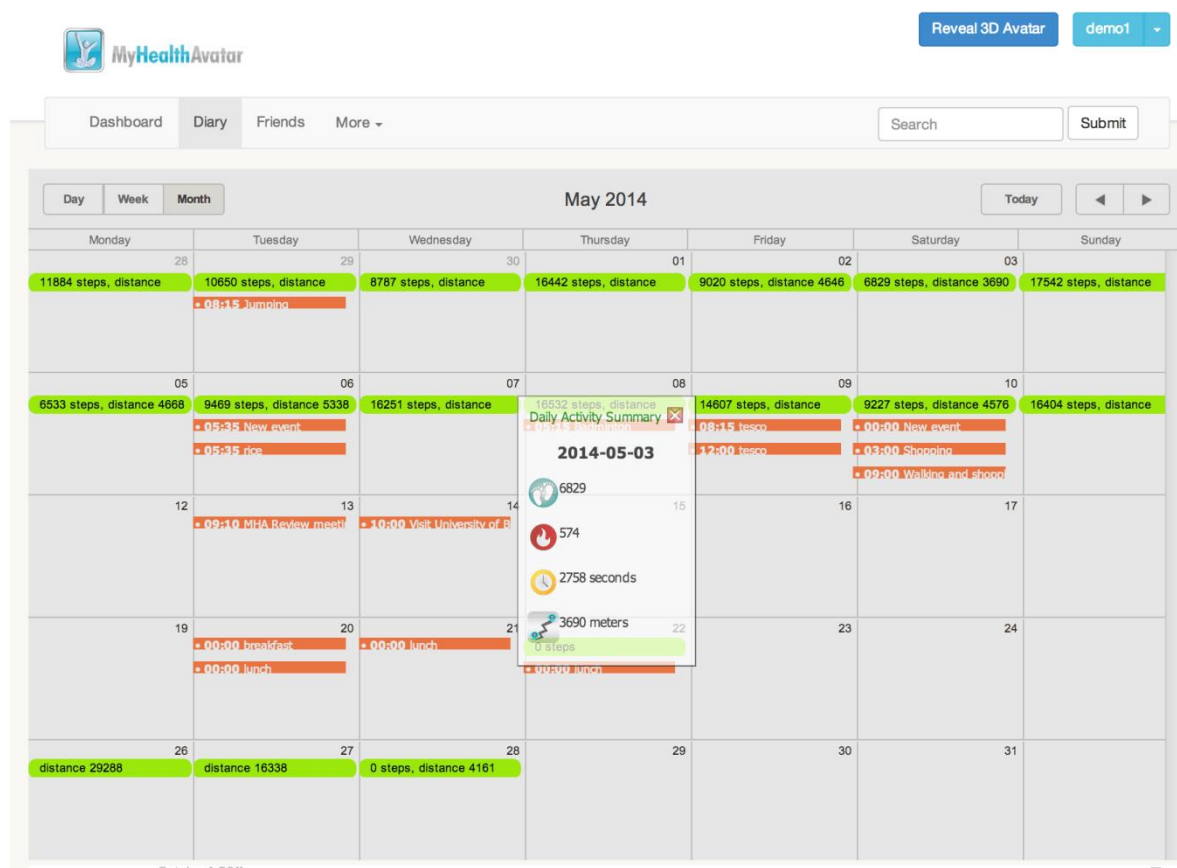


Figure 11: Screenshot of MyHealthAvatar online diary to plan and visualize.

- c) The dashboard shows overall activities & the latest news on the user's health as shown in the screenshot below.

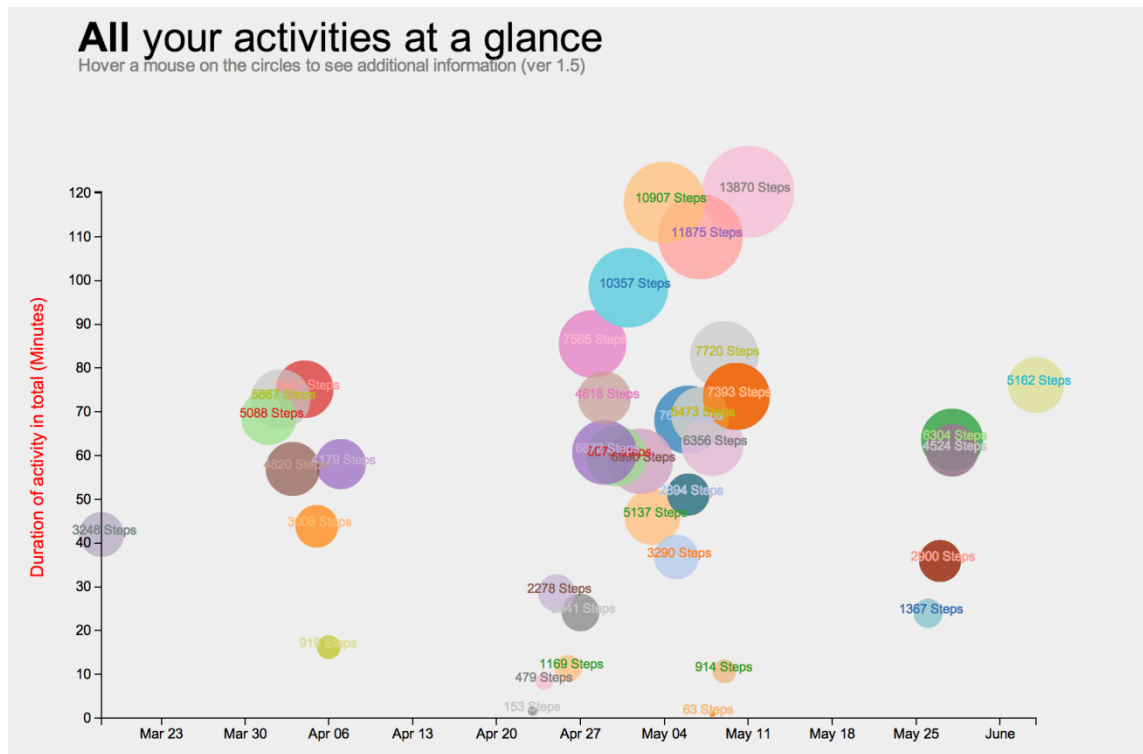


Figure 12: Dashboard Screenshot of MyHealthAvatar to visualize activities over time.

- d) Tweets from your Twitter account can be collected into the MyHealthAvatar platform for further health-related analysis in the future.
- e) A 3D human anatomical model is available to show 3D human anatomy.

## 2) Next stage

- a) More devices will be linked into the platform to allow for the collection of heart rate, blood pressure and body temperature
- b) The diary will allow the users to plan their activities, such as exercises, medications.
- c) There will be reminder services that send alert to the users for their planned activities.
- d) Incentive methods will be introduced to allow the users to get rewarded for their healthy behaviours
- e) More data analysis tools will be made available.
- f) The users will be allowed to make different queries about their own data.
- g) The users will be able to access their health data, as well as health related knowledge through the 3D human anatomical model.

### **3.5.3. Security & Legal Issues**

MyHealthAvatar has a legal partner (lawyers) who is working on the legal framework of the project to make sure that the processing of personal data will meet the legal requirements. This framework envisages the following general policy:

- a) Personal data will be stored in a secured location with security data transmission in compliance with the European laws.
- b) The users will have entire control on the management and sharing of their own data
- c) The users will be fully informed about all the research activities in the projects with respect to the usage of their data.

iManageCancer plans to apply the legal framework of MyHealthAvatar and to extend it where required.

## **4. Clinical perspective of iManageCancer platform**

A semi-structured interview was developed based on models of patient-physician communication and decision-making styles, and on Ajzen's theory of planned behaviour (Ajzen, 1992).

In the first part of the interview, the typical therapeutic pathways for patients were assessed as figures involved in each phase of treatment. The interviews proceeded with questions aimed at exploring the role assumed and the type of communication between figures involved. Possibility, motivation and competence in communication, as well as correspondence with expectations were also investigated. A similar schema was used to explore the area of decision-making and responsibility. In the second part of the interview, the interviewer asked about the difficulties commonly encountered by patients and healthcare providers throughout the therapeutic path, as well as the needs and the resources in the different phases of treatment.

For each difficulty, resource and possible solution, the interviewer tried to explore relevant characteristics in terms of the following features:

- a. Info or Data collection
- b. Activate relations
- c. Communications/interactions
- d. Contents/knowledge
- e. Education/training
- f. Organizers (agendas, tasks, memo)

g. Entertainment

Eight physicians and ten nurses or technicians from the day hospital or from the urology, breast, and radiation therapy units of the European Institute of Oncology were interviewed (see Appendix A).

