Chapter 2
The Development of iManageCancer: The Experience of a Personalised eHealth Platform for Cancer Patients' Empowerment

Chiara Crico and Chiara Renzi

1   Introduction

According to Fleming and colleagues (Fleming et al. 2016), the traditional randomised clinical trial approach may be problematic for the testing of eHealth interventions due to the speed of technology change. They state that alternative models of rapid development and iterative testing should be considered (cfr. Chap. 9), for example, using AGILE software design principles, such as the lean start-up method (Nobel 2011) or scrum (Schwaber and Beedle 2002). In AGILE development processes, the product is tested with users from the outset using rapid development and testing feedback loops. An important component involves the development of a minimal viable product (MVP). A MVP is a barely finished product that contains an essential element, with missing details, and is provided to end-users to gage their reactions and inform the next steps in development. Reponses to the product are measured and used to inform next steps that are rapidly developed and tested in the same way. This iterative process involves close collaboration between designers, software developers, and end-users. Larger-scale testing gradually replaces small opportunistic samples as progressively more complex features are tested. When a near-finished version is ready, more traditional testing can be carried out, for example, via a randomised controlled trial. As described by Mohr et al. (1994), Internet interventions can utilise approaches that focus on evaluating the working mechanisms, rather than a locked-down version of the intervention. Such a framework allows for improvements in functionality to be made during a trial, subsequently resulting in a more generalisable and durable intervention (Favrod and Khazaal 2018).

C. Crico (✉)
Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy
e-mail: chiara.crico@unimi.it

C. Renzi
Applied Research Division for Cognitive and Psychological Science,
European Institute of Oncology IRCCS, Milan, Italy

In accordance with this approach, the iManageCancer platform has been tested already by 19 of end-users as a result of the previous works of the project. Following the feedbacks received, the platform went through major updates and improvements, to get the platform ready for clinical context and to better assess its efficacy (Kondylakis et al. 2017).

2 The IManageCancer Platform

The iManageCancer platform is a set of interconnected health apps and games intended to empower patients with cancer and to support them in the management of their disease. Figure 2.1 illustrates the overall structure of the iManageCancer platform to be tested in the pilot. The platform comprises three apps and a serious game for adult cancer patients (see Fig. 2.1). Basic characteristics of these apps are shown in Fig. 2.2 followed by an explanation of the intended purpose of these apps. All apps operate on a common backbone of the platform that contains the data store with the patients' personal health records, the security and access control services,
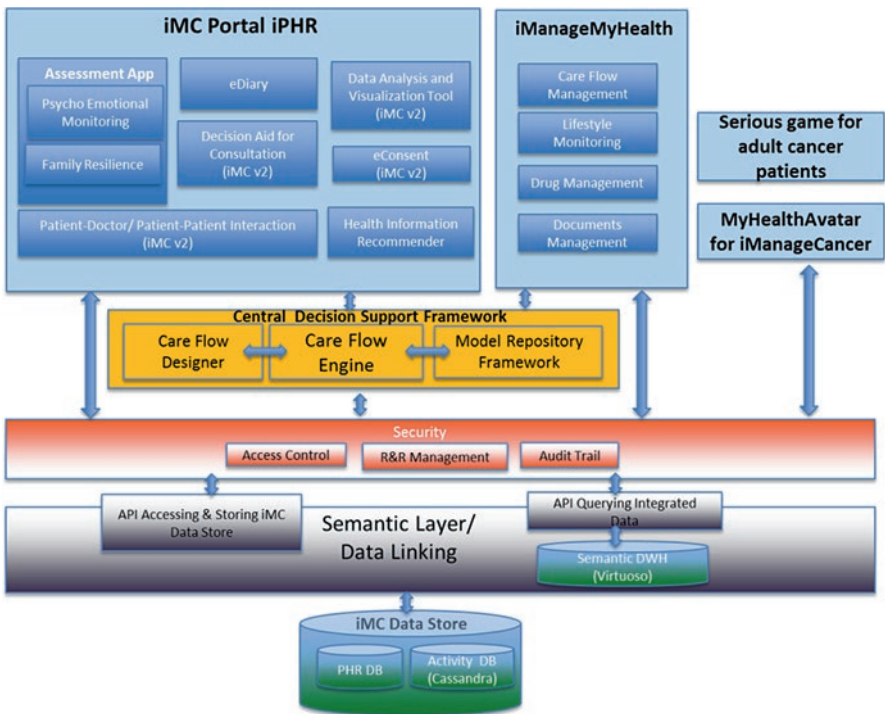

