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**iManageCancer**

***Empowering patients and strengthening  
self-management in cancer diseases***

**Research and Innovation Action**

**PHC-26-2014: Self management of health and disease:  
citizen engagement and mHealth**

***D2.2: Scenarios and use cases including the ethical and  
legal aspects***

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<sup>2</sup> **PU** = Public, fully open, e.g. web, **CO** = Confidential, restricted under conditions set out in Model Grant Agreement

## Document History

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# 1. Executive Summary

This document deals with scenarios and use cases that are important for the iManageCancer project. In addition, the legal and ethical aspects of the project are discussed. The selection of use cases for iManageCancer is based on three activities that are described in chapter three of this deliverable. These activities are a survey, two workshops and the analysis of White Papers provided by ‘PatientView’. As a result, 14 scenarios are described in Chapter 4 that will be further elaborated and translated into use cases in Deliverable 2.3 Technical System Requirement Document. In addition, two serious games are outlined, one for children and the other for adults. They are described in chapter 5. In chapter 6 the legal and ethical framework is illustrated. This framework is based on the ethical and legal framework of the MyHealthAvatar project<sup>3</sup>, which is funded by the European Commission under FP7. The adaptation of the legal and ethical framework of MyHealthAvatar shows the close collaboration of these two European projects and gives a standardized approach to the scientific community. It can be concluded that the chosen scenarios for iManageCancer and the two serious games novel tools will be built to help patients to manage their cancer in all aspects. The described legal and ethical framework will keep data privacy at the highest level and protects all data by technical and contractual measurements to avoid misuse of them. In this respect, the iManageCancer project will provide a cancer disease self-management platform designed accordingly to the specific needs of patients with cancer. In addition, the platform and the developed tools will be able to be used by other patients as well with similar needs.

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<sup>3</sup> <http://myhealthavatar.org/>

## 2. Introduction

“Combining big data with personalized medicine is an unprecedented opportunity. It will probably be cheaper than current practices in the long term, particularly given the questionable effectiveness of many medications (see Reardon S: US precision-medicine proposal sparks questions. *Nature* 517, 540; 2015). Success in this endeavour will depend on training the next generation of clinicians and data scientists to deploy terabytes of data to select from a range of diagnosis and treatment options. Undergraduate and graduate bioinformatics programmes need to embrace data-analytics courses geared towards generating a new type of medical specialist — one who no longer needs to see patients, just their data.” [1]. If this is getting the future in medicine, patient empowerment needs to be addressed in particular. In this respect, the iManageCancer project will provide a cancer disease self-management platform designed accordingly to the specific needs of patients. The platform will focus on the wellbeing of the cancer patient with a special emphasis on their psycho-emotional condition. This deliverable will define scenarios and corresponding use cases for the iManageCancer platform. It describes the evolution of this scenarios and use cases and in addition comments on the legal and ethical aspects.

## 3. Selection of use case scenarios

The selection of use cases is based on the review of existing use case scenarios as reported in D2.1 “Concept definition - The patient’s and clinical care perspective of the iManageCancer platform” and on a survey that was carried out to get feedback from potential end-users of the iManageCancer platform. Together with input from members of the consortium, use case scenarios were then selected in an iterative way at a workshop with all consortium members that took place in Homburg at the 28<sup>th</sup> and 29<sup>th</sup> of May 2015. A second workshop was held in Heraklion at the 22<sup>th</sup> of July 2015 as a joined workshop between the EURECA<sup>4</sup> (Enabling information re-Use by linking clinical REsearch and Care) and the iManageCancer projects. During this workshop the current status of the PHR and the personal health information recommender scenarios were evaluated. In addition, three white papers from PatientView<sup>5</sup> from 2013 to 2015 are taken into consideration.

### 3.1. Survey to define use case scenarios

Together with task 2.1, 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 what kind of scenarios are relevant for them.

#### 3.1.1. Development of the survey

A first draft of the survey was shown at the kick-off meeting of the project in St. Ingbert at the 4<sup>th</sup> and 5<sup>th</sup> of February 2015. All participants of the meeting were asked to comment on the questionnaire and also to answer the questionnaire. These answers of the questionnaire are provided in Appendix 1 of this deliverable.

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<sup>4</sup> <http://eurecaproject.eu/>

<sup>5</sup> <http://www.patient-view.com/>



### 3.1.2. Promotion of the survey

Based on these results, the questionnaire was finalized and advertised via eCancer and different EU funded projects like CHIC, p-medicine, MyHealthAvatar. The English version of the survey can be accessed at <https://de.surveymonkey.com/r/P3D6NC8>

The website is promoted via the *ecancer.org* website (using the news ticker on the home page), through *ecancer* and *ecancerpatient* Twitter, *ecancer* LinkedIn, *Google Plus*, through the *ecancer* monthly newsletter (to over 11,500 followers) and via the Healthcare Information for All (HIFA) online community, which has more than 14,000 members interacting on 5 forums in 3 languages. The English forum was targeted for this survey.

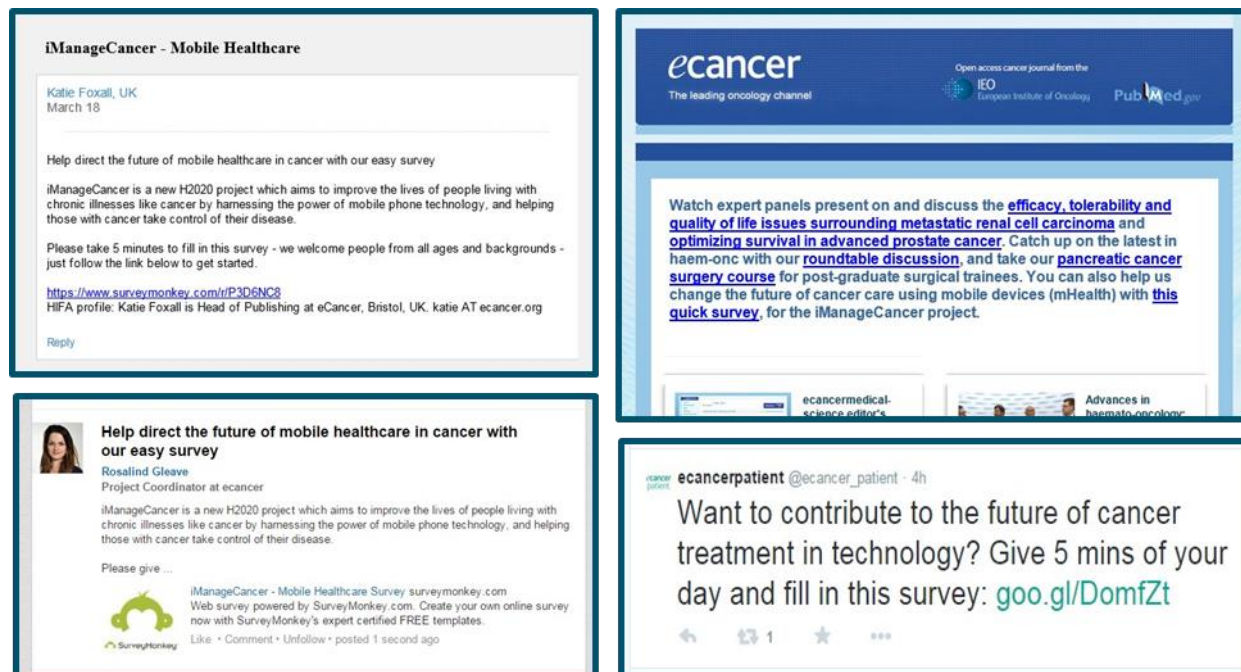


Figure 1. Examples of survey promotion.

Besides the English version, the survey is also provided in German, Italian and Greek languages and promoted via the eCancer, European projects and the following websites of eHealth:

In German language:

- <https://de.surveymonkey.com/s/iManageCancer-de>
- <http://www.ehealthserver.de>
- <http://www.ehealthserver.de/entwicklung/646-imanagecancer-fragebogen>

In Italian language:

- <https://it.surveymonkey.com/s/XQPYTWB>

In Greek language:

- <https://www.surveymonkey.com/s/iMCgr>

### 3.1.3. Results of the survey

The survey started at the 8<sup>th</sup> of February 2015 and lasted up to 14<sup>th</sup> of June. Altogether 226 answers were obtained. Most of them were received from the English version of the questionnaire with

118 answers (52.2%), followed by the German version 59 (26.1%), the Italian version 40 (17.7%) and the Greek version 9 (4.0%).

The following tables display the answers to the different questions of the survey. In Appendix 2 additional information is given regarding answers to questions with ‘others’.

**In summary, the following conclusions can be driven from the survey:**

- The number of responders is sufficient and covers adults from 21 years to 77 years of age. 207 people disclosed their gender. 126 of them are female and 81 are male giving a ratio of 1.55 female to male for the whole cohort. In the subset of the Italian and Greek versions more males did respond.
- In all subsets most of the responders have a high educational degree ranging from 50 to 76 % with a university degree. Their profession is partly academic and non-academic and more are working in the non-medical field than in the medical field.
- Most of the responders are healthy and only few have cancer.
- Around 90% of respondents possess a PC or laptop and a smart phone with up to 95 % in Italy. Most respondents participate in a social network with Facebook the most common.
- Only few participants use personal Health Records (PHR). Most have heard about PHR.
- Online platforms are unknown for around 80% of responders.
- The trust in the healthcare system high, with the lowest trust in Greece. Most patients want to discuss details of their disease with their physician.
- Personal Health data will mainly be shared with the personal doctor and less frequently with friends except of the partner. Depending on the disease, the willingness to share health data is different. There seems to be a difference in the participating countries in the attitude of the respondents towards the sharing of their health information with others. 100% of UK participants would share their data with their doctor, 91% with their partner, and 63 with their closest friend while only 76% of the German respondents would do so with their doctor, 58% with their partner and only 26% with their closest friend (Italian participants: 88%, 69%, 31%).
- Security for sharing is most important for all respondents.
- More than 80% of responders want to have tools for analysing their health data.
- Around 80% are willing to provide their health data for research.
- Most important are tools for uploading health data, giving recommendations, allowing to contact the treating physician and a tool that gives information about drug interaction.
- Around 50% of responders have heard about serious games and less than 20% have ever played a serious game, but most of them would play in case of a chronic illness.
- All types of serious games are interesting to play. They are considered to be most helpful for teenagers.
- Serious games are assumed to be educational, distracting, de-stressing and help to cope with the diseases.
- Around 25% of responders like to participate in a focus group on this topic.

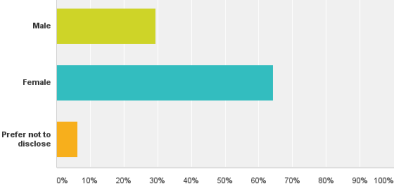
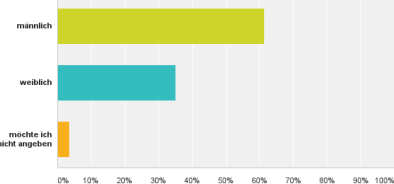
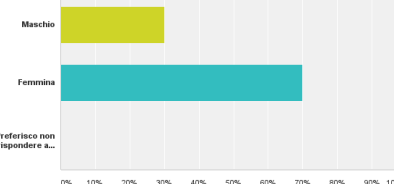
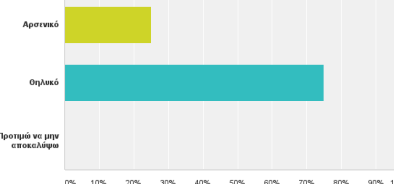
**Number of responses**

UK	Germany	Italy	Greece
118	59	40	9

**Age of responders**

UK	Germany	Italy	Greece
Mean: 41.1 y (21 y – 77 y)	Mean: 45.7 y (25 y – 77 y)	Mean: 37.7 y (25 y – 68 y)	Mean: 42.1 y (28 y – 65 y)

**I identify my gender as**

UK	Germany	Italy	Greece
			
Male: 29 % Female: 64 % Not disclosed: 6 % Skipped: 6 respondents	Male: 61 % Female: 35 % Not disclosed: 4 % Skipped: 2 respondents	Male: 30 % Female: 70 % Not disclosed: 0 % Skipped: 0 respondents	Male: 25 % Female: 75 % Not disclosed: 0 % Skipped: 1 respondents

**What is the highest level of education you have completed?**

UK	Germany	Italy	Greece
Did not attend school: 1 % Primary school: 3 % Secondary school: 10 % University degree: 64 % Other: 23 % Skipped: 7 respondents	Did not attend school: 2 % Primary school: 12 % Secondary school: 12 % University degree: 67 % Other: 7 % Skipped: 2 respondents	Did not attend school: 0 % Primary school: 0 % Secondary school: 25 % University degree: 76 % Other: 0 % Skipped: 0 respondents	Did not attend school: 0 % Primary school: 13 % Secondary school: 25 % University degree: 50 % Other: 13 % Skipped: 1 respondents