In the following sections we present results from the analysis of interviews. In the subchapter “Role of clinicians”, reported interactions among healthcare professionals are described. In the other subchapters, clinical pathways are presented for each Unit (Breast Cancer, Urology, Radiation Therapy, Day Hospital) and relevant critical issues raised by clinicians are discussed. Possible solutions in terms of platform features are proposed. A “General Issues” subchapter presents those themes which were overlapping regardless of the type of cancer disease or hospital unit.

#### **4.1. Role of clinicians**

In the majority of cases, doctors recognize nurses and technicians a fundamental role in patients’ support, providing an intense relation that is important to the patient. They are seen as a valuable source of information about the patient and to the patient, and as a filter to avoid question overload. The value, especially for those professionals who worked in other structures, is that nurses are specialized on a certain disease or on chemotherapy/radiotherapy. Therefore they are able to provide specialized education to patients, and they are well aware of common problems related to each pathology.

Nurses and technicians report positive interactions with physicians. Most positive interactions were those where the physician was seen as easily “accessible”.

Case-manager nurses were also reported to be a pivotal reference for the phases preceding surgery, where all bureaucracy and general clinical information about the patient converge and can be managed. Ward nurses and call centre nurses were also reported as important resources in managing the phase after discharge.

## 4.2. Breast cancer

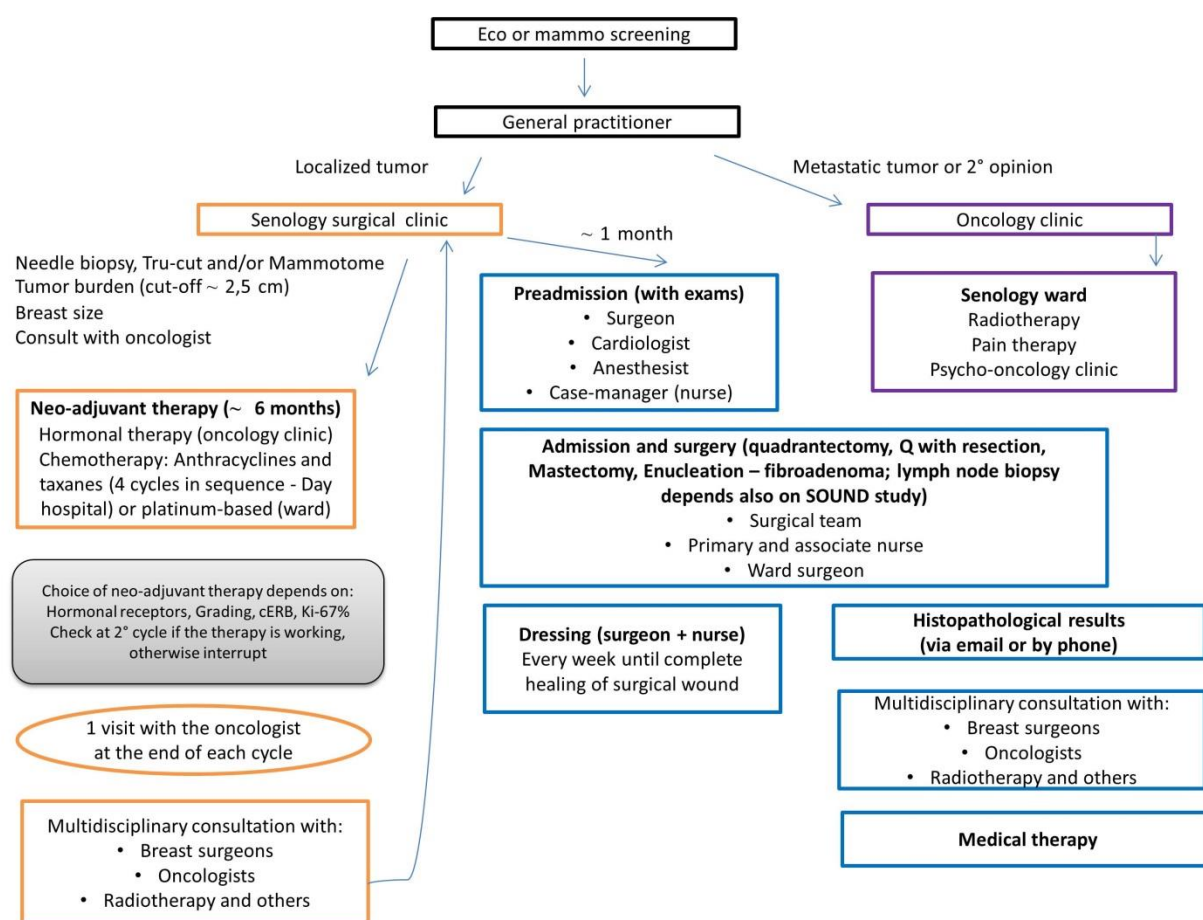


Figure 13: Flowchart of breast cancer patients.

**PROBLEM 1** (Oncologist, nurses): patients undergoing hormonal therapy report sexual problems due to side effects of therapies. For instance, those in therapy with Decapeptyl experience vaginal dryness and decrease of libido. These problems are treated from a strictly medical point of view (e.g., prescription of lubricants), or as anecdotal reports. Patients do not have a reference figure for these type of difficulties. For instance: “patients often tell me things as a women’ confidence. I wonder often if this is a hidden need of my patients”.

### POSSIBLE SOLUTIONS:

- **Contents/knowledge.** *Inform patients about common psycho-emotional status during breast cancer treatment and educate on the role of the psycho-oncologist.*
- **Activate relations.** *Possibility to request psychological or sexological support*



**PROBLEM 2 (Nurses):** Most cancer patients present problems in the sexual area. This has an impact on patient mood and empowerment, on patient's social and relational life and patient's motivation to manage the critical situation.

**POSSIBLE SOLUTIONS:**

- Activate relations. *Sharing experience with other patients and/or psychoeducational support*

**PROBLEM 3 (Nurses):** After surgery (especially surgeries that involve changes in body image) some patients have difficulties in watching their body. This is considered a problem both for nurses in the educational phase and a problem for patients in the management of their situation.

**POSSIBLE SOLUTIONS:**

- Contents/knowledge. *Inform about body image problems and favour awareness (e.g., through an avatar in the platform)*

### 4.3. Prostate cancer

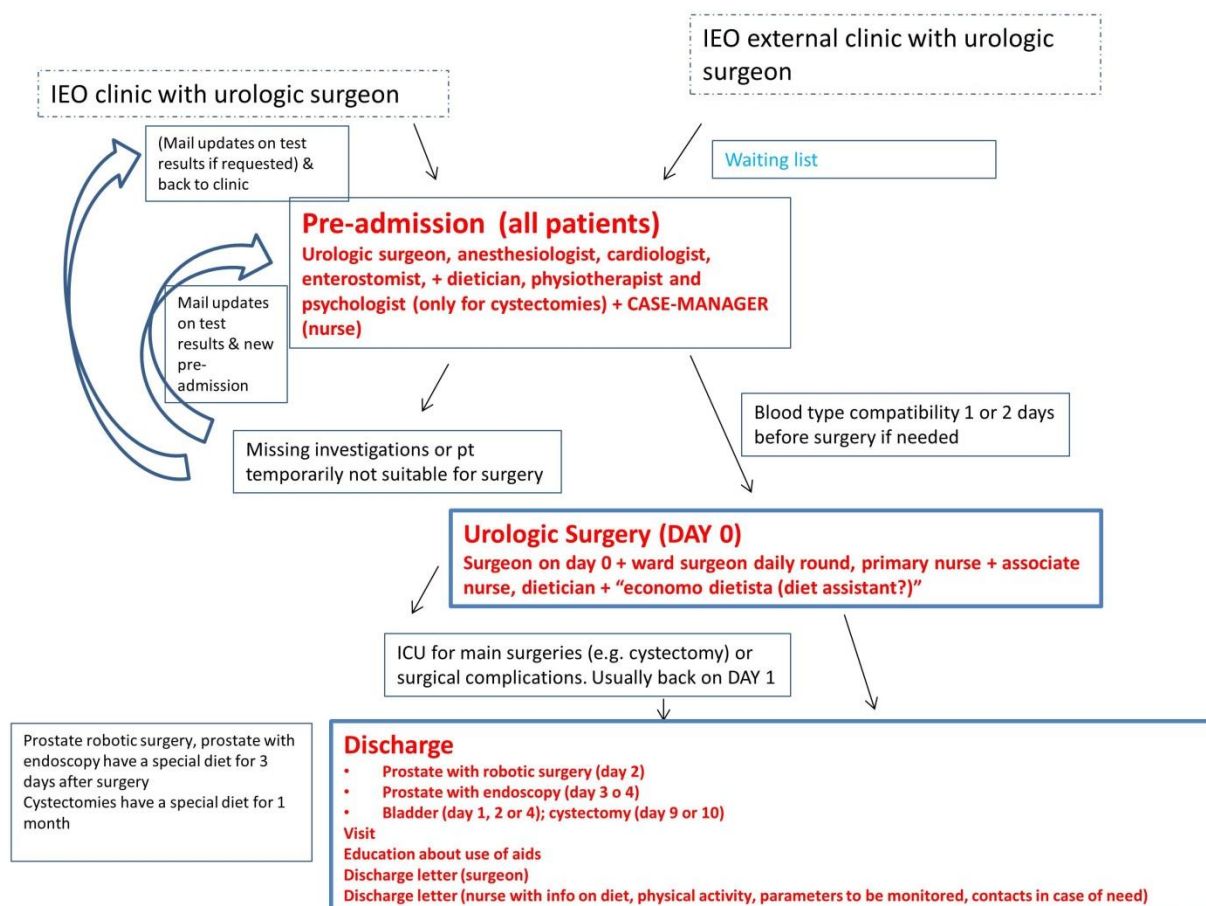


Figure 14: Flowchart of surgery for prostate cancer patients.