Fig. 2.1 High-level architecture of initial iManageCancer platform prototype. The applications shown with a blue background will be provided to the subjects of this pilot
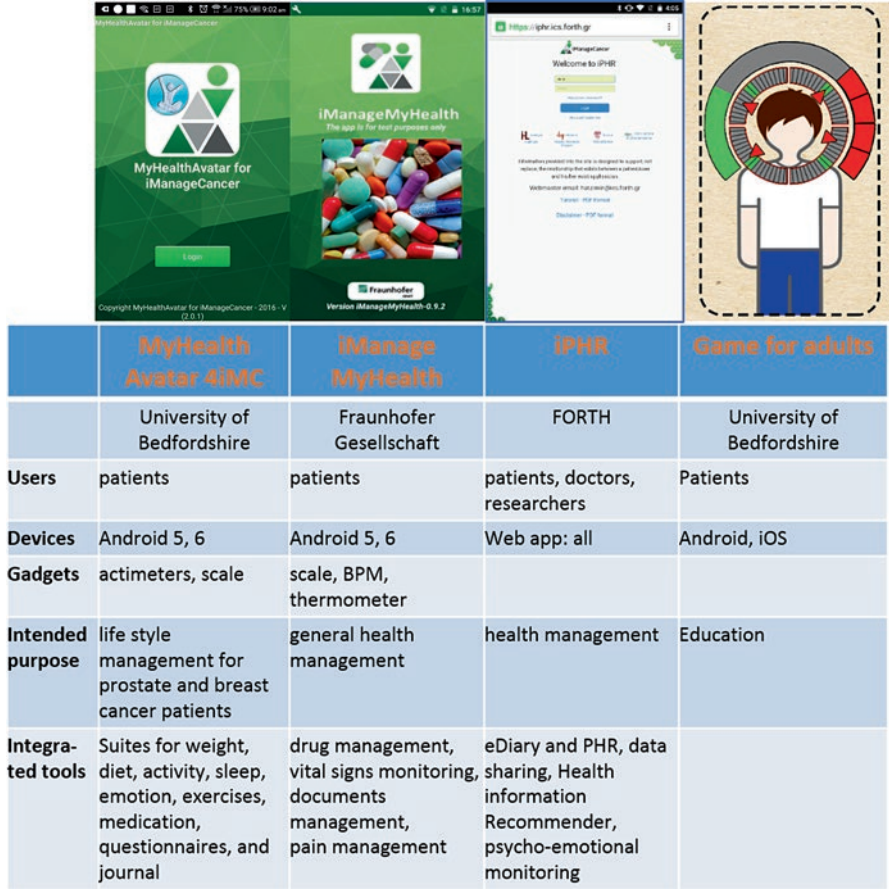
	MyHealth Avatar 4iMC	iManage MyHealth	iPHR	Game for adults
	University of Bedfordshire	Fraunhofer Gesellschaft	FORTH	University of Bedfordshire
Users	patients	patients	patients, doctors, researchers	Patients
Devices	Android 5, 6	Android 5, 6	Web app: all	Android, iOS
Gadgets	actimeters, scale	scale, BPM, thermometer		
Intended purpose	life style management for prostate and breast cancer patients	general health management	health management	Education
Integrated tools	Suites for weight, diet, activity, sleep, emotion, exercises, medication, questionnaires, and journal	drug management, vital signs monitoring, documents management, pain management	eDiary and PHR, data sharing, Health information Recommender, psycho-emotional monitoring	

Fig. 2.2 Overview about the different end-user applications of the iManageCancer platform that will be used in this clinical investigation

and also a central decision support framework. The latter provides for this pilot information services for patients for the management of side effects of cancer therapies such as pain and fatigue.