**What is your profession?**

UK	Germany	Italy	Greece

I do not work: 24 %	I do not work: 5 %	I do not work: 0 %	I do not work: 13 %
Non-academic (no-med): 33 %	Non-academic (no-med): 19 %	Non-academic (no-med): 28 %	Non-academic (no-med): 50 %
Non-academic (medical): 15 %	Non-academic (medical): 14 %	Non-academic (medical): 50 %	Non-academic (medical): 13 %
Academic (no-med): 17 %	Academic (no-med): 48 %	Academic (no-med): 3 %	Academic (no-med): 25 %
Academic (medical): 12 %	Academic (medical): 14 %	Academic (medical): 20 %	Academic (medical): 0 %
Skipped: 9 respondents	Skipped: 1 respondents	Skipped: 0 respondents	Skipped: 1 respondents

### How would you describe your current health status?

UK	Germany	Italy	Greece
<p>Healthy: 63 % Acute illness: 7 % Chronic illness: 24 % I have cancer: 5 % Skipped: 7 respondents</p>	<p>Healthy: 72 % Acute illness: 14 % Chronic illness: 14 % I have cancer: 0 % Skipped: 1 respondents</p>	<p>Healthy: 95 % Acute illness: 3 % Chronic illness: 3 % I have cancer: 0 % Skipped: 0 respondents</p>	<p>Healthy: 50 % Acute illness: 13 % Chronic illness: 0 % I have cancer: 25 % Skipped: 1 respondents</p>

**How much do you trust your healthcare system?**

UK	Germany	Italy	Greece
Weighted average: <b>3.05</b>	Weighted average: <b>2.60</b>	Weighted average: <b>3.23</b>	Weighted average: <b>4.86</b>
1: completely trusting: 11 %	1: completely trusting: 7 %	1: completely trusting: 5 %	1: completely trusting: 0 %
2: 39 %	2: 38 %	2: 30 %	2: 0 %
3: 23 %	3: 45 %	3: 28 %	3: 14 %
4: 6 %	4: 9 %	4: 15 %	4: 0 %
5: 10 %	5: not trusting at all: 2 %	5: 20 %	5: 71 %
6: 7 %		6: 3 %	6: 14 %
7: not trusting at all: 5 %		7: not trusting at all: 0 %	7: not trusting at all: 0 %
Skipped: 7 respondents	Skipped: 1 respondents	Skipped: 0 respondents	Skipped: 2 respondents

**What is your attitude towards your doctor's advice?**

UK	Germany	Italy	Greece
Weighted average: <b>5.15</b>	Weighted average: <b>3.33</b>	Weighted average: <b>4.33</b>	Weighted average: <b>5.13</b>
1: I never discuss details: 3 %	1: I never discuss details: 3 %	1: I never discuss details: 0 %	1: I never discuss details: 13 %
2: 6 %	2: 26 %	2: 23 %	2: 0 %
3: 11 %	3: 23 %	3: 15 %	3: 0 %
4: 13 %	4: 28 %	4: 15 %	4: 13 %
5: 12 %	5: I discuss all details: 19 %	5: 18 %	5: 0 %
6: 32 %		6: 15 %	6: 25 %
7: I discuss all details: 24 %		7: I discuss all details: 15 %	7: I discuss all details: 50 %
Skipped: 8 respondents	Skipped: 1 respondents	Skipped: 0 respondents	Skipped: 1 respondents

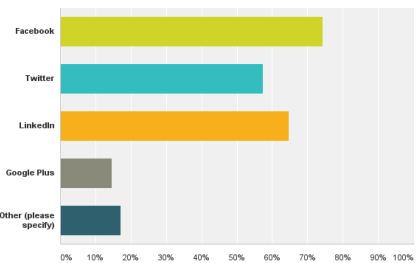
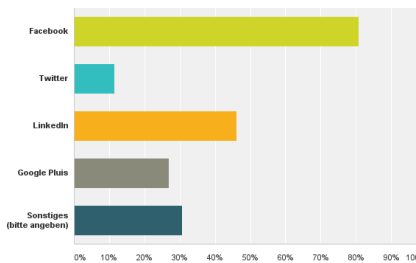
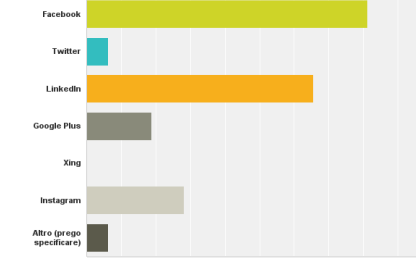
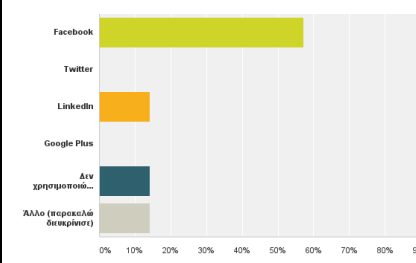
**Do you have any of the following?**

UK	Germany	Italy	Greece
Laptop: 89 % Mobile phone: 56 % PC: 56 % Smart phone: 70 % Tablet: 58 % Skipped: 6 respondents	Laptop: 89 % Mobile phone: 63 % PC: 72 % Smart phone: 86 % Tablet: 53 % Skipped: 2 respondents	PC / Laptop: 98 % Mobile phone: 10 % Smart phone: 95 % Tablet: 50 % Skipped: 0 respondents	Laptop: 75 % Mobile phone: 100 % PC: 75 % Smart phone: 75 % Tablet: 50 % Skipped: 5 respondents

**Are you a member of a social network?**

UK	Germany	Italy	Greece
Yes: 88 % No: 12 % Skipped: 26 respondents	Yes: 48 % No: 52 % Skipped: 5 respondents	Yes: 80 % No: 20 % Skipped: 0 respondents	Yes: 86 % No: 14 % Skipped: 2 respondents

**Which social network do you use?**

UK	Germany	Italy	Greece
			
Facebook: 74 % Twitter: 57 % LinkedIn: 65 % Google Plus: 15 %  Other: 17 % Skipped: 36 respondents	Facebook: 81 % Twitter: 12 % LinkedIn: 46 % Google Plus: 27 %  Other: 31 % Skipped: 33 respondents	Facebook: 81 % Twitter: 6 % LinkedIn: 66 % Google Plus: 19 % Xing: 1 % Instagram: 28 % Other: 6 % Skipped: 8 respondents	Facebook: 57 % Twitter: 0 % LinkedIn: 14 % Google Plus: 0 %  Other: 14 % Skipped: 2 respondents



**Do you use a Personal Health Record (PHR)?**

UK	Germany	Italy	Greece
Yes: 7 % No, but heard about: 31 % No, never heard about: 63 % Skipped: 27 respondents	Yes: 15 % No, but heard about: 33 % No, never heard about: 52 % Skipped: 5 respondents	Yes: 13 % No, but heard about: 45 % No, never heard about: 43 % Skipped: 0 respondents	Yes: 0 % No, but heard about: 57 % No, never heard about: 43 % Skipped: 2 respondents

**Do you know of any online platforms for patients?**

UK	Germany	Italy	Greece
No: 70 % Yes, MyHealthAvatar: 7 % Yes, other: 23 % Skipped: 27 respondents	No: 81 % Yes, MyHealthAvatar: 7 % Yes, other: 11 % Skipped: 5 respondents	No: 87 % Yes, MyHealthAvatar: 5 % Yes, other: 8 % Skipped: 1 respondents	No: 71 % Yes, MyHealthAvatar: 29 % Yes, other: 0 % Skipped: 2 respondents

**With whom of the following people can you imagine sharing your personal health information via a secure website?**

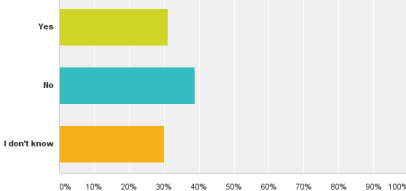
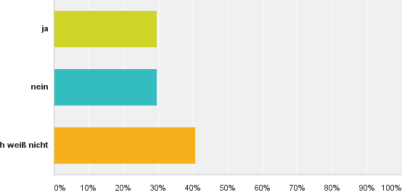
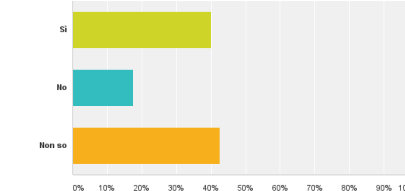
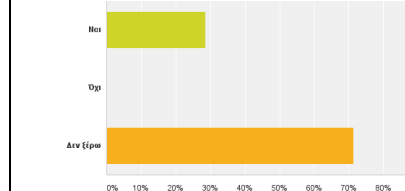
UK						
	My doctor	Doctors in general	Closest friend	All my friends	My partner	My family
General Health information	Yes: 100 % No: 0 % Skipped: 30 respondents	Yes: 73 % No: 27 % Skipped: 30 respondents	Yes: 63 % No: 37 % Skipped: 30 respondents	Yes: 19 % No: 81 % Skipped: 30 respondents	Yes: 91 % No: 9 % Skipped: 30 respondents	Yes: 66 % No: 34 % Skipped: 30 respondents
Sexually transmitted diseases	Yes: 96 % No: 4 % Skipped: 30 respondents	Yes: 44 % No: 56 % Skipped: 30 respondents	Yes: 31 % No: 69 % Skipped: 30 respondents	Yes: 0 % No: 100 % Skipped: 30 respondents	Yes: 87 % No: 13 % Skipped: 30 respondents	Yes: 22 % No: 78 % Skipped: 30 respondents
Mental Health	Yes: 96 % No: 4 % Skipped: 30 respondents	Yes: 58 % No: 42 % Skipped: 30 respondents	Yes: 57 % No: 43 % Skipped: 30 respondents	Yes: 10 % No: 90 % Skipped: 30 respondents	Yes: 88 % No: 12 % Skipped: 30 respondents	Yes: 63 % No: 37 % Skipped: 30 respondents
Cancer	Yes: 98 % No: 2 % Skipped: 30 respondents	Yes: 75 % No: 25 % Skipped: 30 respondents	Yes: 68 % No: 32 % Skipped: 30 respondents	Yes: 23 % No: 77 % Skipped: 30 respondents	Yes: 91 % No: 9 % Skipped: 30 respondents	Yes: 70 % No: 30 % Skipped: 30 respondents
Other	Yes: 54 % No: 46 % Skipped: 30 respondents	Yes: 42 % No: 58 % Skipped: 30 respondents	Yes: 36 % No: 64 % Skipped: 30 respondents	Yes: 10 % No: 90 % Skipped: 30 respondents	Yes: 69 % No: 31 % Skipped: 30 respondents	Yes: 42 % No: 58 % Skipped: 30 respondents

Germany						
	My doctor	Doctors in general	Closest friend	All my friends	My partner	My family
General Health information	Yes: 76 % No: 24 % Skipped: 9 respondents	Yes: 40 % No: 60 % Skipped: 9 respondents	Yes: 26 % No: 74 % Skipped: 9 respondents	Yes: 14 % No: 86 % Skipped: 9 respondents	Yes: 58 % No: 42 % Skipped: 9 respondents	Yes: 44 % No: 56 % Skipped: 9 respondents
Sexually transmitted diseases	Yes: 82 % No: 18 % Skipped: 9 respondents	Yes: 24 % No: 76 % Skipped: 9 respondents	Yes: 16 % No: 84 % Skipped: 9 respondents	Yes: 0 % No: 100 % Skipped: 9 respondents	Yes: 49 % No: 51 % Skipped: 9 respondents	Yes: 24 % No: 76 % Skipped: 9 respondents
Mental Health	Yes: 85 % No: 15 % Skipped: 9 respondents	Yes: 23 % No: 77 % Skipped: 9 respondents	Yes: 28 % No: 72 % Skipped: 9 respondents	Yes: 0 % No: 100 % Skipped: 9 respondents	Yes: 45 % No: 55 % Skipped: 9 respondents	Yes: 40 % No: 60 % Skipped: 9 respondents
Cancer	Yes: 83 % No: 17 % Skipped: 9 respondents	Yes: 28 % No: 72 % Skipped: 9 respondents	Yes: 34 % No: 66 % Skipped: 9 respondents	Yes: 0 % No: 100 % Skipped: 9 respondents	Yes: 49 % No: 51 % Skipped: 9 respondents	Yes: 49 % No: 51 % Skipped: 9 respondents
Other	Yes: 60 % No: 40 % Skipped: 9 respondents	Yes: 20 % No: 80 % Skipped: 9 respondents	Yes: 40 % No: 60 % Skipped: 9 respondents	Yes: 0 % No: 100 % Skipped: 9 respondents	Yes: 20 % No: 80 % Skipped: 9 respondents	Yes: 0 % No: 100 % Skipped: 9 respondents