PROBLEM 1 (surgeons): Many patients afferent to prostate surgery arrive to the consultation or to the pre-admission without knowing the medications they are on or their comorbidities. It is often the case with older patients. In the worst case scenario, it may happen that a patient is prescribed with a therapy that may cause adverse events. Even if this is not the case, having all the information available may allow surgeons to provide a more realistic scenario on the consequences and benefits of an intervention.

POSSIBLE SOLUTIONS:

- Info or data collection. *Patients could fill in comorbidities, familiarity, current and past therapies, medications and other relevant information in the waiting room prior to consultation or at home prior to the pre-admission.*

PROBLEM 2 (nurses): Patients and family are often very confused about side effects of surgery. For instance they have troubles determining whether blood in the urine reflects a complication or if it is compatible with normal side effects of surgery. Other relevant worries concern legs or testicles becoming swollen, or water retention. Even though they receive education before discharge, a consistent load of phone calls in the wards concerns these side effects.

POSSIBLE SOLUTIONS:

- Info or data collection. *Determine whether certain measures have already been taken (e.g., how much water did the patient drink during the day).*
- Contents/knowledge. *Provide information on relevant side effects and materials which could help in solving the patient's questions (e.g., colour palette for blood in urines).*
- Communication/interaction. *Prompt nurse or doctor in case the information was not sufficient or helpful.*

PROBLEM 3 (nurses): Patients and family may often have doubts in managing dressing of surgical wounds or in cleaning the catheter.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Provide educational videos on practical matters for specific surgeries or diseases.*

## 4.4. Therapies (radiotherapy and chemotherapy)

### 4.4.1. Radiotherapy

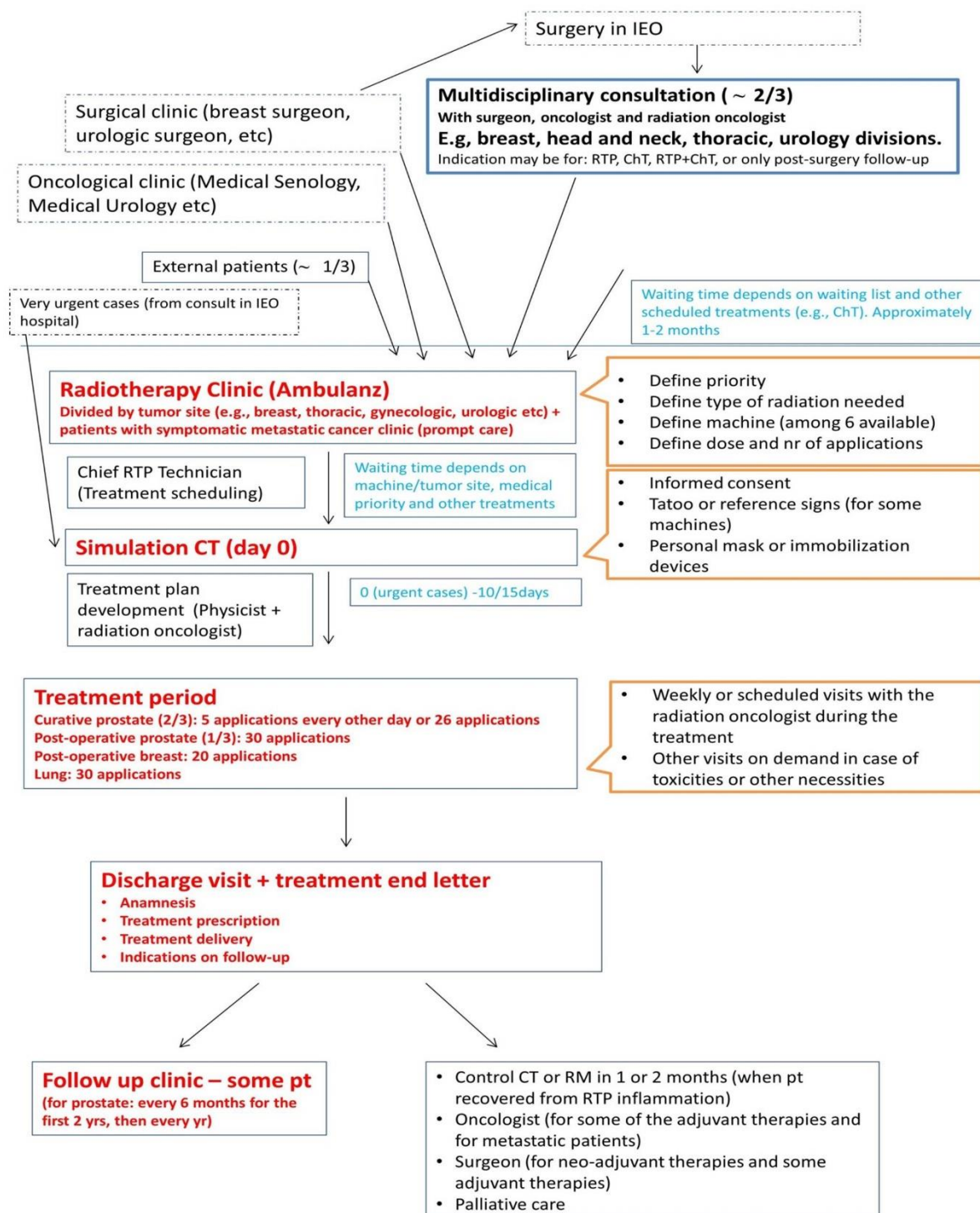


Figure 15: Flowchart of treatment in radiotherapy

PROBLEM 1 (Radiation oncologists, technicians): patients are often very worried when they start radiotherapy. Some diseases require appropriate preparation to therapy. Patients are provided with brochures, and they are instructed orally by the doctor and/or by technicians. However, it happens that patients or their families do not understand the importance of this preparation. Sometimes they forget, sometimes they deliberately ignore it, following someone else's advice.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Explain the basics of radiation therapy and why appropriate preparation is important.*
- Organizers. *Provide each patients with memos and tips about preparation to his/her specific therapy (e.g., when they should start drinking, which foods are good to eat and when to favour intestinal motility)*

PROBLEM 2 (Technicians): Some patients are very scared from the radiation machine, they may refuse to undergo therapy or come very scared. Some patients may encounter claustrophobia in entering closed machines or in wearing the face mask for radiation therapy in the head/neck area.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Provide a virtual tour of the machines. Suggest techniques to control anxiety and claustrophobia. Explain common problems at the beginning of the therapy and normalize anxiety.*
- Info or Data collection. *Measure state anxiety prior to therapy.*
- Communications/interactions. *Automatically report important anxiety status to doctors, technicians, psychologists.*
- Info or Data collection. *Prompt request for anxiety medication from the patient if the doctor has authorized administration*

PROBLEM 3 (Radiation oncologists, technicians): Radiation therapy for prostate cancer or other diseases in the pelvic district may often require to have the bladder full and the rectum empty. Also, the conditions of the pelvic district need to be consistent throughout the therapy and coherent with the simulation CT (e.g., similar bladder filling). Furthermore, inflammation from radiation therapy may affect the sphincters after a few days, and alter sensitivity. Radiation

therapy technicians and radiation oncologists report that this is the most important issue, as patients experience this condition as very stressful, they may feel ashamed and powerless. Sometimes therapy needs to be postponed because the bladder is not yet full even though the patient drank the suggested quantity of water (probably because of dehydration), or because the rectum is not completely empty (in this case enema needs to be performed). Other times the bladder is too full and the patient needs to empty it before therapy starts, thus having to restart drinking. Patients may feel that the rectum is full, but they are ashamed to communicate this to technicians before therapy, because they are afraid to lose their turn. This issues imply delays in therapy, which increase stress and frustration for the patients. In this matter, waiting time is also an important issue. In case of delays patients may have difficulties in calibrating the amount of water.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Explain common problems in radiation therapy. Provide indications on diet which may help intestinal transit or proper hydration.*
- Entertainment. *Appropriate exercises for bladder control or to favour intestinal transit may be suggested in the days between simulation scan CT and actual start of therapy or before simulation CT.*
- Organizers. *Provide a tool to measure water intake in order to favour hydration throughout the day and thus allow the bladder to fill properly at the time of therapy (e.g., Water your body app) with reminders throughout the day and tips to speed up or slow down bladder replenishment (e.g., drinking cold vs. hot drinks).*
- Organizers. *Provide patients with information about approximate waiting time and prompt info request on bladder status.*
- Info or Data collection. *Prompt request for enema from the patients or require information about bladder and rectum status from technicians and doctors.*

**PROBLEM 4** (Radiation oncologists, technicians): patients undergoing treatment perceive to lose the control of their body because of the side effects of treatments or due to the disease. This can turn in non-adherence to treatment.