The following sections briefly present each of the applications and the game with their intended purpose and their main characteristics.

2.1   My HealthAvatar for iManageCancer

MyHealthAvatar for iManageCancer is a solution to support patients with prostate cancer and breast cancer to optimise their lifestyle and to recover from cancer treatment. The app offers access, collection, and sharing of long-term and consistent

personal health status data through an integrated digital representation, which helps deliver prostate cancer patient empowerment, risk prediction, prevention, clinical analysis, and treatment tailored to individual citizens.

A comprehensive set of suite functions let the user manage his/her weight, diet, activity, sleep, and emotions. A specific exercise suite offers four different exercises for the patient to support recovery from prostatectomy or breast surgery (mastectomy or quadrantectomy). And in the man's version, a Questionnaire Suite collects the patient's PSA information after surgery in order to let the doctor monitor the PSA changes for the patient. The patient can create alarms in the Medication Suite to remind him/her the appointments with the physician or to take a drug. A calendar feature allows him/her to easily schedule such events. A journal provides cancer-related health tips and selected health information. A pain and emotion monitor is used to collect the patient's mood and emotion information. The questionnaire of mood and emotion appears three times a day in the journal page. The patient can also set lifestyle-related goals, including weight monitoring, diet, or physical activity. A daily summary displays the daily/weekly/monthly results of the measured values comparing to the goals and reminders that help the patient to achieve his/her goals. The patient can also enable location tracking and check the daily location and tracking path in the app. Patient can annotate the places he/she visited which will be synchronized to the server. Furthermore, the patient can edit his/her health profile and share this information with other users of the app if he/she wants. And in the man's version, A Questionnaire Suite collects the patient's PSA information after surgery in order to let the doctor monitor the PSA changes for the patient.

2.2   iManageMyHealth

iManageMyHealth is a multipurpose informative app intended for citizens and patients for general health management. It supports users (1) in managing their drugs and drug intakes, also by providing a reminder system to facilitate adherence to treatment; (2) in providing information on drugs and their interactions; (3) in managing and understanding their paper-based health documents; and (4) in recording and overviewing specific vital signs and laboratory parameters.

Further, the app also provides specific management services in the context of cancer, as for the record of felt level of pain and the link to public information resources. The app as a whole is not intended for diagnosis and therapy but just as a supportive electronic solution for information provision and management of medical information.The following functionality is offered for the management of drugs:

- Add a new drug to the medication plan. When patients start to enter the medication name, an autocomplete feature proposes drugs with the help of one of the two external drug information services. The user is encouraged to take pictures of the drug package and the drug itself. Furthermore, he can specify drug intake times. The system reminds him with a message to take the drug. There is also

space for personal comments to the drugs. Information on a new drug in the medication plan is also sent to the iPHR (see description below).

- The new drug is checked for potential interactions with other drugs in the medication plan (if the drugs are known to the external drug information service). Warning symbols are shown in the medication plan, and drug-drug interaction information is presented when the user touches the warning symbol. This feature is only offered in the German and English version of the app, as it relies on external national drug information services and their capabilities.
- Delete a drug from the medication plan. All information related to the drug is deleted from the system, and the patient is asked about its effectiveness. This information is also sent to iPHR.
- More information about a drug is shown by forwarding the user to the webpage https://www.drugs.com/ containing structured information about the drug (in English language only).
- This component leverages the Canadian Internet-based drug information service DrugBank of OMx Personal Health Analytics Inc. to select drugs from a list, to present information on drugs, and to check contraindications. The Canadian DrugBank does not only contain approved drugs for the US and Canadian market but also includes drugs registered at EMA for the European market. However, as brand names of the different drugs may differ in Italy, the Italian drug information tables "Lista farmaci di classe A e H per consentire a tutti gli Operatori la prescrizione per principio attivo" published on http://www.aifa.gov.it/content/dati-sulle-liste-dei-farmaci-open-data is used in the Italian version of the app instead. In order to counterbalance the risk of patients self-adjusting drug intakes, the app contains a disclaimer which specifies that the app does not constitute or substitute a medical consultation and that changes to the medication plan should always be discussed with the treating physician(s).