Italy						
	My doctor	Doctors in general	Closest friend	All my friends	My partner	My family
General Health information	Yes: 88 % No: 12 % Skipped: 8 respondents	Yes: 81 % No: 19 % Skipped: 8 respondents	Yes: 31 % No: 69 % Skipped: 8 respondents	Yes: 9 % No: 91 % Skipped: 8 respondents	Yes: 69 % No: 31 % Skipped: 8 respondents	Yes: 63 % No: 37 % Skipped: 8 respondents
Sexually transmitted diseases	Yes: 84 % No: 16 % Skipped: 8 respondents	Yes: 77 % No: 23 % Skipped: 8 respondents	Yes: 10 % No: 90 % Skipped: 8 respondents	Yes: 3 % No: 97 % Skipped: 8 respondents	Yes: 68 % No: 32 % Skipped: 8 respondents	Yes: 35 % No: 65 % Skipped: 8 respondents
Mental Health	Yes: 81 % No: 19 % Skipped: 8 respondents	Yes: 72 % No: 28 % Skipped: 8 respondents	Yes: 19 % No: 81 % Skipped: 8 respondents	Yes: 6 % No: 94 % Skipped: 8 respondents	Yes: 75 % No: 25 % Skipped: 8 respondents	Yes: 47 % No: 53 % Skipped: 8 respondents
Cancer	Yes: 90 % No: 10 % Skipped: 8 respondents	Yes: 90 % No: 10 % Skipped: 8 respondents	Yes: 19 % No: 81 % Skipped: 8 respondents	Yes: 6 % No: 94 % Skipped: 8 respondents	Yes: 71 % No: 29 % Skipped: 8 respondents	Yes: 55 % No: 45 % Skipped: 8 respondents
Other	Yes: 0 % No: 100 % Skipped: 8 respondents	Yes: 0 % No: 100 % Skipped: 8 respondents	Yes: 0 % No: 100 % Skipped: 8 respondents	Yes: 0 % No: 100 % Skipped: 8 respondents	Yes: 0 % No: 100 % Skipped: 8 respondents	Yes: 0 % No: 100 % Skipped: 8 respondents

Greece						
	My doctor	Doctors in general	Closest friend	All my friends	My partner	My family
General Health information	Yes: 71 % No: 29 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents	Yes: 29 % No: 71 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents	Yes: 43 % No: 57 % Skipped: 2 respondents
Sexually transmitted diseases	Yes: 71 % No: 29 % Skipped: 2 respondents	Yes: 29 % No: 71 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 29 % No: 71 % Skipped: 2 respondents	Yes: 43 % No: 57 % Skipped: 2 respondents
Mental Health	Yes: 86 % No: 14 % Skipped: 2 respondents	Yes: 71 % No: 29 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 71 % No: 29 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents
Cancer	Yes: 86 % No: 14 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents	Yes: 29 % No: 71 % Skipped: 2 respondents	Yes: 14 % No: 86 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents	Yes: 57 % No: 43 % Skipped: 2 respondents
Other	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents

**Would you like to share your own health records on a secure website?**

UK	Germany	Italy	Greece
			
Yes: 31 % No: 39 % I don't know: 30 % Skipped: 28 respondents	Yes: 30 % No: 30 % I don't know: 40 % Skipped: 5 respondents	Yes: 40 % No: 18 % I don't know: 43 % Skipped: 0 respondents	Yes: 29 % No: 0 % I don't know: 71 % Skipped: 2 respondents

**How important are data security and privacy issues to your personal health information?**

UK	Germany	Italy	Greece
Weighted average: <b>6.24</b> 1: Not at all: 1 % 2: 2 % 3: 4 % 4: 2 % 5: 9 % 6: 16 % 7: extremely important: 65 % Skipped: 29 respondents	Weighted average: <b>4.76</b> 1: Not at all: 0 % 2: 2 % 3: 4 % 4: 11 % 5: extremely important: 83 % Skipped: 5 respondents	Weighted average: <b>6.00</b> 1: Not at all: 3 % 2: 5 % 3: 0 % 4: 8 % 5: 13 % 6: 11 % 7: extremely important: 62 % Skipped: 1 respondents	Weighted average: <b>6.00</b> 1: Not at all: 0 % 2: 0 % 3: 0 % 4: 0 % 5: 0 % 6: 29 % 7: extremely important: 71 % Skipped: 2 respondents

**Do you use online banking?**

UK	Germany	Italy	Greece
Yes: 82 % No: 18 % Skipped: 27 respondents	Yes: 77 % No: 23 % Skipped: 6 respondents	Yes: 90 % No: 10 % Skipped: 1 respondents	Yes: 71 % No: 29 % Skipped: 2 respondents

**How secure do you feel online banking is?**

UK	Germany	Italy	Greece
Weighted average: <b>5.00</b> 1: Not at all secure: 3 % 2: 9 % 3: 6 % 4: 7 % 5: 17 % 6: 53 % 7: completely secure: 6 % Skipped: 29 respondents	Weighted average: <b>3.32</b> 1: Not at all secure: 6 % 2: 13 % 3: 26 % 4: 53 % 5: completely secure: 2 % Skipped: 6 respondents	Weighted average: <b>5.48</b> 1: Not at all secure: 0 % 2: 5 % 3: 0 % 4: 13 % 5: 8 % 6: 64 % 7: completely secure: 10 % Skipped: 1 respondents	 Not at all secure: 33 % Completely secure: 67 % Skipped: 2 respondents

**If you could get tools for analysing your health data at home, would you use such tools?**

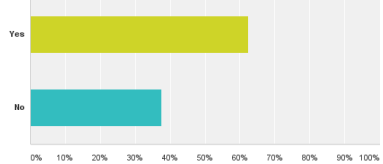
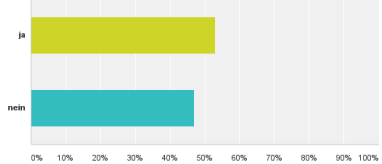
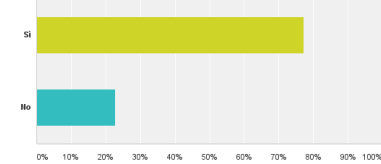
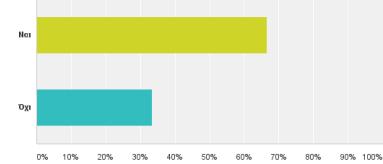
UK	Germany	Italy	Greece
Yes: 85 % No: 15 % Skipped: 27 respondents	Yes: 89 % No: 11 % Skipped: 5 respondents	Yes: 82 % No: 18 % Skipped: 1 respondents	Yes: 86 % No: 14 % Skipped: 2 respondents

**Do you want to provide your health data for clinical research?**

UK	Germany	Italy	Greece
Yes: 73 % No: 27 % Skipped: 29 respondents	Yes: 85 % No: 15 % Skipped: 7 respondents	Yes: 90 % No: 10 % Skipped: 1 respondents	Yes: 86 % No: 14 % Skipped: 2 respondents



**If yes, would you like to give your consent for this online?**

UK	Germany	Italy	Greece
			
Yes: 62 %	Yes: 53 %	Yes: 77 %	Yes: 67 %
No: 38 %	No: 47 %	No: 23 %	No: 33 %
Skipped: 41 respondents	Skipped: 8 respondents	Skipped: 5 respondents	Skipped: 3 respondents

**Here is a list of tools that might be helpful for people with chronic illnesses. Which of them would you like to use?**

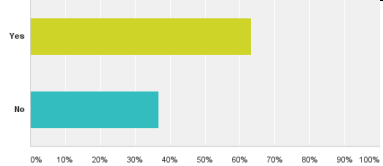
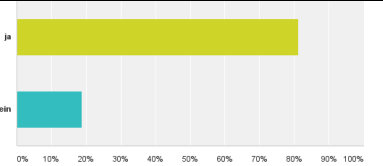
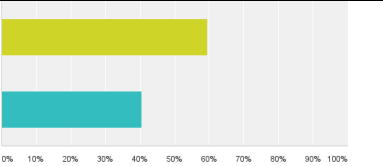
	UK	Germany	Italy	Greece
An online health diary	49 %	35 %	49 %	14 %
An online health diary with the ability to upload photos, clinical reports, etc.	60 %	37 %	49 %	0 %
A tool to upload information to share with your doctor	82 %	69 %	84 %	29 %
A tool to connect to wearable devices (e.g. pedometers)	61 %	59 %	62 %	0 %
A tool to analyse your health information	74 %	71 %	65 %	0 %
A tool to give information and recommendations	70 %	82 %	51 %	14 %
A tool allowing you to contact and interact with your doctor	70 %	75 %	84 %	43 %
A tool that gives information about drug interactions	82 %	80 %	65 %	0 %
A time planer for your medication and/or appointments with the hospital	65 %	43 %	65 %	0 %

The ability to give online consent for your personal information (e-consent)	56 %	31 %	51 %	0 %
Other (please specify)	9 %	6 %	0 %	0 %
Respondents that skipped the question	30	8	3	2

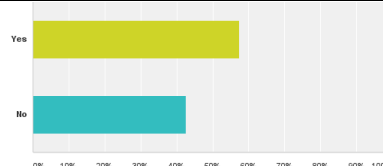
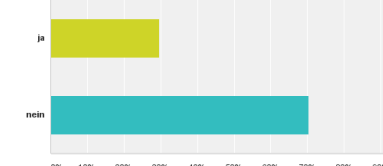
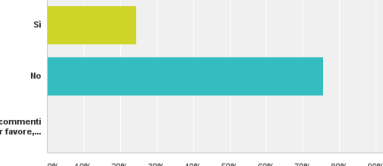
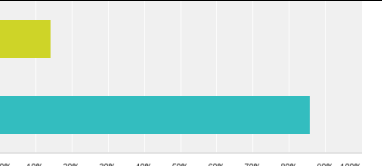
**Please rank in order of preference the tools that you selected above?**

	UK	Germany	Italy	Greece
	Ranking 1 (most preferred) – 10 (less preferred)			
An online health diary	6	10	4	3
An online health diary with the ability to upload photos, clinical reports, etc.	3	8	6	1
A tool to upload information to share with your doctor	2	5	1	5
A tool to connect to wearable devices (e.g. pedometers)	8	6	7	2
A tool to analyse your health information	4	2	2	4
A tool to give information and recommendations	5	3	5	10
A tool allowing you to contact and interact with your doctor	1	1	3	9
A tool that gives information about drug interactions	7	4	8	8
A time planer for your medication and/or appointments with the hospital	9	7	9	7
The ability to give online consent for your personal information (e-consent)	10	9	10	5
Respondents that skipped the question	32	8	7	3

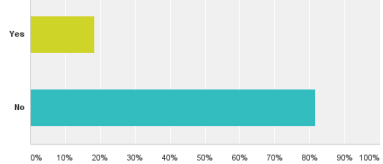
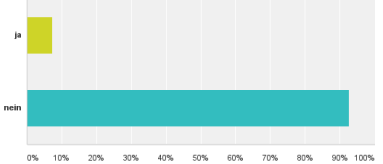
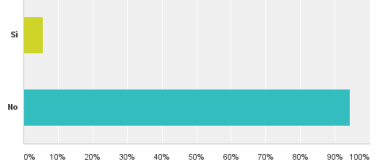
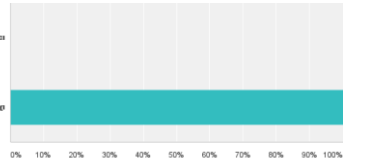
**Do you ever play computer games?**

UK	Germany	Italy	Greece
			No answers available
Yes: 63 % No: 3 % Skipped: 31 respondents	Yes: 81 % No: 19 % Skipped: 6 respondents	Yes: 59 % No: 41 % Skipped: 3 respondents	

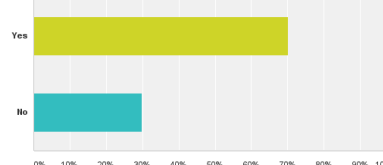
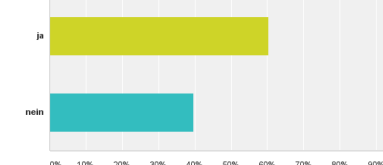
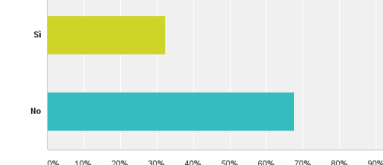
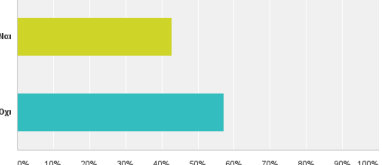
**Serious games are games designed for a primary purpose other than pure entertainment. In medicine such games can be used to educate patients, to fight against diseases, etc.. Have you ever heard of serious games before?**