## POSSIBLE SOLUTIONS:

- Contents/knowledge. *Improve information provision, if side effects or treatment consequences are temporary.*
- Contents/knowledge. *Favour awareness (e.g., through an avatar in the platform), if the negative consequences are prolonged in time.*

## 4.4.2. Chemotherapy

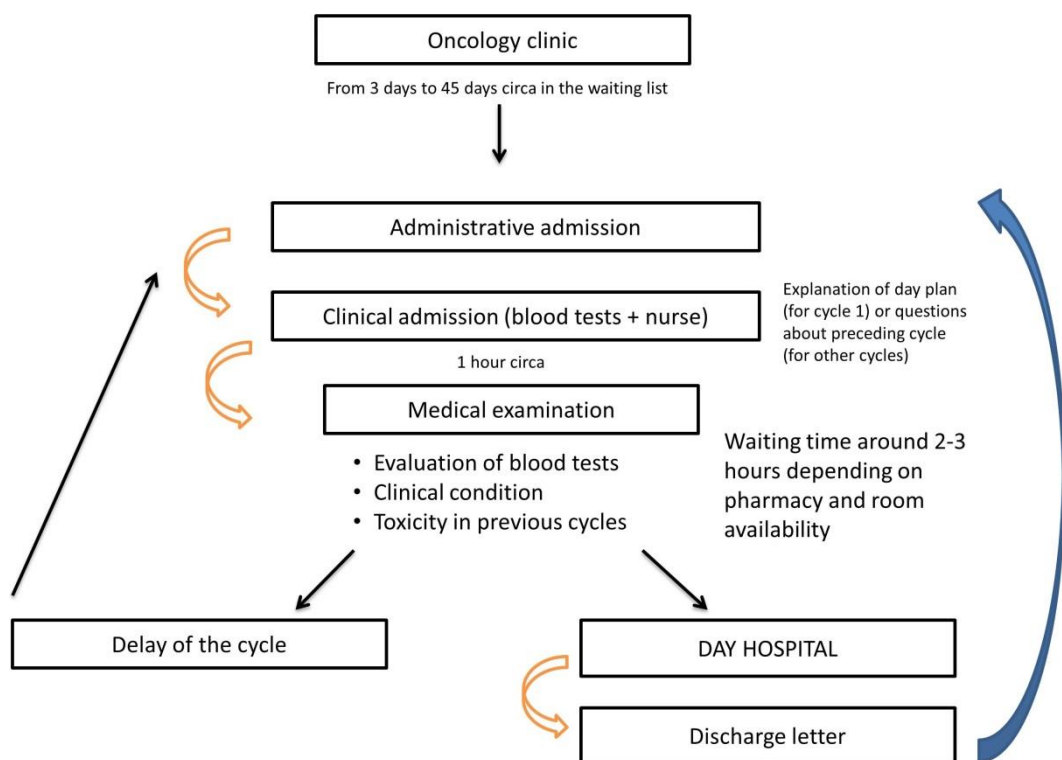


Figure 16: Flowchart of treatment with chemotherapy in the day hospital

PROBLEM 1 (Oncologists, nurses): one of the biggest worries that clinicians recognize in the patients is related to therapy adjustments. Sometimes they fail to report, or minimize side effects of treatment in order to avoid dose reductions or delay in cycle administration. Sometimes information is reported by family members to nurses.

POSSIBLE SOLUTIONS:

- Info or data collection. *Record side effects of treatment on a day by day basis from a list. Embed explanations of side effects and gravity as a link in the list.*
- Contents/knowledge. *Explain side effects of treatment, educate about importance to report side effects, inform about dose reductions and treatment delay.*

PROBLEM 2 (nurses): When veins become stiff from chemotherapy, nurses propose the adoption of a central line, to reduce pain from needle insertion and to facilitate infusions. This moment is always very delicate, as patients, despite reassurance and explanation, often interpret it as a sign that the disease is in a terminal phase or they are very worried about management at home. Pros and cons of this option are usually discussed with a nurse. This issue was also reported from patients (see ‘Patient’s perspective of iManageCancer platform’ chapter).

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Inform about central lines, provide information on reasons for adoption and home management (especially for women) with detailed instructions about the type of movements or activities which is possible to perform.*

PROBLEM 3 (nurses): administration of chemotherapy often require long waiting times in the hospital, where patients are not allowed to leave the building. Patients often enjoy being entertained during these hours, or may feel the need to have their privacy, which is not always possible in the waiting room of a hospital. A common worry is that if they will leave the waiting room, they will lose their turn.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Propose educational videos or content during waiting time.*
- Entertainment. *Propose entertainment during waiting time.*
- Organizers. *Prompt an alert (alarm) e.g. 15 minutes prior to actual chemotherapy administration (sent from the nurse in DH)*

PROBLEM 4 (nurses): When leukocytes are too low or side effects are important, the doctor may decide to delay chemotherapy administration. When this is the case for patients who come from other cities, it may represent an important stress and involve considerable economic efforts.

POSSIBLE SOLUTIONS:

- Info or data collection. *Record side effects of treatment on a day by day basis from a list. Include the possibility to send a report to the doctor containing side effects and lab tests.*
- Info or data collection. *Alert the doctor when side effects are consistent or if leukocytes are too low.*

#### **4.5. General issues**

PROBLEM 1 (Oncologists): Oncologists report that there is often a gap of information between the surgical and the oncological divisions or within the same unit because the doctor may change from a visit to another visit. For instance, reasons leading to the choice of a type of surgery are not always clear, comorbidities are not always described. This may be linked to a tight time schedule.

POSSIBLE SOLUTIONS:

- Info or data collection. *Patients could fill in comorbidities, familiarity, current and past therapies, menopausal status and other relevant information in the waiting room prior to consultation.*
- Communication/interactions. *Prompt the request for additional info from one doctor to another (with pre-compiled options: e.g., choice of treatment)*

PROBLEM 2 (Oncologists, Surgeons, nurses): time slots for visits are very tight. All doctors report this issue as a major problem. They often have 10 to 20 minutes to visit a patient. In this time, they have to fill in the anamnesis, explain the surgery or the treatment plan, pro and cons of surgery or treatments, and possible side effects. In some divisions patients are given informative documentation about surgery, but they are often very long and they seem to be designed to protect against law suits rather than as an actual informative tool. In other cases there is no specific explanation of the treatment the patient will be going through, so they have to repeat aspects or details, which may be hard to understand. Even those who are willing to involve the patient in decision making often feel demotivated in doing so, because there is a



constant lack of time. Some patients or caregivers arrive very well informed to the consultation, but they often don't have the ability to match what they read to their actual condition. Although they are informed, doctors report they lack the context and thus have no power to really decide. In units where prolonged treatments are performed (day hospital and radiotherapy unit) lack of time can be compensated by periodic visits (e.g., beginning of treatment cycle or by request). A few nurses report similar problems in having enough time to appropriately train patients and family for home management after surgery.