The following functionality is offered for managing health documents:

The app offers the user to scan paper-based health documents and to store them in the Android device and to annotate them. Scanning is done with the camera, and a document is assembled as a set of images. The user can go through a document page by page and can zoom in and out in a page. He can mark a section with a keyword and search with this marked text in Wikipedia or in the Personal Health Information Recommender. Results are presented to the user.

The following functionality is offered for monitoring vital signs and lab parameters:

- The patient can enter results of blood pressure readings, his weight, and his body temperatures. The values are presented in charts.
- The patient can enter lab results of the blood parameters PSA, leucocytes, and neutrophils.

2.3   iManageCancer Portal iPHR

The iPHR enables an individual to own and manage a complete, secure, digital copy of his/her health and wellness information. It integrates health information across sites of care and over time. The system is essentially an inversion of the current approach to medical records, in that the record resides with the patients and the patients grant permissions to institutions, clinicians, researchers, and other users of medical information. iPHR is a distributed, web-based, personally controlled electronic medical record system that is ubiquitously accessible to the nomadic user, built to public standards.

The iPHR is composed of many applications including:

- eDiary – Calendar: A timeline view of all available information showing medications, problems, appointments, and procedures.
- Demographics: View and update patient information such as gender, date of birth, contact information, name, and surname.
- Labs: View and update laboratory result values.
- Problems: View and update diseases, illnesses, injuries, and physiologic, mental, or psychological condition or disorders.
- Procedures: View and update medical treatments or operations of the patient.
- Allergies: View and update abnormal reactions to encountered allergens.
- Medications: View and update drugs or other substances received.
- Measurements: View and update vital signs that indicate the status of the body's vital functions.
- Contact: A form to communicate with other users of the system.
- Appointments: View and update appointments between the patient and doctors.
- Upload Documents: Upload your health data documents.
- Psychoemotional and health assessment tools.
- Personal Health Information Recommender: Allow patients to search in a high-quality document repository for useful information.

2.4   Game for Adults

The aim of the serious game is to promote self-efficacy, i.e. the belief of the patients to be able to manage and face their disease, also to help the patient deal with the psychological dimension of their disease, and to promote a healthier lifestyle and disease management. The serious game for adults puts the user in the role of an authority figure who manages a small town where they help residents with their cancer-related lifestyle problems. The user is invited to think critically and strategically in order to balance their resources and time, while also viewing the issues surrounding their cancer from a different perspective. The game is intended to promote the concept that a good management of a person's cancer disease is possible, together with the achievement of a sense of wellbeing.

The serious game's implementation is a full 3D simulation utilising the unity 3D platform and running on Android mobile devices. The game world itself is a colourful and stylised representation of a town, providing an environment for the user's avatar to exist and interact with town services and other characters. The game provides an easy-to-use social interface to allow users to make and manage friends. The serious game also links into the iMC back end services in order to leverage a user's personal activity as an in-game resource. Users can also customise their avatar's appearance and clothing using the simple character builder and in-game item store. The game avoids making recommendations about the user's real cancer disease; instead, the game attempts to provide generalised knowledge related to health and lifestyle through the trivia mini-game and the instructions given to the simulated cancer patient (not the user) by the in-game doctor.

3   iManageCancer Within the p5 Approach

The iManageCancer project is a good example of how an eHealth intervention can be integrated with the properties of the P5 medicine towards the improvement of patient empowerment and quality of life: the following paragraphs will give an overview on how eHealth-based projects can lead medical practice towards a preventive, personalised, predictive, participatory, and psychocognitive approach (Pravettoni and Gorini 2011).