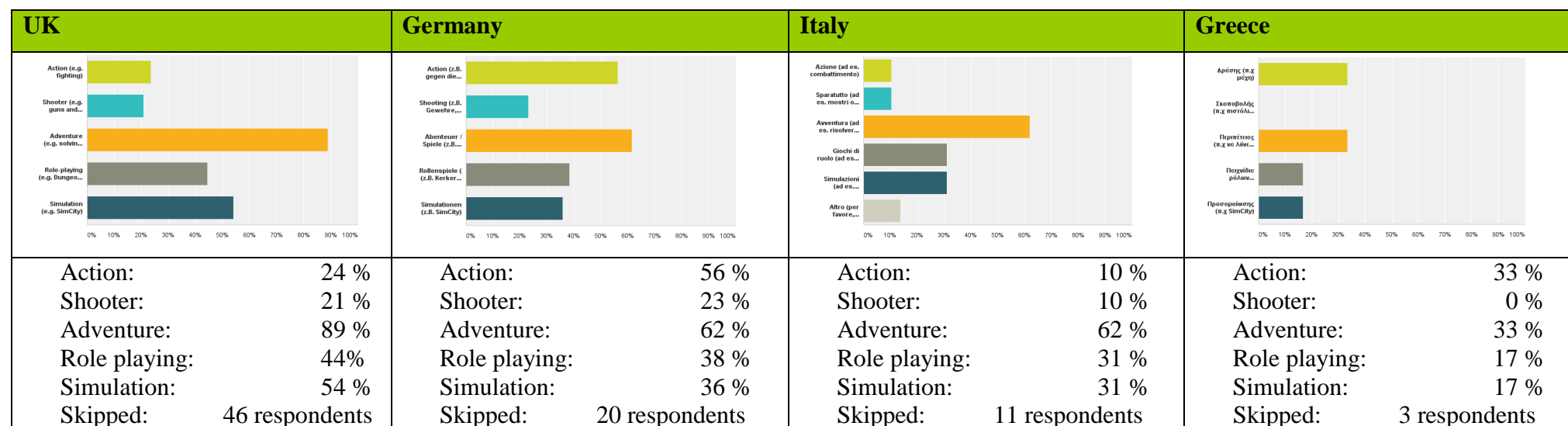
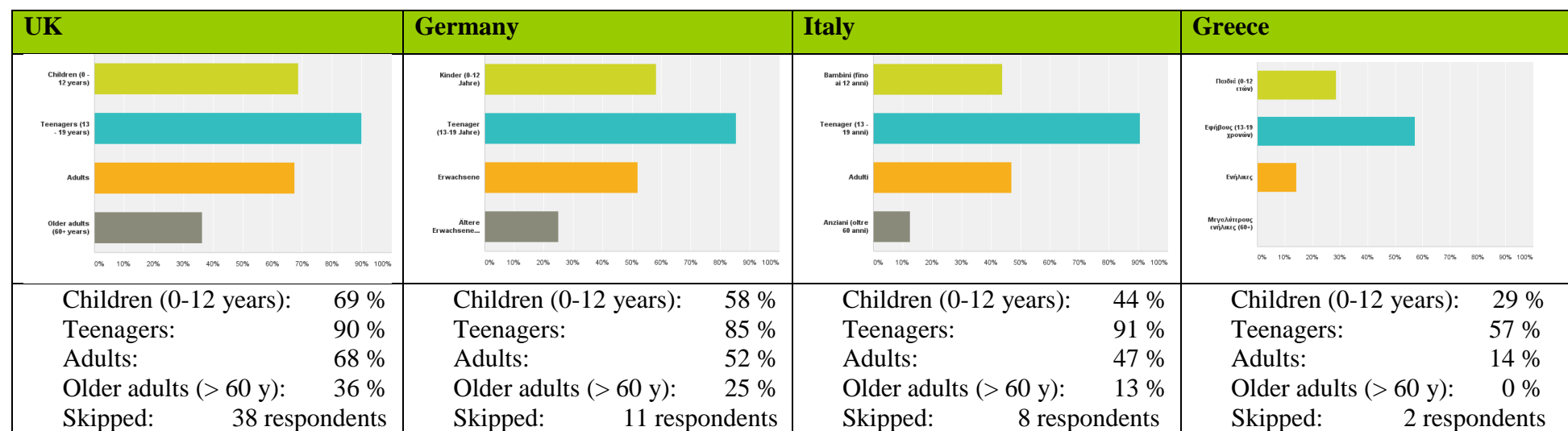
UK	Germany	Italy	Greece
			
Yes: 57 % No: 43 % Skipped: 31 respondents	Yes: 30 % No: 70 % Skipped: 5 respondents	Yes: 24 % No: 76 % Skipped: 3 respondents	Yes: 14 % No: 86 % Skipped: 2 respondents

**Have you ever played a serious game?**

UK	Germany	Italy	Greece
			
Yes: 18 % No: 82 % Skipped: 31 respondents	Yes: 7 % No: 93 % Skipped: 5 respondents	Yes: 6 % No: 94 % Skipped: 5 respondents	Yes: 0 % No: 100 % Skipped: 2 respondents

**If you had a chronic illness, do you think playing a serious game would be helpful?**

UK	Germany	Italy	Greece
			
Yes: 70 % No: 30 % Skipped: 34 respondents	Yes: 60 % No: 40 % Skipped: 6 respondents	Yes: 32 % No: 68 % Skipped: 9 respondents	Yes: 43 % No: 57 % Skipped: 2 respondents

**Which types of serious game would you like to play?****For whom do you think serious games would be helpful?**

**How are serious games helpful?**

UK	Germany	Italy	Greece
Educational: 82 % Distracting: 53 % De-stressing: 65 % Disease coping: 65 % Other: 9 % Skipped: 39 respondents	Educational: 62 % Distracting: 60 % De-stressing: 47 % Disease coping: 60 % Other: 6 % Skipped: 12 respondents	Educational: 33 % Distracting: 45 % De-stressing: 27 % Disease coping: 27 % Other: 21 % Skipped: 7 respondents	Educational: 0 % Distracting: 14 % De-stressing: 86 % Disease coping: 0 % Skipped: 2 respondents

**Would you like to participate in a focus group on this topic?**

UK	Germany	Italy	Greece
Yes: 29 % No: 71 % Skipped: 35 respondents	Yes: 13 % No: 87 % Skipped: 5 respondents	Yes: 24 % No: 76 % Skipped: 3 respondents	Yes: 29 % No: 71 % Skipped: 2 respondents

### 3.2. Workshop to select use case scenarios

At the 28<sup>th</sup> and 29<sup>th</sup> of May 2015 a workshop to select the use case scenarios that will be developed in iManageCancer did take place at USAAR in Homburg, Germany. During these two days an intensive discussion did take place between all partners to define the most important scenarios based on the results of the survey carried out in WP2 (see chapter 3.1 of this deliverable) and the knowledge gained from D2.1 about similar platforms and eHealth use cases. In addition, preliminary results of the European project *MyHealthAvatar* was taken into consideration as well. After defining the most relevant use case scenarios from an end-user perspective, each of them was elaborated in an iterative way and responsible partners were assigned to develop them in an iterative process. This process included clinicians and other end-users right from the beginning to test the usability and the functionality and to answer the question if the developed tool provides those results that are expected by end-users. In addition the workload to develop each end-user scenario was calculated and asked, if the resources of the project allow their building.

In the following chapters the different use-case scenarios are described. This result of the workshop is the basis to derive technical requirements for the system in D2.3.

### 3.3. Workshop together with the EURECA project

At the 22<sup>th</sup> of July 2015 a workshop did take place at Crete-Heraklion, Greece. The join workshop between EURECA<sup>6</sup> and iManageCancer projects aimed at evaluating the current status of the PHR and the personal health information recommender scenarios.

The goal of EURECA is to enable seamless, secure, scalable and consistent linkage of healthcare information residing in electronic health record (EHR) systems with information in clinical research information systems, such as clinical trials. Achieving semantic interoperability among EHR and clinical trial systems is at the core of the EURECA project, as it is the basis for enabling many of the software services and tools developed in the project. EURECA is co-funded by the European Union under the FP7-ICT programme and ends on July 2015. PHILIPS coordinates it and USAAR, FRAU and FORTH are also involved as partner. More specifically, FORTH built intelligent reasoning mechanisms for patients within a custom-tailored PHR system.

For the purposes of the workshop, potential end-users had been asked to sign-up for one-hour slot using e-mails. Volunteers were clinicians from the University Hospital of Heraklion. Six end-users visited the workshop all of them evaluating the two tools. A diverse set of clinicians was selected, one endocrinologist, one gastroenterologist, one plastic surgeon and two paediatricians. The distribution of end-users per tool is shown in Table 1.

*Table 1. The number of end-users that evaluated each tool at the workshop.*

Tool Name	No. of participants
Patient Diary & Long-term follow up	6
Personal medical information recommender	5

The evaluation was based on the EURECA validation & evaluation procedures. For each tool, evaluation forms covering all the appropriate quality characteristics from the product quality

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<sup>6</sup> <http://eurecaproject.eu/>

model of the ISO/IEC 25000<sup>7</sup> series were available. The evaluation forms consisted of a list of questions where the end user had to answer with a degree of satisfaction with Likert<sup>8</sup> scale. Likert scale is based on forced-choice questions, where a statement is made and the respondent then indicates the degree of agreement or disagreement with the statement on a 5-point scale. For each tool, the end user had to fill in two forms and answer to three questions. Form 1 consisted of the selected sub-characteristics and its translation into a simple question for the end user. The form 2 was the System Usability Scale<sup>9</sup> (SUS) for global assessment of systems usability and the final questions to the end users were:

- What you would like to change in the functionality of the tool?
- What you would like to change/add in the user interface of the tool?
- Would you propose to your patients to use such a tool?

### 3.3.1. PHIR

The evaluation of the PHIR tool in the evaluation workshop focused on usability, functionality and quality in use for patients, evaluated by clinical personnel able to assess both the accuracy and relevance of the retrieved pages of the tool.

For each of the evaluators, a session of approximately 20 minutes was allocated, where they had to carry out the evaluation scenario and thereafter they were requested to provide feedback (including both verbal remarks and the evaluation questionnaires).

The steps for the scenario that the end users had to follow during the evaluation of the PMIR tool were:

1. Login to the system.
2. Your user/patient is Peter Davies, a lung cancer patient with initial symptoms wheezing, cough, headache, bone pain and chest pain. On the first page some relevant sites are recommended to the patient according to their profile.
3. You can submit an empty query or a string query. In that case, all the relevant documents with the user's profile are retrieved.
4. Pose a query in natural language, such as "lung cancer therapy".
5. You can rate the pages you like/dislike, and your preferences will be taken into account next time when the ordering of the documents is calculated.
6. Pose new queries.

Most of the evaluators reported that the system is complete, clear and easy to use and that they would not change anything in the functionality or the interface. In addition, they claimed that they would recommend to their patients using such a tool.

In addition, the evaluators made some minor comments. For example, one evaluator recommended suggestions and explanations to be added, which are essential for the elderly users. She would also prefer more patients' data in the system to achieve a more complete test. Another evaluator pointed that links were not patient oriented and he would suggest that documents from

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<sup>7</sup> ISO/IEC FCD 25000, Software Engineering – Software Product Quality Requirements and Evaluation (SQuaRE) - Guide to SQuaRE, Geneva: International Organization for Standardization

<sup>8</sup> Likert, Rensis (1932). "A Technique for the Measurement of Attitudes". Archives of Psychology 140: 1–55

<sup>9</sup> Brooke, John. "SUS-A quick and dirty usability scale." Usability evaluation in industry 189, no. 194 (1996): 4-7



Mayo clinic<sup>10</sup> and MedScape<sup>11</sup> should be included. He also suggested that documents included should be simple and understandable for a basic user without medical knowledge. Finally, in one occasion the evaluator had problems with understanding the rating system and suggested that more details and information should be visible for the user to understand how to rate a document.

The tool got positive feedback from all the evaluators. None of the evaluators detected a weakness and each of the evaluators would suggest the tool to their patients. Comments of the evaluators were positive, and all of them completed the scenario in short time and without any problems indicating that the tool is easy to use and usable.

### **3.3.2. PHR**

The scenario for the PHR included all available individual applications installed in the Indivo-X and also all the available actions on each application. A session of twenty minutes was allocated for each of the evaluators. A simple description of the tool was given in order to evaluate whether users could easily use and understand the tool.

The first user reported that the system is complete and easy to use and that it combines simplicity and functionality. Two users had used previously a similar tool, which implies that they were familiar and it was easier for them to complete the scenario. All users completed the scenario of the tool in around twenty minutes. One user was satisfied with the tool except from the colour of the text in a particular application and he described it as easy and understandable. He completed the scenario and the extra navigation he did by himself in 25 minutes.

Another evaluator was a professor and a research dietician who tested in detail the tool. She thought it was a complete tool but it would be better help pages to be present in each step and function of the tool. She would also use it because it has the ability to add multiple tabs, which represent different patients. She finally proposed that it would be better for patients to attend a training section before starting to use it for managing their health information.

The rest of the evaluators suggested similar modifications. They all suggested changes in the medications application and more precisely in the medications “end date” field, which could be in some cases forever or for many years. They also suggested that more information should be entered considering dosage because many times dose is adjustable. They also pointed out that for psychological reasons it is better for the patients not to be reminded every day about a chronic or lethal disease. Other suggestions was to add help, examples and detailed information in each application of the system and finally, to keep forms simple and clear in each application and especially in medications in order for the patients to insert their information without wasting a lot of time.

The tool got positive feedback from all the evaluators. Only minor details were suggested as improvements. None of the evaluators detected a weakness of the system concerning safety, functionality and comprehension. Each of the evaluators would suggest the tool to their patients and some of the evaluators would suggest it to other physician in order to access their patient’s information. Comments of the evaluators were positive and all of them completed the scenario in short time and without any problems or questions. Completing the scenario easy and without questions indicates that it is easy to use the tool and understand its functionality because in the beginning of each evaluation the description of the tool was basic and general without informing the evaluators for each applications included or tips of using it.

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<sup>10</sup> <http://www.mayoclinic.org/>

<sup>11</sup> <http://www.medscape.com/>

### 3.4. PatientView White Papers

There are three white papers from PatientView cited in this chapter. The most important parts are copied and at the end of each of these chapters a summary is given that is most relevant for iManageCancer.