#### POSSIBLE SOLUTIONS:

- Info or data collection. *Prompt information request to patients prior to consultation through the app with the possibility for the doctor to copy and paste it (or to embed it) in the hospital chart management systems.*
- Contents/knowledge. *Provide a summary of pros and cons of surgeries or treatments offered to the patient (selected from the doctor), that the patient can read at home or in the waiting room.*

PROBLEM 3 (Oncologist, technician, nurses): Patients (as reported by clinicians) feel the need to report what is changed in their life, in their families, what are their fears. “As a doctor I can offer my empathy, but I lack adequate competence. A lot of them need to some extent psycho-emotional support and likely a proper psychological evaluation or intervention.” (Oncologist, female). “There are things that make you feel sad or that really shock you, and often I don't know what I should answer. Nobody teaches you this, we don't have a training and we have no reference point for this type of issues” (Radiation therapy technician, female)

#### POSSIBLE SOLUTIONS:

- Education/training. *Develop or include educational videos or pages on psycho-emotional aspects for clinical staff (including a part concerning “when should I activate a psycho-oncological consultation?”)*
- Contents/knowledge. *Inform patients about common psycho-emotional status during breast cancer treatment and educate on the role of the psycho-oncologist.*
- Activate relations. *Possibility to request a psychological support*

PROBLEM 4 (Oncologist): patients report the need to return to “daily routine” and ask for suggestions on physical activity and on food regime. Especially, female patients are very

informed about food, homeopathic and natural therapies, but they want to discuss this aspect with the doctor.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Include documentation on food, physical activity and natural therapies in the PHR.*
- Activate relations. *Ask for consultation with a dietician.*

PROBLEM 5 (Oncologists, nurses): nurses in the wards report an overload of phone calls from discharged patients, and doctors report similar problems with emails. The problems for which their attention is requested are of various nature, ranging from questions relative to appointments, to screening or follow-up schedules, to treatment regime. Sometimes they receive requests about common medical questions (e.g., anti-influenza vaccines) from patients who are no longer treated at the hospital. Both doctors and nurses describe this issue as a relevant work load, but they are reluctant to conceive it as an automatised task. Rather, they would envision the idea to sort requests and automatised responses to a restricted number of questions.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Include most common questions in a FAQ section (e.g., how to inject heparin, how to appropriately wash the hands before handling the wound). Questions should be organized based on treatment phase, so that it is for the patient to decide whether he/she wants to read something related to an anticipated problem or if they prefer to face “a problem at a time”.*
- Organizers. *Propose relevant questions & answers at the beginning of each phase or while waiting for a phase to begin.*
- Communications/interactions. *Organize the communications section in order to deliver the right question to the right person.*

PROBLEM 6 (Oncologists, nurses): Support in the territory is often not sufficient. Many patients come from outside of the city area, and their hosting condition are often less than suboptimal. Patients and families are often very stressed by this condition, and it may dramatically affect their economic situation.

POSSIBLE SOLUTION:

- Activate relations. *Provide a list of territorial agencies which may provide support to find a place to stay during treatment.*

PROBLEM 7 (Oncologists, technicians, nurses): when there is a need for palliative care, patients exit from the hospital circuit and are referred to local services. In this case both the patient and the family feel a sense of abandonment. to this end, domiciliary assistance through the general practitioner may be activated but patients and families often do not see this figure as a resource or as a reference. This is sometimes due to a prejudice, because they trust the oncologist more or to the fact that the general practitioner seems uninterested or not present.

POSSIBLE SOLUTIONS:

- Communications/interactions. *Share information with the general practitioner*
- Activate relations. *Possibility to browse for local domiciliary assistance services (e.g., VIDAS in Italy)*

PROBLEM 8 (Oncologists, nurses, surgeons): when patients conditions worsen during treatment, they often come back to the Day Hospital, or come back to the clinic without an appointment. Sometimes they wait until they can reach us and do not go to the Emergency Room even if it would be advisable, because they are worried that they will not be treated properly. Sometimes, there are actual communication and relational problems with professionals working in other structures with ERs.

## POSSIBLE SOLUTIONS:

- Contents/knowledge. *Include a section (pre-compiled or agreed with the doctor) that includes a list of occurrences when the patient should refer to the emergency room.*
- Info or data collection. *Acquire information on patient status. Suggest referral to the emergency room when needed.*
- Activate relations. *Share documentation with emergency room doctor or more generally with other hospitals in such a way that when the professionals open the PHR can have more updated information.*

PROBLEM 9 (Nurses): when patients are in the ward or when they are discharged, they assume pain therapy. Nurses usually explain that patients should not be in pain, but some of them do not report or do not assume oral therapy at home because they are under the impression that taking medications is not good. Nurses write it in their discharge letter and give this information at discharge but it may often go unnoticed. Often the caregiver calls the ward to ask permission for pain therapy.

## POSSIBLE SOLUTIONS:

- Contents/knowledge. *Inform patients and caregivers about pain management and criteria to determine whether or not to take medications.*
- Communications/interactions. *Prompt request to the nurse or to the doctor in case information is not enough.*
- Organization tools. *Provide memos about pain management at discharge.*

PROBLEM 10 (Nurses, Oncologists): many patients would require assistance from a psychologist, they are often very scared especially in the phase that precedes surgery or the first intervention. However, often this need goes unnoticed or there are no sufficient resources to guarantee access.

## POSSIBLE SOLUTIONS:

- Info or data collection. *Monitor psycho-emotional status using relevant questionnaires for each phase of treatment.*

- Contents/knowledge. *Inform patients and caregivers about psychological support in oncology.*
- Activate relations. *Possibility to request psychological consultation.*

PROBLEM 11 (Oncologists): During program changes patients show more difficulties in managing the situation, especially for the attribution of meaning to specific change (e.g., a change can be interpreted as a progression of disease and can elicit negative emotional reactions and a decrease in motivation).

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Improve information provision on the aim of different intervention and treatments (e.g., through web-video that the patient can watch at home)*
- Activate relations. *Activate family support or psycho-social assistance.*

PROBLEM 12 (Surgeons): Patients often feel a sense of abandon after discharge, because of the communication modalities that usually imply email exchange. Furthermore, a reference figure is missing that help patients manage the journey.

POSSIBLE SOLUTIONS:

- Activate relations. *Individuate reference health professional (not necessarily a medical doctor) that may guide and support the patient.*

#### **4.6. Considerations on the adoption of a platform**

All interviewed clinicians demonstrated a positive attitude toward the adoption of a technological platform for cancer management and patient empowerment.

The majority of clinicians imagine the platform to be easy, quick, working mainly by clicks rather than by keyboard typing. The greatest concern is related to the time required to learn how to use the platform and to interact with the platform. All clinicians reported a consistent overload of e-mails or phone calls even for matters which are not related to the oncologic disease or treatment. Even though they consider this load to be very consistent and time-consuming, there is a certain degree of reluctance at the idea of delegating their workload to automatized workflows. However, they consider useful the idea to sort out questions or to prompt a number of standard questions which may help in determining the situation of the patient. Two clinicians (one surgeon and one nurse) envision that the application is compatible

with hospital applications in order to directly import or copy and paste the data from the platform.

All clinicians consider useful the inclusion of educational videos on disease management. As an example, they reported the following topics: hand washing, dressing and care of surgical wounds, how to make the heparin injections, management of catheters, management of stomas, management of central venous line or infusion sites, explanation of clinical investigations (e.g., what is a cystography), exercises that should be performed after surgery (for breast surgery with axillary dissection and prostate surgery). Other relevant contents concern: discrimination of urine colour after prostate surgery (in order to determine when the colour is normal and when it is a symptom of a surgical complication), indications on pain therapy administration at home, indications on when the patient should refer promptly to the emergency room.

A third of clinicians would like the app to include training contents for clinicians, especially for what concerns management of psycho-emotional aspects for non-psychologists, and indications on how to support patient-clinicians and family-clinicians relations. Furthermore, more two thirds of the clinicians (including all nurses and clinicians) considers very relevant the use of patients' psycho-emotional monitoring, and to provide education about the possibility of psychological support.

All clinicians reported waiting time and time management as a very relevant aspect for patient. The possibility to include information on queue length and waiting times is considered to be a strong improvement in patients' quality of care and distress management, especially during therapy administration (radiotherapy and chemotherapy).

One nurse expressed concerns relatively to patients' motivation in using a platform, given the high degree of distress they experience.

## **5. Patient's perspective of iManageCancer platform**

### **5.1. Description of the interview and sample**

A semi-structured interview was developed based on models of patient-physician communication and decision-making styles, and on Ajzen's theory of planned behavior (Ajzen, 1992).

In the first part of the interview, the individual therapeutic pathway of the patient was assessed as well as figures involved in each phase of treatment. The interviews proceeded with questions aimed at exploring the role assumed and the type of communication with the figures involved.

Possibility, motivation and competence in communication, as well as correspondence with expectations were also investigated. A similar schema was used to explore the area of decision-making and responsibility. In the second part of the interview, the interviewer asked about the difficulties encountered by the patient throughout the therapeutic path, as well as the needs and the resources in the different phases of treatment.

For each difficulty, resource and possible solution, the interviewer tried to explore relevant characteristics in terms of the following features:

- a. Info or Data collection
- b. Activate relations
- c. Communications/interactions
- d. Contents/knowledge
- e. Education/training
- f. Organizers (agendas, tasks, memo)
- g. Entertainment

Five females and five male patients from the European Institute of Oncology were interviewed. Three of the female patients were affected by breast cancer, two were affected by neuroendocrine tumours. Male patients were affected by prostate cancer.