The multiple monitoring functions of the iManageCancer platform act as a *preventive*, according to its definition as the ability to proactively address diseases. Some of the apps are meant to give patients and clinicians the possibility to achieve a complete medical profile of patients and easily monitor their quality of life, by assessing both psychological and physical condition. In the iPHR, patients are provided with a set of three questionnaires to assess psychological wellbeing by measuring factors that play an important role in the care path. The questionnaires are ALGA, developed to assess physical and mental characteristics of cancer patients (Gorini et al. 2015); a psychoemotional monitoring tool; and FaRe, a questionnaire to assess the family resilience (Faccio et al. 2018). Moreover, the MyHealthAvatar (Zhang et al. 2018) is an activity tracker and a lifestyle monitoring app: it keeps track of sleep, weight, diet, sedentary lifestyle, and motor activities. The app promotes a good lifestyle and encourages healthy habits by helping patients manage their activities; it also monitors psychological status by proving a journal and a mood state to be updated every day from patients. In addition, the three questionnaires give an insight about the psychological status of patients and monitor potential changes in their mental wellbeing. Thanks to all these features, the platform that provides health professionals – both physicians and psychologists – with real-time data allows capturing any situation at risk and intervening in advance in order to address potential pathologies and provide patients with the necessary medical or psychological support.

As we have seen in the detailed description of the apps, many of their internal functions have been conceived as containers in which patients can insert all the specific information of their personal state: from the average information, such as values and findings, to the details of their lifestyle and habits and from the emotional and psychological status to their decision preferences. All the contents in this virtual database create a personalised profile of the patient, which can be used as a basis for a tailored intervention. For instance, the iPHR provides the psychological questionnaires to assess not only physical but also mental health degeneration and social alienation and to provide personalised information for coping strategies. Even the iManageMyHealth app is totally customisable, helping patients manage the variety of their drugs, prescribed by different factors for different clinical conditions and comorbidities. It acts as a container for all medical reports and prescriptions, and patients can insert the drugs they are taking, including time and mode of intake. This app is programmed to give back personalised information as output, including potential integrations among drugs and predictable side effects related to their clinical condition. A comprehensive consideration of all this aspects, which go beyond the mere biological information, points towards a more *personalised* medicine (Cutica et al. 2014; Renzi et al. 2016), as described in the P5 model. Also, the application contains specific features, such as the digital avatar to represent the user and his/her own health state, which could be important for personalisation in terms of self-expression (cfr. Chap. 4).

Putting together the advances of systems biology in the diagnostic field with the potential of the technological tools available today opens up new scenarios and increasingly important challenges for eHealth to predict the onset of pathological events. Considering that the exploitation of ICT in all its forms is, in this field, a recent development, one of the objectives of iManageCancer has been (Kim et al. 2018) to develop and incorporate in the platform *predictive* models for the early detection of severe adverse reaction to chemotherapy, in order to increase patients safety and wellbeing.

The general aim of the iManageCancer project is to empower patients by giving them tools to gain a more active role in their therapeutic path. Not only patients and clinicians are called to participate in the process of healthcare, but also patients' family and caregivers play an important role. This is even more true in the case of oncological diseases, which have repercussions and consequences not only on the patient but also on people close to him or her (Mohr et al. 1994; Pitceathly and Maguire 2003; Woźniak and Iżycki 2014). Within the iManageCancer platform, the serious game is the app that more effectively promote social wellbeing. Serious games are meant to support the patient in reducing stress, anxiety, and related negative impact of the disease on their lives and social relations and thus to contribute to keep a positive attitude towards the disease and life (Kelley et al. 2017; Sardi et al. 2017). In addition, family resilience is an important factor in the oncological therapeutic path, which is why family members are encouraged to answer the FaRe questionnaire (available on the iPHR), allowing the healthcare professionals to capture any uneasy situations and intervene. The iManageCancer platform mostly encourages a more direct involvement from the patient but also involves families and

caregivers, thus promoting an effective alliance among all the actors of the therapeutic path, according to the P5 *participatory* property (Gorini and Pravettoni 2011; Kabat-Zinn 2000).