#### 3.4.1. What do people want from health apps? (release 2013)

The following summary is given in this white paper that can be downloaded from <http://alexwyke.wordpress.com/2013/10/14/what-do-people-want-from-their-health-apps/>:

“During May to June 2013, PatientView undertook a pilot survey of 250 disparate patient and consumer groups worldwide. The aim was to determine the qualities people seek in their health apps, learn which of these qualities is the most important, and find out how needs vary among different patients and people. The study was a scoping exercise, with more substantive research by PatientView (in conjunction with myhealthapps.net) scheduled to follow in 2014. The results of this pilot study have been skewed by the fact that 81% of the participants came from one country (the UK). However, analysis of the data indicates that people who experience similar health challenges (lifestyle issues, for instance, or heart disease) share common needs from a health app irrespective of their location in the world.

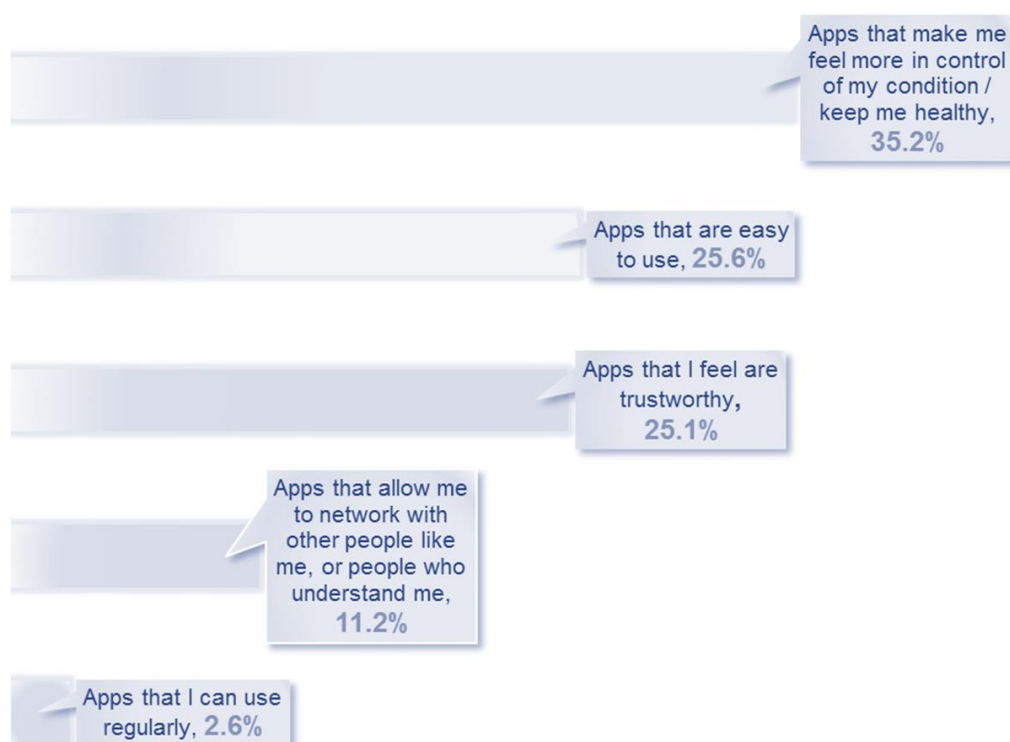
The survey results confirm:

People specify five main requirements of health apps.

Apps need to

1. Give people more control over their condition, or keep them healthy
2. Be easy to use
3. Be able to be used regularly
4. Allow networking with other people like them, or with people who understand them.
5. Be trustworthy

These needs carry different priorities. When the 250 respondents were asked to state the single most important property that health apps should have to meet their needs, the following results were obtained:



Also clear is that people with different medical conditions and lifestyle challenges nevertheless share

priorities in what they are seeking out of health apps. Thus:

- People with a long-term chronic condition (such as diabetes, gastrointestinal problems, HIV/AIDS, learning difficulties, a rare disease, or urinary complaints) all specify that their top priority for a health app is for it to give them more control of their disability. This finding is important, as it shows that people do not just want passive information they wish to receive support in managing their condition.
- People with a disability that affects personal mobility (such as a skin disorder or a rheumatologic condition) place ease of use as top priority for their apps. Conversely, other patients or members of the public are happy to compromise on ease of use provided that the app really helps them.
- People with a complex condition, which might be difficult to diagnose or treat (such as a bone disorder or an endocrine condition), see trustworthiness as the top priority for their apps. A reduced emphasis on trustworthiness among other respondents may simply be because many people assume that apps are innately trustworthy.
- People with a sexual health problem, or an infectious disease, or ordinary members of the public, stipulate that the top priority for a health app is that it ought to allow them to network with other people like them, or with people who understand them.
- Surprisingly few people insist that the priority for a health app is that it should be capable of regular use (although 42% stated that this is one of the desirable properties of a health app). The main message here is that patients and the public might view apps as a regular solution, as one among a series of tools to support their health situation. Apps help build up different capabilities in dealing with a condition, acting like steps during a journey to improved health.

Other takeaway messages

- Older people and people with a disability are already wide beneficiaries of both device-based and Internet-based apps that offer solutions for cognitive behavior, deafness, dexterity, mobility, speech, and vision.
- App stores are a key distribution point for the public, and may need to consider their role in determining user trust and confidence in apps.
- A need to link mobile to Internet seems to exist, and would be particularly helpful for people with a disability, who sometimes prefer the Internet to mobile.
- An app may or may not be written, recommended, or prescribed by a clinician—all are forms of clinician approval of the app. The majority of apps are not approved as such. However, clinician approval (in whatever form) ought to be made transparent, to help guide consumers. Clinician approval is not the sole route to public confidence in an app, and, for some apps, such as exercise apps, the approach might be inappropriate. But for apps that seek to help in medical emergencies, or for those that focus on some long-term conditions, clinician approval may be advantageous.
- Clarity of how and when apps should be regulated is required. The regulation currently appearing is highly fragmented (for instance, approved by the FDA, the MHRA, the NHS Library of Health Apps, etc.). Both mobile and Internet fall under different regulatory regimes, adding further potential confusion to the take-up of health apps.”

(from <http://alexwyke.wordpress.com/2013/10/14/what-do-people-want-from-their-health-apps/>)

**Summary – Most important in respect to this white paper are the following points:**

1. A legal and ethical framework is needed.
2. Mobile Apps are important.
3. Clinical approval of the Apps are necessary. This includes easy usage on a regular basis.
4. Important Apps are those that give patients more control about their disease and disabilities.
5. Apps should allow communicating with other people.

### 3.4.2. White paper ‘Health apps: Where do they make sense?’ (Released 2014)

The white paper is based on a seminar held at the King’s Fund, London, 28<sup>th</sup> of October 2013. The white paper can be downloaded from: <http://alexwyke.wordpress.com/2014/03/17/white-paper-health-apps-where-do-they-make-sense-white-paper-health-apps-from-the-perspectives-of-patients-standards-and-policies-based-on-a-seminar-held-at-the-kings-fund-london-28-oc/>.

As a result of the above-mentioned seminar, five key messages are given that are also relevant for iManageCancer:

#### “Overhauling healthcare systems—making them patient-centric

Healthcare systems will need to be redesigned if they are to be made truly patient-centric. Such change cannot occur, however, without closer partnerships between health professionals, policymakers, all health industries, and, of course, the patient community. Funds will need to be found to escalate the process (but most likely will not come from the NHS). The great advantage of health apps is that the infrastructure of these products already exists outside the NHS. Therefore, health apps might be able to catalyse any drive to make healthcare more responsive to patients.

#### Engaging doctors in the prescribing of health apps

Patients and members of the public are embracing the health apps that are designed for consumers. Doctors, on the other hand, are yet to help their patients do so. If health apps are to move into mainstream healthcare, the regulatory requirements for prescribing apps will need clarification (and perhaps the creation of some sort of accreditation system). The key is trust. If doctors prescribe health apps, these apps are likely to be trusted by patients.

#### Overseeing quality standards for health apps

Regulators may regulate, but their regulations need to be policed. The question is: by whom? The seminar identified various candidates for the job of ‘quality arbiter’ for health apps, including: app stores (such as Google Play and iTunes); the mobile operators; and consumers (the general public). However, problems beset each possible choice. The general consensus at the seminar was that no single entity, or section of society, seems equipped to take on the role of sole arbiter of quality standards. The likelihood is that several bodies (including patients/the public) might take on joint responsibility for curating the trustworthiness of apps.

#### Ensuring that health apps remain of a high standard throughout their lifetime

Health apps face significant challenges if they are to maintain high quality throughout their time in the marketplace. Medical information quickly becomes superseded; the regulatory environment is reformed or adapted; changes sweep away other elements of the systems in which health apps work. Health apps need to be upgraded to reflect external change, but app developers (and their funders) and the remodelling of apps to be both time-consuming and costly. As such, one possible unfortunate consequence of implementing quality standards for health apps could be higher prices of the products for users, undermining a key virtue of health apps—their accessibility to the public.

#### Considerations for policymakers wishing to oversee health apps

The consensus at the seminar was that the adoption of smartphone technology will not create health inequalities, but rather can increase healthcare sustainability. The interfaces of smartphones and health apps do have to improve, though, to become more readily usable by older people and people with a disability. Regulations governing health apps are opaque and outdated. Developers are unaware of their legal responsibilities. Clarification is certainly needed about whether health apps require a CE marking (that is, are classified as a medical device). A number of issues obstruct the crafting of new regulations that can cope with rapid technological change—not least the poorly-informed nature of health professionals (who should be major advocates of mHealth). However, on the plus side, helpful advice for the developers of health apps is available from the EU and national regulatory agencies. Furthermore, the EU (and the UK, for that matter) do not want to discourage the burgeoning market for health apps by producing excessive red tape.”

**Summary - Consequences to be taken from this white paper:**

1. Patient empowerment is much important
2. Doctors and policymakers need to be enrolled in the iManageCancer platform
3. All tools and Apps need to be developed according to high quality standards and regularly updated.

**3.4.3. White Paper ‘What do patients and carers need in health apps - but are not getting? (Released 2015)’**

“What do patients and caregivers need in health apps - but are not getting? And how can developers respond and deliver better apps accordingly?” These are the two key questions from a global survey and multi-stakeholder workshop, published on the 24<sup>th</sup> of June 2015 by PatientView, in conjunction with Health 2.0 and TICBioMed, coordinator of the EU-funded GET project. The results of the survey and the workshop are presented in a white paper that can be downloaded from <http://we.tl/aSZW2lydGi>. This white paper synthesises the input and feedback from patients’ organisations, healthcare professionals, app developers, healthcare policymakers and regulators, the pharmaceutical industry, mobile technology industries, and academia to identify and help address patients’ unmet needs in health apps. 1.130 respondents answered the questionnaire from 31 countries (82.3% from Europe) with either a chronic illness or caring for someone with such a disease. 60% were between 41 and 64 years of age. Their long-term condition lasted for more than 10 years in 60%. One of the five most affected diseases of respondents was cancer. In addition, 30% were active on social media channels and 90% sought healthcare information via the Internet. 30% used health Apps and only 10% sensors or devices of which half of them were provided by their doctor or the healthcare system.

As written in the white paper the survey aimed to:

“

- Provide information to app developers about how to work with patients and healthcare professionals to improve apps to help meet unmet patient and carer needs
- identify specific examples of unmet needs across different therapy areas

The survey concluded that patients and carers:

- Are using apps but largely to gather information
- Aspire to do a lot more with apps
- Want to use technologies in conjunction with their healthcare professionals
- Need guidance on which apps are best for them
- Want understandable information on their medical symptoms and conditions.

“

Most importantly respondents want to get the following from Apps:

“

- To help them understand their condition and treatment choices (61%)
- To provide support (such as care planning) (55%)
- To track and monitor symptoms in order to benchmark their progress (46%)
- To provide a way to communicate with their doctor or nurse (45%)
- To raise public awareness of conditions which are important to them (38%).

“

The main barriers to using health Apps:

“

- Confusion over the vast number of apps to choose from (37%)

- Uncertainty about which apps to use (32%)
- Preference for face-to-face interaction with doctors or nurses (31%)
- Lack of knowledge of health apps that may be relevant to them (30%)
- Lack of trust in health apps as unsure who develops or funds them (27%). “

“

Following the analysis of the survey a workshop with 50 stakeholders (patients, caregivers, people with disabilities, app developers, clinicians, representatives of the pharmaceutical industry, and telecoms industries, experts in medical communications and health education, and policymakers) was held in London on 12<sup>th</sup> of November 2014. For cancer, the key need that was identified during this workshop was an App that provides support in the management of screening requirements and test results. In addition, critical design and concept features a cancer App should address were identified. These are: “

- Tracks my symptoms and informs me of tests needed, even books them for me
- Tracks tests, including blood pressure, temperature, sleep, mood, appetite
- Checks against my weight, size, nature of sleep - so everything seems appropriate
- Organises my test results to share with ALL my doctor/nurses and health clinics
- Has room for my medical information and records
- May conduct tests as well and help avoid biopsies when possible
- Keeps me up to date with research
- Communicates with health professionals
- Communicates with people in a similar situation “

### **Summary**

As general success factors simplicity and usability of the design and content was mentioned. In addition, there are further needs to have better cooperation between developers and patients.

In the following chapters the different use-case scenarios are described. These descriptions are the basis for the development of technical use cases that will be given in detail in Deliverable D3.1 ‘SoA analysis of self-management tools and services, mHealth architectures, technologies, tools and standards’ of this project.

## 4. Description of selected user scenarios

This chapter describes all selected user scenarios that were developed in an iterative process with all stakeholders. The selected scenarios are based on the results of chapter 3 after intensive review of existing scenarios and use cases, analysis of the questionnaire and the described workshop.