## **5.2. Main results**

The age ranged from 20 to 72 years of age. Seven individuals were married, one was widowed, and two were single. Education level ranged from elementary school to university degree. Patients arrived from all parts of Italy, only two reside in Milan City Area. All but one patients visited at least another hospital for his/her disease before being treated at the European Institute of Oncology.

All but one individuals reported a member of his/her family as a significant figure in their family. Significant clinical figures reported were the surgeon and/or the oncologist, and in some cases the nurses or the technicians, as well as the case-manager. All individuals were being treated with radiation therapy, and underwent surgery. All women underwent chemotherapeutic treatment. Four women and one men assumed or had assumed with hormonal therapy.

Patients experiences with communication were coded as passive in five cases: this was when the information received from specialized physicians, general practitioners, or nurses in at least one of the interactions they had, was experienced as a) not clear or not sufficient, b) strictly medical

or technical, not personal, or c) did not include information related to treatment consequences, and the patient did not ask or receive further information. All but one individual reported this as a reason to activate relations with other clinical figures. In the other five cases the type of communication was coded as shared. This was the case when patients felt they could ask questions, demand for clarifications, or if they felt that the information was clear and exhaustive.

Four patients had a systemic approach to information: here, family or close friends were significantly involved in communication concerning the patient's clinical status. In the other cases the approach was individual: here, patients decided from time to time whether or not to share information with family or friends.

In most of the cases, individuals reported that they actively chose the current treating physician or hospital structure, but once trust was established, they felt they could completely rely on the clinicians. In seven out of ten cases, the patient wanted to be informed about treatment or other clinical decisions, and felt they could contribute to this decision, or that it was sufficiently motivated in order to accept it. Two patients reported that they had benefit from discussion with other fellow patients or close friends in evaluating a clinical decision (e.g., use of central venous access).

Organizational resources used by patients concerned organizing consults with specialists prior to treatment. During treatment, they mainly involved the economic aspects (exemptions, hotel booking, travel booking), working (organizing absence from work to undergo treatments), and daily schedule (e.g., not being too far from home or out too long due to incontinence or intestinal problems) during treatment. Relational resources that were activated by the patients were related to finding new coping strategies, learning to ask for help either for emotional adjustment, discussing decisions concerning treatment options or the clinical situation, or concerned more practical matters e.g., help with home duties or clinical management after surgery or treatment.

After diagnosis, patients often tend to “shop” for doctors and information. They look for consult from different specialists, with the aim of having a clearer picture, until they eventually find a clinician or a structure they sufficiently trust. Decisional ability in this phase seems extremely reduced, because of significant emotional activation and because of contrasting opinions from specialists. In this phase, decisional support, helping to clarify values and individual preferences in terms of communication and decision-making may represent a great benefit and a relevant empowerment process.



Schedules and timing are the greatest issues during therapy, especially when this requires physical preparation. Food and health indications are another important concern. In this phase relational difficulties, either with healthcare professionals or with family members, may represent an important topic to be addressed.

In most cases, patients report the lack of a reference figure, either by complaining continuous change in specialists or insufficient involvement of the general practitioner. A reference may help to address daily problems after or during therapy, which is perceived as a very relevant matter.

Difficulties encountered and possible solutions through the platform are listed below divided by phase: prior to treatment, during treatment, after treatment.

### 5.2.1. Prior to treatment

PROBLEM 1: Waiting for exams, test result or for the date of surgery was reported as a very critical moment. Often patients may become very anxious if an exam is delayed or if the appointment is scheduled later than expected.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Read and prepare for exams, or for surgery. Read section on exams and delay (e.g., “I am supposed to do a mammography every 6 months. How long can this be delayed?”)*
- Activate relations. *Obtain support from family members, fellow patients or specialists.*
- Organizers. *Browse for alternative hospital which can perform the exam.*

PROBLEM 2: The majority of patients reported the choice of the treating physician or of the hospital as an important moment in their clinical history. The decision to refer to a structure far from home requires often an important economic investment and may have relevant consequences on daily routines. In this phase, patients may benefit from support to decide which structure may fit best their situation, or which factors should be considered in deciding the structure depending on their situation.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Provide content on choice of the structure or of a healthcare professional.*
- Info or data collection. *Possibility to share clinical documentation with a new physician.*
- Activate relations. *Provide a list of specialized centres or professionals, provide a ranking of structures or feedback from fellow patients.*

PROBLEM 3: Half of the patients reported having significant relational difficulties with healthcare professionals at some point of their clinical history. This may cause important delays in treatment, scarce trust in the healthcare professionals, and eventually lead to complications with surgery or therapies.

#### POSSIBLE SOLUTIONS:

- Info or data collection. *Provide patient profiling including information and decision making preferences.*
- Content/knowledge. *Provide educational material on patient empowerment.*
- Training. *Provide specialists with information on communication and decision-making styles. Inform about shared decision making.*

PROBLEM 4: Two patients (one male, one female) reported they were prescribed to lose weight prior to surgery or after treatment. However, indications on how to lose weight were very poor, and they felt “left alone” in this task.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Explain basics on weight loss and why it is important. Provide general information on weight loss and how to conduct a healthier life-style.*
- Info or data collection. *Keep track of progresses in weight loss and physical activity.*
- Entertainment. *Embed weight loss objective in serious games. Keep track of progresses in weight loss and physical activity.*
- Activate relations. *Inform on the possibility to contact specialized professionals for weight loss.*

PROBLEM 5: Four patients reported searching the internet for information about their condition or their treatment. Three of them reported being extremely confused, experiencing an overload

of information, losing the perception of which information were relevant for them or not. One patient reported asking family members, or friends to look for information on their behalf. All patients reported that information overload was considered a major issue and a source of anxiety.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Design the content in order to gradually deepen the details of the information provided, allowing the patient to choose if information is sufficient and clear.*
- Info or data collection. *Keep track of progresses in weight loss and physical activity.*
- Entertainment. *Embed weight loss objective in serious games. Keep track of progresses in weight loss and physical activity.*
- Activate relations. *Inform on the possibility to contact specialized professionals for weight loss.*

#### 5.2.2. During treatment

PROBLEM 1: Waiting times for treatment (chemotherapy or radiotherapy) are reported as a major issue by almost all patients. These hours are extremely stressful, both from an emotional as well as a practical point of view. All prostate cancer patients found extremely stressful the preparation to radiation therapy. Uncertainty about timing (therapy is often delayed unpredictably) makes urine continence very difficult for all patient. Analogously, intestinal status may often delay therapy.

#### POSSIBLE SOLUTIONS:

- Contents/knowledge. *Explain the basics of radiation therapy and why appropriate preparation is important. Describe which foods are good to eat and when to favour intestinal motility, or how to delay or speed up bladder filling.*
- Info or data collection. *Provide information on intestinal motility and trigger request for enema if necessary.*
- Organizers. *Provide each patients with memos and tips about preparation to his/her specific therapy (e.g., when they should start drinking to fill in the bladder, drinking reminder throughout the day to avoid dehydration).*
- Organizers. *Receive information on waiting times from clinicians.*

PROBLEM 2: Patients are often prescribed with laxatives, anti-emetic, anti-diarrhoeal drugs or pain killers. Two patients reported they did not assume this therapies regularly or they modified doses and schedules without consulting the physician because they were worried that the therapy would cause them habituation or side effects.

POSSIBLE SOLUTIONS:

- Info or data collection. *Possibility to record the therapy*
- Communication/interactions. *Possibility to adjust therapy in accordance with the physician depending on patient's symptoms.*
- Contents/knowledge. *Educate on prescribed therapy (e.g., explain why it is important to take pain killers if you are in pain)*
- Organizers. *Reminders for therapy.*

PROBLEM 3: Under the public healthcare regime, specialists may vary from one visit to the other. The continuous change of the doctor often led to information being missed or going unnoticed. Patients with a very long clinical history report this as a major issue, as they have to explain their experience again at every appointment, which is usually very short. Furthermore, these patients may experience the feeling that they have no reference physician.

POSSIBLE SOLUTIONS:

- Info or data collection. *Possibility to share the clinical record with the new physician.*

PROBLEM 4: During chemotherapy and occasionally during radiotherapy, patients reported fatigue, and difficulties in carrying out their normal daily activities. This is experienced as a major issue, especially by women with children or grandchildren.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Provide information on fatigue during treatment and suggest possible strategies for management.*
- Info or data collection. *Acquire information about family and caregivers, family relations and resources.*
- Activate relations. *Activate family support or social assistance.*

PROBLEM 5: During therapy two patients had severe side effects which eventually required hospitalization. They reported being unsure whether or not to go to the emergency room, or trying to contact the referring physician (in one case late in the evening) without success.