The iManageCancer project perfectly matches the *psychocognitive* approach suggested by Pravettoni and Gorini (Gorini and Pravettoni 2011; Pravettoni and Gorini 2011); its objective is the patient's empowerment, starting from the belief that patient empowerment in medical care is only possible if based on a multi-level consideration of patients. As a matter of fact, the platform itself promotes a broad consideration of patient health: every feature of the platform has been designed to meet all the need of patients in managing their health as persons and therefore as a set of complex biological systems but also as a subject of emotions, fears, hopes, and needs, who has relationships and lives in a social context. In some cases, the idea behind an application has been to support an all-inclusive wellbeing of patients, with a specific focus on the psychological aspects.

Above all the apps, the serious game aims at helping patients to manage the psychological impact of the diagnosis and consequent treatment. Serious games have been proposed as a strategy to encourage healthy habits and the participation in social life, face disease in a different perspective, and promote illness management (Hoffmann and Wilson 2018; Kelley et al. 2017; Sardi et al. 2017). Serious games can also enhance patient's knowledge through education, reduce feelings of uncertainty, and simultaneously increase confidence in decision-making. From this perspective, serious games will provide also the opportunity to experience skills and coping strategies in facing cancer (Reichlin et al. 2011).

The iPHR also promotes a personalised approach, as it gives patients the chance to fill the previously mentioned questionnaire; this provides clinicians an interactive psychoemotional health assessment tool for the monitoring of psychological and physiological health status of patients.

4 Conclusion

The advances of technology allow today an ever better degree of participation, thanks to the tools of virtual and augmented reality that offer a much more direct interaction between the user and the external environment and a much more all-encompassing experience. Also in terms of prevention, research combined with eHealth can go a long way, exploiting the potential for data collection and interaction with the user of today's tools in conjunction with recent knowledge in systems biology.

Certainly, we can say that iManageCancer is an attempt to put technology at the service of medicine, with the aim of giving patients a device that can increase the involvement in their own care path, and clinicians a set of tools to personalise care processes by the consideration of patient as a whole, from biological factors to quality of life. As we have extensively debated, every constituent aspect of patients as human beings has been taken into account in the design and development of the

platform. Thanks to the first tests of usability, the platform has been renewed for the first time, and the pilot study on efficacy will allow us to rethink and implement some of the functions of the platform, in order to always meet the requests of patients and respond more effectively to their concrete needs during the course of care. P5 considers the impact on quality of life as an additional fundamental marker of effectiveness.

References

Cutica, I., Vie, G. M., & Pravettoni, G. (2014). Personalised medicine: The cognitive side of patients. *European Journal of Internal Medicine, 25*(8), 685–688. https://doi.org/10.1016/j.ejim.2014.07.002.

Faccio, F., Renzi, C., Crico, C., Kazantzaki, E., Kondylakis, H., Koumakis, L., … Pravettoni, G. (2018). Development of an eHealth tool for cancer patients: Monitoring psycho-emotional aspects with the Family Resilience (FaRe) questionnaire. *Ecancermedicalscience, 12*, 852. https://doi.org/10.3332/ecancer.2018.852.

Favrod, J., & Khazaal, Y. (2018). *Computers and games for mental health and well-being*. Lausanne: Frontiers Media.

Fleming, P. S., Koletsi, D., Ioannidis, J. P. A., & Pandis, N. (2016). High quality of the evidence for medical and other health-related interventions was uncommon in Cochrane systematic reviews. *Journal of Clinical Epidemiology, 78*, 34–42. https://doi.org/10.1016/j.jclinepi.2016.03.012.

Gorini, A., & Pravettoni, G. (2011). P5 medicine: A plus for a personalized approach to oncology. *Nature Reviews Clinical Oncology, 8*(7), 444. https://doi.org/10.1038/nrclinonc.2010.227-c1.