Figure 4.1 gives a schematic overview of selected user scenarios together with the responsible stakeholders in the consortium. The figure provides five categories of scenarios: assessment, management & decision support, information, communication, gaming, and analysis scenarios. This categorisation matches well the outcome of the end-user questionnaire results. Altogether 14 scenarios are selected that are described in more detail in the following chapters.

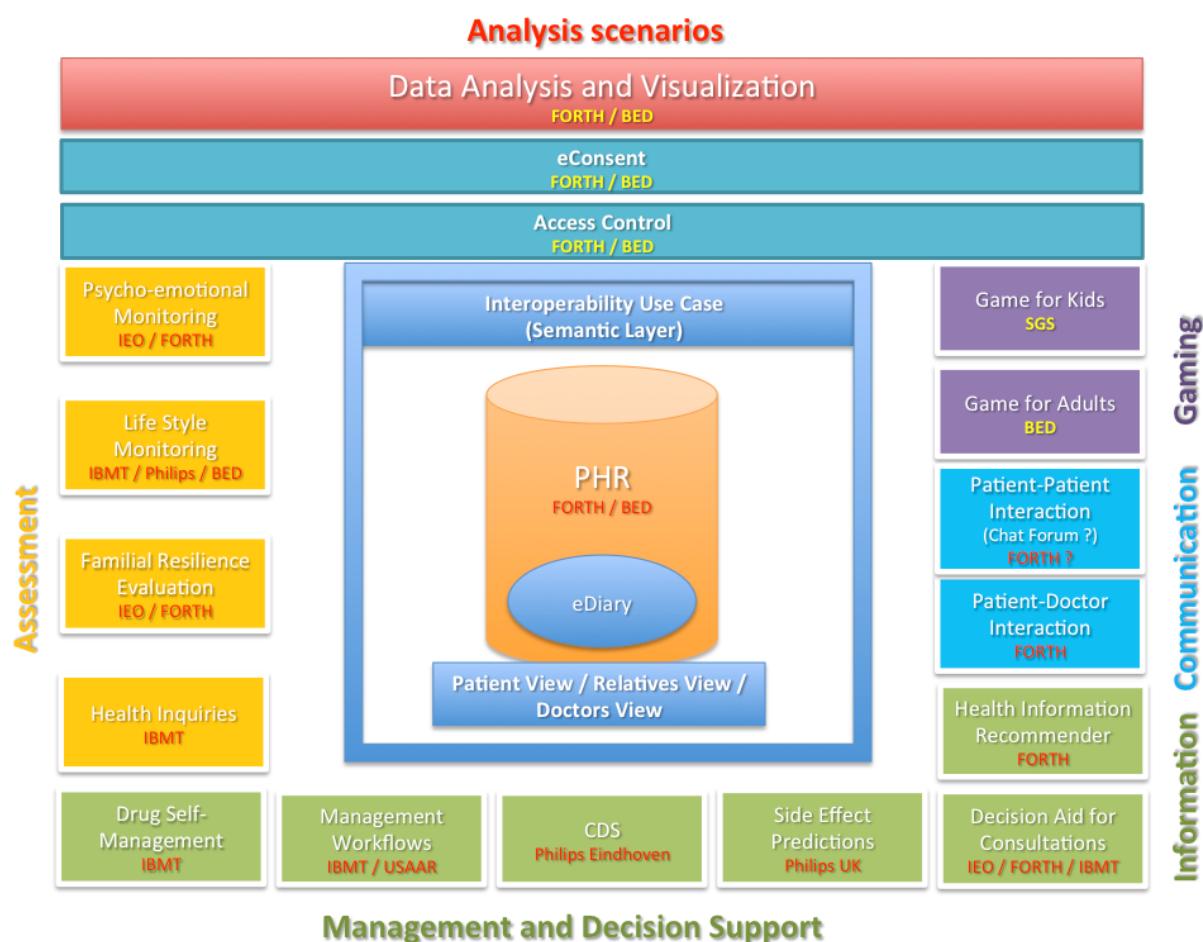


Figure 2: Schematic overview of selected user scenarios giving also the responsible stakeholders for each of the scenarios.

The following chapters describe the 14 scenarios in the same format that is given here:

### - Tracking Information

Information to reference the scenario in the technical documentation (use cases etc.) consists of the scenario identifier, version number, date and change history in the following format:

Scenario Identifier: SC1

Issue Date	Version	Changes Made



- **General description and goals**  
General setting and main goals of the scenario.
- **End Users and workflow**  
End users, to which scenario is targeted and detailed description of the workflow for this scenario from the viewpoint of the end user(s).
- **Data**  
Detailed description of all kind of data needed for the scenario (e.g. input data, output data)
- **Interaction with other user scenarios (including the scenario identifier)**

**As an introductory remark, it is important to mention that some of the scenarios described in the following chapters are very complex and can only be partly implemented during the lifetime of the project.**

## **4.1. Scenario PHR and eDiary (FORTH, BED, USAAR)**

### **4.1.1. Tracking information**

Scenario Identifier: SC1

Issue Date	Version	Changes Made
15.03.2015	1.0	Initial Version
13.07.2015	2.0	Final Version

### **4.1.2. General description and goals**

In the iManageCancer project the Personal Health Record (PHR) is a central element of the platform. A patient using a PHR has the ability to run different applications that are defined within this deliverable. A most important tool is to upload data to the PHR and to use an eDiary.

Every patient registered to the platform can upload all kind of clinical data into his PHR. This includes:

- Any type of scanned clinical documents (JPG-, PDF documents) that he has received from his health professionals (i.e. discharge letters, reports with clinical findings, laboratory results, pathological reports, surgical reports, radiology reports).
- Electronic clinical documents (Word-, Excel-, PDF Documents) that he has received from his health professionals (i.e. discharge letters, reports with clinical findings, laboratory results, pathological reports, surgical reports, radiology reports).
- Imaging studies in DICOM or JPG format including results of tumour volume (i.e. prostate cancer)

For each of these uploaded documents the patient can enter the following metadata:

- the date of the examination
- the name of the healthcare organisation
- the name of the doctors
- the reasons for the examination



- the diagnosis
- comments

In addition, the patient can enter all kind of data he/she creates. Such data are measurement results like blood glucose, temperature, weight, blood pressure, heart rate, pain or mood data on a scale range and others. Furthermore, he/she will be able to enter the main data of his/her tumour disease (passport screening) including treatment plan and other medications. In this regard, the patient can enter any kind of information in an electronic diary, i.e. symptoms, problems with therapies, mood, level of pain, level of anxiety, and level of appetite. He/she can also provide a personal profile with habits, hobbies, favourite meals, etc. The patient can decide if he/she wants to link his social network with the PHR.

He/she can view the documents on a timeline, or see the data as charts or in a tabular format. For each of the documents or data the patient is able to select those he wants to share with other people like other clinicians or relatives. He/she can grant access to them for a selected time period and he/she is able to withdraw such a granting at any time without giving an explanation.

The information needs to be entered in an intuitive way. The software behind has to structure the information in a way that further processing of data by the system is possible.

If appointments to a clinical visit or schedules for medications are entered then a notification for the patient will be visually or acoustically provided by the system at the actual time point.

#### 4.1.3. End users and workflow

1. The patient enters the iManageCancer platform.
2. A list of all available categories is shown and visualization options are available to the patient.
3. The Patient selects an eCRF category.
  - a. The previous records on this category appear.
  - b. The patient can select a previous record to examine all details.
  - c. The patient can select an option to add a new record.
  - d. The patient fills in the eCRF and/or uploads the corresponding clinical documents (scanned documents, electronic clinical documents, JPG images, DICOM images etc.).
  - e. After filling and saving the eCRF a report is presented to the patient about the submitted eCRF.
  - f. As soon as the eCRF is submitted, the data are saved.
4. The patient is visualizing information.
  - a. The patient can select the appropriate visualization method of choice (timeline, chart etc.).
  - b. The data are visualized according to the selected visualization.
5. The patient is sharing information with others.
  - a. The patient selects the *Share Information* form.
  - b. The patient selects the specific information he wants to share.

- c. The patient enters the username / email address of the persons that he wants to share information with.
  - d. If the person is not a registered user of iManageCancer, the person shall receive an invitation by e-mail such as “Peter Patient has invited you to register at *imanagecancer.eu* in order to get access to health data of Peter that he wants to share with you”. If the person is a registered user, he shall receive a notification about the information that a patient wants to share with him.
6. A patient is notified with an alert.
    - a. A patient is alerted both visually and acoustically about a nearby clinical visit or a medication.
    - b. The patient can click to the notification to see the details of the notification.
  7. The patient logs-out from the diary portal.

#### 4.1.4. Data

There are two categories of data for input into the system.

1. Data provided by the hospital or the treating physician
2. Data entered by the patient himself

Data being entered can be structured and unstructured. The unstructured data will be PDF-, Word- or imaging documents including DICOM and JPG files. These files are namely reports from the clinical chart of the patient. Files on CD will provide the imaging studies. For all data a patient enters, a structured and easy-to-use tool needs to be developed and integrated at the iManageCancer platform.

As structured and unstructured data are related to a time point the patient will be able to enter the data or upload data to a given time point (eDiary functionality). It will be necessary that the patient enters always a date for a given document he /she uploads or for data he/she enters. All other metadata as described in 4.1.2 will be displayed to the patient and he/she can choose to fill them in or not.

A description of the data is already given in 4.1.2.

#### 4.1.5. Interaction with other user scenarios

- SC5: Personal health information recommender - the patient can mark terms in the documents on which he wants explanations or other additional information.
- SC6: Drug self-management - for retrieving drug information
- SC3: Chemotherapy management
- SC4: Management workflows
- SC10: Health Enquiries

## 4.2. Scenario Health avatar (**BED, FORTH, USAAR**)

### 4.2.1. Tracking information

Scenario Identifier: SC2

Issue Date	Version	Changes Made
27.05.2015	1.0	Initial Version

19.07.2015	2.0	Edited Version
30.07.2015	3.0	Final version

#### 4.2.2. General description and goals

This scenario will demonstrate the capacity of the iManageCancer platform in terms of its support of lifestyle management of the cancer patients by providing them the services to help their cancer management as a good complement to the existing cancer care systems. The platform offers a one-stop service for the cancer patients for data collection, and self-management services. The system will support the visualization of the behaviours and daily activities of the patients. It will function as a supportive environment to empower the patients in self-management, encouraging their good lifestyles and behaviours, hence enabling more effective care of the cancer through improving the patients' compliance with healthy lifestyle recommendation. The scenario will allow the patients to play a key role in the cancer care.

More specifically, we are aiming at the following objectives:

- Monitoring the patients' behaviour and lifestyle by using lifestyle sensors and mobile apps, allowing for easy behaviour data upload into the platform (e.g. their activities, movement, step accounts, mood, blood pressure, alcohol, and smoking). Visual analytics will be used to display the data to allow easy interpretation of the data by the patients.
- Supporting personal behaviour interventions that allow planning and reminding services for daily physical exercises, diet control and medication. The system will send reminder messages for diet, physical exercises, medical testing, medication and hospital visit, etc. Also, we will consider offering programmes (e.g. weekly or monthly) for diet and life style control for the patients at certain conditions by delivering these programme materials to the patients in need.

#### 4.2.3. End users and workflow

- The patient registers in the iManageCancer system.
- A list is shown of all available sensors/mobile apps for lifestyle and behaviour tracking
- The patient can make selections of a number of available sensors/mobile apps to use
- The patient can press a synchronisation button to upload all of the data of the selected sensors to the iManageCancer platform.
- The patient can use the user interface to set the targets for diet, physical exercises. He/she can also set the time for medical testing, medication and hospital visit, etc.
- The patient may also be able to choose a health programme (e.g. diet control) which is pre-set by experts.
- The patient can visualise the information about the lifestyle and activities that are uploaded from the sensors and mobile apps using an appropriate visualization method. She/he can also see his/her (daily/weekly) targets, medication time, and all the medical appointments with the doctors.
- The patient receives reminders for medication, his/her daily and weekly targets and the medical appointment.
- The patient can share information with others by selecting the users (e.g. doctors) and information she/he wants to share. She/he can stop the sharing at any time.

#### 4.2.4. Data

The various types of input and output data have been included in the description above.

#### 4.2.5. Interaction with other user scenarios

These are the relevant scenarios:

- SC1: PHR and eDiary - for data storage
- SC8: Psycho emotional status and management -for retrieving patient information for storage
- SC12: Data analysis and data mining - to discover useful information to patients
- SC4: Management workflow - to support management in the diary
- SC6: Drug self-management: part of behaviour intervention
- SC5: Personal health information recommender - for education materials
- SC9: Family resilience - for social interaction
- SC11: Lifestyle monitoring

### 4.3. Scenario Chemotherapy management (PHILIPS, USAAR, FRAU)

#### 4.3.1. Tracking information

Scenario Identifier: SC3

Issue Date	Version	Changes Made
1.5.2015	1.0	Initial Version
14.7.2015	1.9	Use case diagram and end users updated
17.07	2.0	Final Version

#### 4.3.2. General description and goals

Cytotoxic chemotherapeutic agents, radiotherapy and the tumour itself can result in myelosuppression and damage to barriers, which protect against infection. Severe neutropenic complications reduce the patient's quality of life, lead to hospitalisation and increase their risk of mortality. Without swift intervention, infections in patients with neutropenia may ultimately lead to death. The main goal for this scenario is to produce prototype predictive model(s) able to stratify patients into low and high-risk groups with respect to serious adverse event(s) such as febrile neutropenia. It is envisioned that, following appropriate clinical validation, the risk score(s) produced should improve the clinician's ability to intervene before such an event occurs, as well as increase patient awareness with respect to their disease state.