POSSIBLE SOLUTIONS:

- Info or data collection. *Acquire information on patient status. Suggest referral to the emergency room when needed.*
- Activate relations. *Share documentation with emergency room doctor.*

### 5.2.3. After treatment

PROBLEM 1: Management of catheter at home and incontinence management was reported by two patients as a difficulty after prostate surgery. Patients experienced burning sensations without being able to determine whether it was normal or if they had to refer to the specialist. They had worries that the catheter would move from its position or that it was incorrectly positioned.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Educational videos on catheter management; provide information on how the catheter works and about incontinence management.*

PROBLEM 2: Patients or family were instructed about heparin administration after surgery but they often referred to a private nurse once at home.

POSSIBLE SOLUTIONS:

- Contents/knowledge. *Educational videos on heparin administration.*

PROBLEM 3: One patient reported severe difficulties in managing relations with family members, which were perceived as too intrusive and controlling on the health status of the patient. This caused the patient an extremely stressful condition: “not only I have to cope with my disease and with the fact that I may die, but I also have to manage them, which are so anxious and treat me like a child. This is the most difficult part for me.”

POSSIBLE SOLUTIONS:

- Info or data collection. *Monitor family relations through a family resilience tool.*
- Contents/knowledge. *Educate family members on support and caregiving.*
- Activate relations. *Activate psychological or social assistance consult.*

### 5.3. Characteristics of the platform according to patients

The last part of the interview was focussed on exploring patient attitudes towards the use of a technological platform, which may provide support in the management of the oncologic disease.

Patients' attitude towards the use of the app was generally positive. One patient, who delegated disease management to a family member, had no attitude toward the use of the platform: "My daughter-in-law takes care of me, and my sons are those who write emails to the doctors. You would have to ask them."

Individuals reported to be generally well organized with their clinical record. However, for those who travelled to go to hospitals, having an **electronic record** would be greatly beneficial in order to avoid carrying the weight, to be sure of having always all the necessary documentation, and to avoid loss of documents in the passage from one hospital to the other. It should **favour information sharing** with professionals consulted. They expect the app to provide also a **summary of their clinical history and their actual condition**. Importantly, it should also contain **information on hospitals** (clinical paths and services offered), and **support decision-making** in this phase. The app should automatically synchronize with their personal computer or provide access through internet (especially to browse for information and contents). If possible, it should allow to directly **download or receive notifications on test results**.

Patients imagine that the platform could **provide information on possible difficulties** they could encounter on their way, organized by treatment phase and based on their own personal treatment plan. They would appreciate help with **medication schedules and interactions**, as well as with **doctors' appointments and tasks**, automatically setting up alarms and reminder. Information on **diet, physical activity and life-style** was also very popular.

Another relevant feature for patients concerns **waiting times** for treatment (especially for those who need a special preparation for therapy or lab tests), and **indications on the tasks** to be performed at the arrival in the hospital (e.g., admission, documents needed). Critically, the platform should contain information on **treatment or medication side effects**, and provide personalised indication on **when the doctor should be contacted and with which priority**. It should allow to **send questions** to healthcare professional concerning treatment, or side effects and **share information** with them, including pictures (e.g., lesions on the skin or possible new formations).

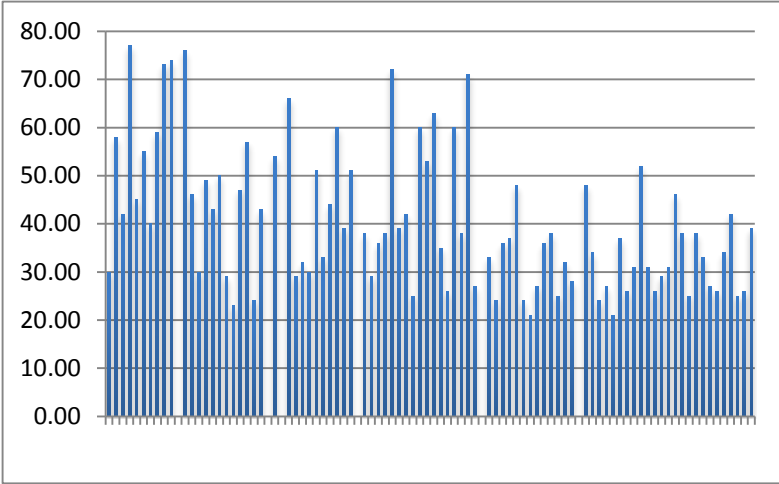
Also the possibility to **share experiences or questions with other patients** in the same condition, phase, or undergoing the same treatment was considered an important characteristic (e.g., ask questions about daily routine with the central venous access or share feelings). However privacy is also considered of great importance (it is not envisioned as a social network). A sort of tutoring program was also hypothesized. A young patient also spontaneously reported the interest in **playing games** while waiting, which should not be directly related to her condition. She envisioned the app to be coloured and fancy. Women reported also interest in content concerning **make-up and personal care** during chemotherapy (e.g., video-tutorials on how to draw eyebrows, or different ways to use kerchiefs).

## 6. Citizens' perspective of the iManageCancer platform

Together with task 2.2 a survey was developed to understand on one hand the needs of citizens and patients in using a platform like iManageCancer and on the other hand to get feedback from end-users regarding what kind of scenarios are relevant for them. The final questionnaire was developed in an iterative way starting with a first draft of the survey that was shown at the kick-off meeting in St. Ingbert, Germany at the 4<sup>th</sup> and 5<sup>th</sup> of February 2015. All participants of that meeting were asked to comment on the questionnaire and also to provide answers. The questionnaire is provided in English translated in German, Italian and Greek language. As we want to get as many answers as possible we continued to collect them beyond the submission time of this deliverable. For that reason D2.2 will provide a complete analysis of the questionnaire answers. In this deliverable a first analysis is given based on the English version of the questionnaire and focuses solely on the feedback on questions that is important getting knowledge about the perspectives of patients dealing with such a platform.

The first part of the above listed answers gives just a description of the participants in the survey. Most of the 96 responders are females. Their age ranged from 21 to 77 years with an average of 41 years. 6 respondents are older than 70 years and around 10% are older than 60 years, showing that also older people participate in the survey giving a good representation of the population.

<b>Number of responses</b>	96
<b>Gender</b>	Male: 28 %
	Female: 65 %
	Not disclosed: 7 %

	Skipped:	3 respondents
	Range:	21 – 77 years
	Mean:	41 years
	Skipped:	6 respondents
<b>Age</b>		
<b>Highest level of education</b>	Did not attend school:	1 %
	Primary school:	2 %
	Secondary school:	11 %
	University degree:	65 %
	Other:	21 %
	Skipped:	5 respondents
<b>Profession</b>	I do not work:	22 %
	Non-academic (no-med):	33 %
	Non-academic (medical):	17 %
	Academic (no-med):	16 %
	Academic (medical):	12 %
	Skipped:	6 respondents
<b>Current Health Status</b>	Healthy:	22 %
	Acute illness:	33 %
	Chronic illness:	17 %
	I have cancer:	16 %
	Skipped:	4 respondents

The following part of the answers are dealing with questions that are dealing with perspectives of end-users.

<b>Trust in Healthcare</b>	Weighted average:	<b>3.13</b>
	1: completely trusting:	11 %
	2:	37 %
	3:	21 %
	4:	8 %



	5:	10 %
	6:	8 %
	7: not trusting at all:	5 %
	Skipped:	4 respondents
	Facebook:	69 %
	Twitter:	59 %
	LinkedIn:	63 %
	Google Plus:	14 %
	Other:	20 %
	Skipped:	32 respondents
<b>Member of Social network</b>	Yes:	7 %
	No, but heard about:	34 %
	No, never heard about:	59 %
	Skipped:	23 respondents
<b>Usage of PHR</b>	Yes:	68 %
	Yes, MyHealthAvatar:	7 %
	Yes, other:	25 %
	Skipped:	23 respondents
<b>Knowledge about online platforms</b>		

**Sharing of data with:**

	My doctor	Doctors in general	Closest friend	All my friends	My partner	My family	
General Health information	Yes: 100 %	Yes: 73 %	Yes: 61 %	Yes: 21 %	Yes: 90 %	Yes: 65 %	
	No: 0 %	No: 27 %	No: 39 %	No: 79 %	No: 10 %	No: 35 %	
	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	26
Sexually transmitted diseases	Yes: 97 %	Yes: 42 %	Yes: 31 %	Yes: 0 %	Yes: 87 %	Yes: 24 %	
	No: 3 %	No: 58 %	No: 69 %	No: 100 %	No: 13 %	No: 76 %	
	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	26
Mental Health	Yes: 98 %	Yes: 60 %	Yes: 58 %	Yes: 12 %	Yes: 89 %	Yes: 65 %	
	No: 2 %	No: 40 %	No: 42 %	No: 88 %	No: 11 %	No: 35 %	
	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	26
Cancer	Yes: 97 %	Yes: 75 %	Yes: 67 %	Yes: 26 %	Yes: 90 %	Yes: 68 %	