Gorini, A., Mazzocco, K., Gandini, S., Munzone, E., McVie, G., & Pravettoni, G. (2015). Development and psychometric testing of a breast cancer patient-profiling questionnaire. *Breast Cancer (Dove Medical Press), 7*, 133–146. https://doi.org/10.2147/BCTT.S80014.

Hoffmann, S., & Wilson, S. (2018). The role of serious games in the iManageCancer project. *Ecancermedicalscience, 12*, 850. https://doi.org/10.3332/ecancer.2018.850.

Kabat-Zinn, J. (2000). Participatory medicine. *Journal of the European Academy of Dermatology and Venereology*. https://doi.org/10.1046/j.1468-3083.2000.00062.x.

Kelley, C., Wilcox, L., Ng, W., Schiffer, J., & Hammer, J. (2017). Design features in games for health: Disciplinary and interdisciplinary expert perspectives. *DIS. Designing Interactive Systems (Conference), 2017*, 69–81. https://doi.org/10.1145/3064663.3064721.

Kim, I., Choi, H. J., Ryu, J. M., Lee, S. K., Yu, J. H., Kim, S. W., … Lee, J. E. (2018). A predictive model for high/low risk group according to oncotype DX recurrence score using machine learning. *European Journal of Surgical Oncology*. https://doi.org/10.1016/j.ejso.2018.09.011

Kondylakis, H., Bucur, A., Dong, F., Renzi, C., Manfrinati, A., Graf, N., et al. (2017). iManagecancer: Developing a platform for empowering patients and strengthening self-management in cancer diseases. In *Computer-based medical systems (CBMS), 2017 IEEE 30th international symposium on* (pp. 755–760). Los Alamitos: IEEE.

Mohr, V., Allen, S., & Malin, M. (1994). The psychosocial impact of cancer on older versus younger patients and their families. *Cancer, 74*(S7), 2118–2127.

Nobel, C. (2011). Teaching a 'Lean Startup' strategy. *HBS Working Knowledge*, pp 1–2.

Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer, 39*(11), 1517–1524. https://doi.org/10.1016/S0959-8049(03)00309-5.

Pravettoni, G., & Gorini, A. (2011). A P5 cancer medicine approach: Why personalized medicine cannot ignore psychology. *Journal of Evaluation in Clinical Practice, 17*(4), 594–596. https://doi.org/10.1111/j.1365-2753.2011.01709.x.

Reichlin, L., Mani, N., McArthur, K., Harris, A. M., Rajan, N., & Dacso, C. C. (2011). Assessing the acceptability and usability of an interactive serious game in aiding treatment decisions for patients with localized prostate cancer. *Journal of Medical Internet Research, 13*(1), e4. https://doi.org/10.2196/jmir.1519.

Renzi, C., Riva, S., Masiero, M., & Pravettoni, G. (2016). The choice dilemma in chronic hematological conditions: Why choosing is not only a medical issue? A psycho-cognitive perspective. *Critical Reviews in Oncology/Hematology.* https://doi.org/10.1016/j.critrevonc.2015.12.010.

Sardi, L., Idri, A., & Fernández-Alemán, J. L. (2017). A systematic review of gamification in e-health. *Journal of Biomedical Informatics, 71*, 31–48. https://doi.org/10.1016/J.JBI.2017.05.011.

Schwaber, K., & Beedle, M. (2002). *Agile software development with scrum* (Vol. 1). Upper Saddle River: Prentice Hall.

Woźniak, K., & Iżycki, D. (2014). Cancer: A family at risk. *Przeglad Menopauzalny = Menopause Review, 13*(4), 253–261. https://doi.org/10.5114/pm.2014.45002.

Zhang, X., Deng, Z., Parvinzamir, F., & Dong, F. (2018). MyHealthAvatar lifestyle management support for cancer patients. *Ecancermedicalscience, 12*, 849. https://doi.org/10.3332/ecancer.2018.849.