#### 4.3.3. End users and workflow

As detailed below, the intended end users of the final product are clinicians (oncologists and nurses) and patients. The risk score(s) produced by the validated predictive model(s) should be calculated on data input into the electronic health record by the clinician, into the personal health record by the patient with informed consent for home monitoring (if applicable) or by an automated system. Following appropriate validation, when a patient's risk is deemed to be significant an alert is sent to the clinician, providing them with a personalised indication of their patient's predicted risk(s) given the information provided. The clinician could then choose to take appropriate action based on their patient's predicted risk. Personalised advice can be displayed to the patient via the application with respect to their calculated risk scores once appropriate clinical validation has been achieved.

### Workflow

1. The therapy management subscribed patient visits the clinic for a scheduled consultation.
2. The clinician enters the patient information into the clinical repository.
3. Relevant input patient information is loaded into the predictive model(s) as parameters. The patient's predicted risk(s) are calculated.
4. Significant predicted risk score(s) for serious adverse event(s) are sent to the clinician.
5. The clinician may make informed adjustments to the patient's treatment plan intended to lessen the risk of the event(s). Benefits may include:
  - a) Decreased patient anxiety due to improved preparation with personalised risk warnings.
  - b) Increased patient education possibly aiding symptom management through advice on action(s) the patient can take if the adverse event occurs.
  - c) Further guidance for the clinician's decision to administer granulocyte-colony stimulating factor (G-CSF).
  - d) Any other interventions as applicable.
6. The patient finishes their consultation and continues their clinical care pathway.
7. Additional relevant patient information is collected over time. Sources may include:
  - a) The patient or an automated system during home monitoring with patient informed consent.
  - b) The clinician or an automated system if the patient has unscheduled contact with the hospital during their treatment.
  - c) The clinician during the patient's next scheduled appointment.
8. Predicted risk score(s) are recalculated for this patient based on any new information.
9. The clinician may make informed adjustments to the patient's treatment plan.

#### 4.3.4. Data

##### Input data

A successful model will require input on patient demographic, therapeutic and diagnostic information. In 2011 Lyman *et al.*<sup>12</sup> produced a model able to predict severe or febrile neutropenia in cycle 1 of chemotherapy with a validation area under curve (AUC) of 0.8 using a prospective dataset of 3,750 patients from the United States. The following variables were found to be indicative: age, prior chemotherapy, aspartate transaminase (AST), alkaline phosphatase (ALP), bilirubin, glomerular filtration rate (GFR), white blood cell (WBC) count, cancer type (small cell lung, non-small cell lung, ovary, breast, lymphoma and colorectum as a control), immunosuppressives, planned relative dose intensity (RDI), chemotherapy type (anthracyclines, platinums, taxanes, alkylating agents, topoisomerase II inhibitors, gemcitabine, topoisomerase I inhibitors, vinorelbine) and primary colony-stimulating factor (CSF) prophylaxis.

Lyman's paper limited their data to only six cancer types, however we would want the model to be applicable to as broad a range of patients as is feasible. Therefore, a cohort of similar or greater size (to account for the expected lower prevalence) would be required, with the appropriate legal and ethical consent obtained. The anonymised English language dataset, in Excel spreadsheet, CSV, TSV, Minitab or SPSS format, would be transferred to Philips via secure data transfer. The

<sup>12</sup> Lyman GH, Kuderer NM, Crawford J, Wolff DA, Culakova E, Poniewierski MS, Dale DC. (2011) Predicting individual risk of neutropenic complications in patients receiving cancer chemotherapy. *Cancer*. 117(9):1917-27.

following details routinely collected patient information for which we would like to investigate the predictive power:

Category	Measure	Explanation
<b>Outcome</b>	Age at admission	Age in days is de-identified information
	Age at discharge	
	Admission method	e.g. emergency, planned
	Reason for admission	
	Temperature	Indicates fever
	Blood culture taken	Indicates suspected infection
	Blood culture result	Confirms sepsis
	Full blood count	Indicates neutropenic state
	Symptoms	
	Age at death	If applicable
	Cause of death	
<b>Demographics</b>	Age	Known to be predictive
	Gender	
	Weight	
	Height	
	Ethnicity	
	Deprivation score	
	Comorbidities	e.g. COPD, diabetes
<b>Diagnosis</b>	Age at diagnosis	
	Cancer type	Known to be predictive
	ICD10	
	Morphology	
	Staging	
<b>Chemotherapy</b>	Receptor status	e.g. HER2+ in breast cancer
	Age when cycle started	
	Cycle number	Initially a pre-treatment model
	Regimen	Known to be predictive
	Drug administered	Known to be predictive
	Relative dose intensity	Known to be predictive
<b>Radiotherapy</b>	Age at radiotherapy	
	Radiotherapy type	
	Radiotherapy site	
<b>Pharmacy</b>	Drug name	Indicates G-CSF, immunosuppressives
	Drug type	
	Dose given	
<b>Surgery</b>	Age at surgery	
	Procedure	
<b>Laboratory</b>	Age at result	
	White blood cell (WBC) count	Known to be predictive
	Neutrophil count	
	Monocyte count	
	Basophil count	
	Eosinophil count	
	Large unstained cell level	

	Mean corpuscular volume (MCV)	
	Haemoglobin level	
	Haematocrit (PCV)	
	Platelet count	
	Red blood cell (RBC) count	
	RBC width	
	C-reactive protein (CRP)	
	AST	
	ALT	
	Albumin	
	Bilirubin	
	Creatinine	
	GFR	
<b>Markers</b>	Tumour markers	e.g. CA125
	Comorbidity markers	e.g. HbA1c

N.B. age also required for results where applicable to maintain a temporal relationship

#### Output data

Prototype model(s) to predict individual patient risk of adverse event(s) such as febrile neutropenia.

#### 4.3.5. Interaction with other user scenarios

The predictive modelling scenario is expected to interact with the following other scenarios, details to be determined during later phases of the project:

- SC4: Management workflows
- SC7: Decision aid to support patients' participation in consultation
- SC11: Live style and vital sign monitoring
- SC12: Data analysis and data mining

### 4.4. Scenario Management workflows (FRAU, USAAR)

#### 4.4.1. Tracking information

Scenario Identifier: SC4

Issue Date	Version	Changes Made
15.03.2015	1.0	Initial Version
13.07.2015	2.0	Final Version

#### 4.4.2. General description and goals

In this section, a selection of scenarios is described, which can be represented by care pathways. The main idea is that patients will be guided through specific aspects of the disease management by the application and receive support in decision making at certain points.

We propose the following initial scenarios for potential management workflows of the iManageCancer platform. A final decision on those scenarios that will be implemented in the

system will be taken until month 12 in the context of deliverable 5.1 'Initial set of knowledge models for self-management'. Limiting factors will be the capabilities of the planned Care Flow Engine in combination with the applications of the users, availability of required content from the domain and required efforts.

### *Pain Management Support*

This scenario aims to ensure patient's freedom from pain. This is motivated by

- Preservation of the patient's life quality through pain release.
- Increase of patient's well-being, efficacy and thus the therapeutic success.
- Best information on patient's pain perception for the attending physicians.

In particular, it should be prevented that the patient wants to endure pain and to avoid the intake of pain medication.

### *Nutrition Planning and Drinking Protocol*

This scenario aims to control patient's nutrition and drinking behaviour, especially for the early detection of malnutrition (i.e. primary anorexia cachexia syndrome due to tumour, or secondary anorexia cachexia syndrome due to the treatment). This is motivated by

- Improving the patient's general well-being and quality of life.
- Prevention or restriction of malnutrition.
- Ensuring the supply of nutrients.
- Retention or improvement of the body's defences.
- Delay or prevention of severe weight loss and stabilization of body weight.
- Adaption diet to changes in the organism caused by the therapy.
- Palliation of side effects triggered by the therapy.
- Preservation of joy and pleasure of eating.
- Provision of meaningful and useful information about nutrition in cancer.

However, this procedure should not lead that the patients should feel forced to eat.

### *Motion and Exercise Planning*

Several studies suggest that exercising (including light- to moderate-intensity walking programs) has potential benefits for people with cancer. The benefits shown in these studies and observed in clinical settings include improved physical energy, appetite stimulation, and/or enhanced functional capacity, with improvements in quality of life and in many aspects of psychological state.

This scenario aims to provide the best motion and exercise plan to improve the well-being and efficiency of the patients. This is motivated by the following rational:

- Too much rest leads to complications, such as weakens the entire musculoskeletal system and the cardiovascular system.
- Patients will be strengthened mentally (feeling of success and "to be able doing something against cancer").
- Sport in a community avoids isolation (social aspect of motion).



- A balance between exercise and rest is important.
- Sufficient movement is important in all phases of the disease (acute phase of treatment, rehabilitation, care and prevention).

### *Fatigue management*

Numerous studies confirmed also the beneficial effects of exercise on fatigue as the US NIH National Cancer Institute promotes on its website<sup>13</sup>. According to this institute, reductions in fatigue of about 35% and improvements in vitality of 30% have been shown in randomized trials, with stronger effects being shown during cancer therapy in some studies and after therapy in other studies. In addition, the dietary supplement ginseng has shown in a phase III, randomized, placebo-controlled trial showed that after 8 weeks of treatment with ginseng there was a significant and clinically meaningful difference of the level of fatigue favouring the ginseng group.

This scenario aims to reach the best treatment and handling of chronic fatigue in cancer ("tumour fatigue" caused by cancer disease, or accessory symptom caused by e.g. drug side effect or associated cancer symptoms like anaemia, mental stress). This shall support the patients to budget their own energy and to avoid that they are overwhelmed as well as not enough challenged.

Health professionals can work with patients with cancer to develop an activity/rest program based on an assessment of the patient's fatigue patterns that allows the best use of the individual's energy. Any changes in daily routine require additional energy expenditure. Individuals with cancer are advised about setting priorities and maintaining a reasonable schedule.

### *Treatment and Follow-Up Guidance*

This scenario aims to support the patient in managing his treatment and follow-up schedule. It comprises

- Smart scheduling of diagnosis and therapy examinations.
- Reminders to necessary appointments and recognizing treatment gaps.
- Assistance in preparing appointments (e.g. creation of checklists).
- Supporting the treatment of side effects and symptoms.

### **4.4.3. End users and workflow**

Actors of the management scenarios are patients, attending physicians as well as patient's supporters (e.g. relatives and friends). In the following section the management workflows proposed above will be outlined.

#### *Pain Management Support*

- The patient enters the iManageCancer platform.
- The patient can enter the current intensity of his pain using a scale (1 - 10 points or corresponding emoticons (smileys)). This inquiry can be on patient's demand or triggered regularly (e.g. daily, weekly or in the context of a therapy).

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<sup>13</sup> [http://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-hp-pdq/#link/\\_94](http://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-hp-pdq/#link/_94)

- If the reported pain intensity has increased over the time or is above a threshold the patient will be asked to fill in an additional questionnaire for her/his (subjective) pain perception (including e.g. pain sense, localisation, accompanying symptoms like nausea, vomiting or dizziness).
- The entered data shall be stored as eDiary items.
- The patient can grant access to the pain entries in the eDiary for physicians or supporters (e.g. the partner of the patient).
- In addition, the patient can rate the intensity of symptoms or side effects of the treatment by using scales. This can be executed on patient's demand or regularly.
- Depending on the entered values the patient will be asked to measure certain vital signs (blood pressure, pulse, and/or temperature).
- Patient's supporters and the attending physician will be informed about worsening of the patient's pain perception, symptoms or side effects
- The patient receives recommendations or advises on pain. The iMC system selects appropriate recommendations or advices based on the entered values, PHR data (e.g. kind of cancer, stage of disease, medication plan, similar eDiary entries) and reference guidelines (e.g. WHO degree system).
- Recommendations can be e.g.:
  - For freedom or abatement of pain:
    - Take additional medication if authorised by the treating physician (on demand or adjusting the medication plan).
    - Execute physiotherapeutic methods, such as liniments, compresses, and cold or heat applications.
    - Execute psychotherapeutic methods, such as combating general or drug specific anxiety (like to get addicted to pills or fear for side effects) and relaxation exercises.
    - Instruct for taking the medication, e.g. sustained-release pill should not be crushed, melt sublingual tablets under tongue.
  - For the prevention or elimination of side effects:
    - Take concomitant medications such as laxatives, antiemetic, cortisone (appetite enhancing, encouraging, analgesic), antidepressants, and anticonvulsants (for seizures).

Visit your attending physician for e.g. adaptations to the treatment plan or intravenous intake of the analgesic (in case of uncontrolled severe pain).

- Patient's supporters will be informed about the recommendations on patient's pain. If patient has authorized it, the supporter could verify these.
- Recommendations can be accepted, rejected and/or rated by patient. This will also be recorded in the PHR and the eDiary.
- Patient's supporters will be informed if the patient has rejected the recommendations.