	No: 3 %	No: 25 %	No: 33 %	No: 74 %	No: 10 %	No: 32 %	
	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	26
Other	Yes: 54 %	Yes: 42 %	Yes: 36 %	Yes: 10 %	Yes: 69 %	Yes: 42 %	
	No: 46 %	No: 58 %	No: 64 %	No: 90 %	No: 31 %	No: 58 %	
	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	Skipped: 26 respondents	26
	Weighted average:				<b>6.10</b>		
	1: Not at all:				1 %		
	2:				3 %		
	3:				6 %		
Importance of security:	4:				3 %		
	5:				10 %		
	6:				17 %		
	7: extremely important:				61 %		
	Skipped:				25 respondents		
Usage of tools for data analysis	Yes:				88 %		
	No:				12 %		
	Skipped:				23 respondents		
Helpful tools							
An online health diary						51 %	
An online health diary with the ability to upload photos, clinical reports, etc.						66 %	
A tool to upload information to share with your doctor						83 %	
A tool to connect to wearable devices (e.g. pedometers)						63 %	
A tool to analyse your health information						76 %	
A tool to give information and recommendations						72 %	
A tool allowing you to contact and interact with your doctor						70 %	
A tool that gives information about drug interactions						82 %	
A time planer for your medication and/or appointments with the hospital						65 %	
The ability to give online consent for your personal information (e-consent)						56 %	
Other (please specify)						10 %	
Respondents that skipped the question							25
Is playing of serious games	Yes:			70 %			
helpful	No:			30 %			

Skipped: 30 respondents

It is important to see that nearly 60% of respondents never heard about PHRs but most of them are a member of a social network. Security of a platform like iManageCancer is of outmost importance. If that is guaranteed then sharing of data with the own doctor will be done by everybody. On the other hand it is important that participants of the platform can choose with whom they would like to share medical data. Regarding sexually transmitted diseases none would share this with his friends via such a platform. Most important for the participants of the questionnaire are tools that can upload information for sharing data and tools giving new knowledge like information about drug interaction. 70% would also think that playing serious games is helpful. Altogether there is acceptance by citizens using such a platform if relevant tools are available and security issues are solved.

## **7. Stakeholders' perspective of the iManageCancer platform**

### **7.1. German Childhood Cancer Charity Foundation**

Telephone interview with Dr. Renate Heymans

On February 25th, 2015 Norbert Graf from USAAR had a telephone interview with Dr. Renate Heymans, who is a physician and the deputy chair of the 'Deutsche Kinderkrebs Stiftung' (German Childhood Cancer Charity Foundation). The topic of the call was to present the iManageCancer project to the Deutsche Kinderkrebsstiftung and to ask, if they are willing to be a member of the external advisory board of iManageCancer and to give critical feedback to the project.

In summary, the project is of interest for the Deutsche Kinderkrebsstiftung in many aspects. First they acknowledge that this project is dealing with children with cancer and that it provides to the parents and their kids a platform to empower them and to help them to manage their disease. Secondly the serious game for children is of great interest to them, as they are considering to support and to evaluate the usage of serious games in children with cancer.

In this respect the Deutsche Kinderkrebsstiftung is more than interested to join the advisory board of iManageCancer and being informed about the progress of the project. They want to receive info about developed tools within the project on a regular basis and they are willing to

give us feedback at different stages of tools' development. In case of successfully evaluated tools and the serious game for children they will support us in dissemination and exploitation within parent groups for childhood cancer.

It was agreed that the project will invite the Deutsche Kinderkrebsstiftung regularly to discuss the progress and to get feedback from them.

## **8. Conclusions**

The first part of the document contains a global overview on current state of the art on patient self-management, patient empowerment, and self-management intervention with a focus on technology-based applications. Currently available social media platforms, online sources of information as well as cancer-specific applications are presented and discussed. The concept and state of the art on personal health records and their use was also described. Here, a particular focus was given to MyHealthAvatar implementation of PHR, which will be in the core of iManageCancer platform.

In the second part of the document, the results of assessments on patients' and clinicians' needs for self-management and patient empowerment were presented, as an outcome of interviews performed at one of the clinical sites. Time was shown to be a major issue but for patients and clinicians. Providing reliable and synthetic sources of information, facilitating collection of information about patient's status and activating relations were also considered relevant by both clinicians and patients. Expected characteristics of a platform for cancer patients were elicited and discussed. The citizens' perspective was also taken into account with a questionnaire developed for the purposes of the project. This aspect will also be further discussed in D2.2. Finally, interviews with relevant stakeholders were reported.

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## **Appendix A – Structure of semi-structured interview for healthcare providers**

### **TREATMENT FLOW**

- 2) Could you please describe the diagnostic and therapeutic path of the patients you usually assist?
- 3) Which figures are usually involved in this path (e.g., other professionals, family, social)?
- 4) Could you describe your interactions with these figures? (To what extent are you involved with them? Could you describe your role with them? How do you experience these interactions?)
- 5) How do you consider in general the communication between you and patients/ patient's family to be?

### **RESPONSIBILITY AND DECISION**

- 6) How would you evaluate your role in information exchange with the different figures involved?
- 7) Does it correspond to your expectations? If not, please explain.
- 8) Do you feel able to engage patients and family in information exchange?
- 9) In your experience, did you ever ask patients to take a decision regarding their diagnostic path or therapeutic treatment? If yes, when?
- 10) Do you think that patients can be actively involved in the decision process?
- 11) In your experience, do you usually want to engage patients and or family members in decisions? And do they want to be engaged?
- 12) In your experience, did you feel able to engage patients and/or family members when you decided to do so?

### **RESOURCES AND DIFFICULTIES**

- 13) Which resources do you have to use throughout the different steps when it comes both to the relational point of view and to disease management by the patients and/or their familiars?
- 14) Do you think there are important needs which are currently not taken into consideration?
- 15) During patients treatment did you ever experience or encounter difficulties in the relational area or in patients' self management? When? Of which type?
- 16) Which difficulties do you think patients and their family experience or do they report you in these aspects?
- 17) With respect to the difficulties you described, what was done to overcome them? What could be done to overcome these difficulties?
- 18) If you were proposed through the regional/national cancer network to start using today an app to help healthcare professionals, patients and their families in disease management:
  - a. Would you consider adopting the platform?
  - b. Which question would you ask before deciding whether or not to use it?
  - c. Which are the worries or the strengths?
- 19) Is there something else you would like to tell us based on your experience?

## **Appendix B – Structure of semi-structured interview for patients**

### **TREATMENT FLOW**

- 1) Could you please describe your diagnostic and therapeutic path?
- 2) Which figures were involved throughout these phases (e.g., professionals, family members, social)?
- 3) Could you describe your interactions with these figures? (To what extent were/are you involved with them? Could you describe your role with them? How do you experience these interactions?)
- 4) How was the communication between you and the healthcare professionals throughout the flow?

### **RESPONSIBILITY AND DECISION**

- 5) Do you think that the information about treatment and disease management you received in the different phases were enough? If not, please explain
- 6) Do you think that the information you received in the different phases were comprehensible? If not, please explain
- 7) Do you think that the information you had in the different phases were correspondent to your knowledge needs? If not, please explain
- 8) How would you evaluate your role in information exchange with the different figures involved?
- 9) Does it correspond to your expectations? If not, please explain.
- 10) Do you feel able to be engaged in information exchange? If not, please explain.
- 11) In your experience, were you asked to make a decision regarding the diagnostic path or therapeutic treatment?
- 12) Do you think that you were actively involved in the decision process?
- 13) Did you want to be engaged in the decisional process about diagnosis or about treatment and management?
- 14) Did you feel able to be engaged?

### **RESOURCES AND DIFFICULTIES**

- 15) Which resources did you have to use throughout the different steps when it comes both to the relational point of view and to disease management?
- 16) Do you think there were/are important needs which were/are currently not taken into consideration?
- 17) Did you experience difficulties in the relational area or in managing your disease? When? Of which type?
- 18) Which other difficulties did you experience?
- 19) With respect to the difficulties you described, what was done to overcome them? What could be done to overcome these difficulties?
- 20) If you were proposed through the regional/national cancer network to start using today an app to help patients and their families in disease management:
  - a. Would you consider adopting the platform?
  - b. Which question would you ask before deciding whether or not to use it?
  - c. Which are the worries or the strengths you would foresee?
- 21) Is there something else you would like to tell us based on your experience?