### *Nutrition Planning and Drinking Protocol*

- Initially, the patient can fill in a questionnaire he/she finds in his/her PHR for the recording of his/her eating and drinking habits (e.g. favourite food, number of meals).
- Patient can record his meals and drinks in the eDiary (on demand or regularly triggered), e.g. by taking pictures.
- Patient can enter her/his current appetite using a scale (points or smileys). This shall be done regularly or on patient's demand.
- If the entered appetite score decreases or is low the patient will be asked to fill in an additional questionnaire (e.g. using Omlin and Strasser's "Why I have no appetite?" form).
- The patient will be asked to measure her/his weight regularly (e.g. daily at the same time with similar clothing).
- If there is suspicion of malnutrition or a lack of liquid intake the patient, the attending physician and/or patient's supporters will be informed.
- The patient can enter scores (points or smileys) for intensity of attendant symptoms and side effects of treatment (e.g. nausea, dysgeusia, difficulties with chewing and swallowing, dry mouth, sores in the mouth, heartburn, diarrhoea, obstipation). This will be executed on patient's demand or regularly.
- Patient's supporters and the attending physician will be informed about worsening of the symptoms or side effects.
- The patient gets advises and recommendations for the treatment of these symptoms. The iMC system selects appropriate recommendations or advices based on the entered values, PHR data (e.g. kind of cancer, stage of disease and similar eDiary entries) and reference guidelines.
- Patient's supporters will be informed about these recommendations.
- The patient receives a recommendation for a personal diet and a nutrition plan. The iMC system selects this recommendation based on the entered values, PHR data (e.g. kind of cancer, stage of disease, medication plan, similar eDiary entries) and reference guidelines (e.g., amount of proteins, fats, carbohydrates, vitamins, drinking quantity).
- The nutrition plan shall be reviewed daily by the iMC system and possibly adjusted, especially to act against a weight loss (anorexia-cachexia syndrome) e.g. by recommending food with fat accumulation or high protein intake.
- Patient's supporters will be informed about the recommendations for a nutrition plan. If patient has authorized it the supporter could verify these.
- The recommended nutrition plan can be accepted by the patient and/or adapted in the eDiary.
- Patient's supporters will be informed if the patient has adapted the recommended nutrition plan.
- Patient can give feedbacks after meals (e.g. how much eaten, assessment of wellbeing).

### *Fatigue management*

- Initially the patient should fill in a questionnaire he/she finds in his PHR about her/his daily living habits, hobbies and daily routine such as personal care, housework, shopping, etc.

- The patient can rate activities of daily living by scoring the effort as well as the enjoyment of these. These will be recorded in the eDiary.
- Patient's activity shall be tracked as well as his sleeping, (e.g. using smart devices like Fitbit or smartphone apps).
- The patient can enter her/his vitality using a scale (points or smileys), for instance in the morning and in the evening. This will be executed regularly or on patient's demand. Optionally, his cognitive capabilities could be tested with i.e. a number-connection-test.
- If the entered vitality score decreases or is low the patient will be asked to fill in an additional questionnaire to assess the degree of exhaustion (e.g. using the criteria of international definition of fatigue symptoms such as Multidimensional Fatigue Symptom Inventory-Short Form or ALGA-C).
- Patient's supporters and the attending physician will be informed about worsening of the patient's fatigue.
- The patient can enter the intensity of attendant symptoms and side effects of treatment (e.g. mood, sleeping disorder, somnolence, pallor). This will be executed on patient's demand or regularly.
- Patient's supporters and the attending physician will be informed about worsening of the symptoms or side effects.
- The patient receives a recommendation for his/her daily's schedule for the following days. This schedule will be created based on the entered values, PHR data (e.g. kind of cancer, stage of disease, diagnosis and treatment plan) and a calculation of daily personal energy points. The daily energy quota of the patient will be revised regularly by the iMC system:
  - Check that the daily energy supply is not exceeded (e.g. eDiary entries are recommended to move to another day).
  - Important schedules (e.g. therapy) will be handled in prior.
  - The energy quota will be increased if patient's condition allows this.
- Patient's supporters will be informed about the recommendations for patient's daily schedule. If patient has authorized it the supporter could verify these.
- The recommended daily schedule can be accepted by the patient or adapted in the eDiary.
- Patient's supporters will be informed if patient has adapted the recommended daily schedule.

### *Motion and Exercise Planning*

- Initially the patient will be asked to fill in a questionnaire he/she finds in his/her PHR for patient's motion habits (e.g. physical activity before disease, favourite sport).
- The patient's physical fitness will be monitored by the diagnostic data, measurement of vital signs, movement tracking and physical performance test (e.g. an adapted Cooper test).
- The patient can enter the intensity of attendant symptoms and side effects of treatment (e.g. pain, bleeding signs, anaemia, activity, seizure) by using scales (points or smileys). This will be executed on patient's demand or regularly.

- Patient's supporters and the attending physician will be informed about worsening of the symptoms or side effects.
- The patient receives a recommendation for a motion plan. This plan will be created based on the entered values, PHR data (e.g. kind of cancer, stage of disease, diagnosis and treatment plan) and reference guidelines, e.g.:
  - Do exercises three times a week, 60 minutes each, or five to six units per week spread of 30 minutes each.
  - Make moderate movements such as walking, Nordic walking, and gentle swimming.
  - If strenuous training is possible (for example, device-based strength training) increase intense but train shorter.
  - Do no sports, e.g. with acute bleeding, severe pain and fever.
- The iMC system regularly adjusts motion plan (e.g. increasing the intensity) based on the current data (diagnostic data, patient's condition).
- The attending physician can check and verify these recommendations.
- Patient's supporters will be informed about the recommendations for motion plan. If patient has authorized it, the supporter could verify these.
- The recommended motion plan can be accepted by the patient or adapted in the eDiary.
- Patient's supporters will be informed if patient has adapted the recommended motion plan.
- Afterwards the patient can rate each motion and exercise by scoring energy effort and well-being.
- The iMC provides (personal) high score list in order to increase patient's motivation.
- The patient can grant access for the training plan to supporters and can send invitations for participation.

#### *Treatment and Follow-Up Guidance*

- The patient can enter appointments for treatments and examinations in eDiary.
- The patient can grant access rights for the treatment plan to her/his supporters.
- The iMC system will arrange these appointments in the context of the treatment plan, PHR data (e.g. type of cancer, disease stage) and reference guidelines.
- Potential conflicts (e.g. with other appointments) will be indicated to the patient and suggestions for rescheduling will be generated.
- Indicated modifications in the medication plan will be proposed because of the nature of the appointment (e.g. surgery event → interrupt anticoagulants treatment).
- The iMC system creates a checklist ("To-Do list") for the next examinations, e.g.
  - Arrange transportation (e.g. by car, taxi or ambulance).
  - Schedule required preliminary examinations.
  - Collect required documents (e.g. consent forms).

- Keep food and drinking limitations.
- Consider impacts on medication plan.
- Take in account a suggested list of questions for next physician's visit.
- Schedule appointments for required control and follow-up examinations (e.g. laboratory controls).
- The patient will be reminded for open tasks from checklist. She/he can close, postpone or reject these tasks.
- Patient's supporters will be informed about appointment and To-Do list.
- The patient can upload and assign findings and reports to the past appointment. In addition, he can add notes about results of the appointment.
- The patient can report about symptoms and side effects according to the treatment schedule using questionnaires and scales (points or smileys). This will be executed on patient's demand and in the context of the treatment plan.
- According to the treatment plan, the patient will be asked to control specific vital signs.
- Patient's supporters and the attending physician will be informed about new symptoms or worsening of symptoms or side effects.
- The patient receives recommendations for symptom's treatment/management based on the entered data.
- Patient's supporters will be informed about the recommendations for symptom's treatment if patient has authorized it.

#### 4.4.4. Data

- Inputs of patients (e.g. inquiries, questionnaires and measurements) will be collected and stored in PHR and eDiary.
- The creation of plans and the decision support relies on the data of the PHR and eDiary as well as on reference guidelines and knowledge bases.

#### 4.4.5. Interaction with other user scenarios

The management scenarios potentially interact with all other scenarios, in particular with

- SC1: PHR and eDiary
- SC5: Personal health information recommender
- SC7: Decision aid to support patients' participation in consultations

### 4.5. Scenario Personal health information recommender (FORTH, USAAR)

#### 4.5.1. Tracking information

Scenario Identifier: SC5

Issue Date	Version	Changes Made
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27.03.2015	1.0	Initial Version
13.07.2015	2.0	Final Version

#### 4.5.2. General description and goals

Personal Health Information Recommender is targeted at improving the opportunities that patients have to inform themselves in the internet about their disease and possible treatments, and providing to them personalized information and recommendations. Its goal is threefold:

1. to deliver relevant information to patients, based on their current profile as represented in their PHR data,
2. to ensure the quality of the presented information by giving medical experts the chance to control the information that is given, and
3. to facilitate an easy uptake of the new system by minimizing the necessary manual effort.

By providing high quality information targeted to their actual information goal we give the patients a better starting point to search for the information that they need. Well-informed patients will also find better sources of information, understand better the content and decide what is relevant for them.

To achieve this goal, the domain experts (doctors, practitioners etc.) select high-quality web document that are automatically semantically annotated and indexed. In addition, the experts provide some meta-data on the level of quality and the language used.

Then, a patient can mark a term in his PHR and request additional information to describe the term or he can request additional information to a topic of interest. Again, he can mark terms in such information and request further explanations to the term or further info. The system takes advantage of his psycho-emotional status and his level of education in order to provide adequate context specific information.

Besides these goals that are based on user action, intelligent alerts will be automatically produced to recommend specific informative applications, serious games and literature according to the disease type and his psycho-emotional status.

#### 4.5.3. End users and workflow

##### *Domain Expert Workflow*

Prerequisite: A doctor identifies a high-quality web document with useful content, which he wants to index in the Personal Health Information Recommender.

1. A doctor is logging in his Clinician-Patient interaction e-diary account
2. The doctor selects the Personal Health Recommender Annotation App
3. The doctor pastes the URL of the Web Document
4. The doctor selects the quality level of the document (in a scale from 1 to 5), the cognitive level and the level of education required to understand the aforementioned document.
5. The doctor selects to save the entry.
6. The doctor logs-out of the system.

##### *Patient Workflow*

1. A patient logs in to his PHR account

2. In the first page of his PHR account some interesting documents are recommended to him according to his profile. Besides interesting documents also serious games or multimedia information might be recommended to him.
3. The patient selects the Personal Health Recommendation App
4. A search engine appears, allowing the patient to search for information on a specific term or query.
5. The patient enters the query term and presses enter
6. The list of the results appears and the patient can navigate among them
7. In addition the patient can rank one or more results
8. The patient logs out of his PHR account.

#### 4.5.4. Data

There are two categories of data for input to the system:

1. High Quality web documents identified and initially annotated by domain experts.
2. Data in the PHR for constructing patient's profile

The first category of data is unstructured data that are being annotated by a set on ontologies and can be PDF or WORD documents.

Data belonging to the second category can be structured and/or unstructured. The unstructured data will be PDF, Word or JPG files. These files are namely reports from the clinical chart of the patient. On the other hand the structured data will be those that the patient enters in the PHR by completing eCRFs or answering questionnaires.

#### 4.5.5. Interaction with other user scenarios

- SC1: Scenario PHR and eDiary - to retrieve the patient's profile used as input for recommendations.

### 4.6. Scenario Drug self-management (FRAU, USAAR)

#### 4.6.1. Tracking information

Scenario Identifier: SC6

Issue Date	Version	Changes Made
27.03.2015	1.0	Initial Version
29.07.2015	2.0	Final Version

#### 4.6.2. General description and goals

Patients' ability to manage medications known as medication management capacity (MMC) is one of the main drawbacks to effective care and disease control. It includes the capability to identify medications correctly and to describe how they should be taken. A mobile application (app) for drug self-management, which we plan to develop in the iManageCancer project as a patient-centered approach, will enable patients to successfully manage an increasing number of



prescriptions and avoid dangerous drug interactions and side effects. Support of medication management shall include the following characteristics:

- *Patient's Profile* – contains patient's data (e.g. user name in iManageCancer, password (encrypted), date of birth, weight, gender and other options like pregnancy and smoking)
- *Medication Plan* – includes information about prescribed drugs
- *Drug Taking History* - includes information about all drugs which patient has already taken.
- *Drug-Drug Interaction Checker* – checks if substances of drugs affect their activity when they are administered together. This action can be synergistic (when the drug's effect is increased) or antagonistic (when the drug's effect is decreased) or a new effect can be produced that neither produces on its own.
- *Drug Contraindications Checker* – checks if the patient should not use a drug because of his disease and comorbidities. Some treatments may cause unwanted or dangerous reactions in people with allergies, high blood pressure, or pregnancy. For example, Isotretinoin, a drug used to treat acne is absolutely contraindicated in pregnancy due to the risk of birth defects. Certain decongestants are contraindicated in people with high blood pressure and should be avoided.
- *Drug Dosage Checker* – checks if a drug dosage for the patient is correct according to data recorded in the *Patient's Profile* (see above)
- *Drug Information Receiver* – provides a structured information about a drug (like instruction leaflet)
- *Drug Taking Reminder* – reminds the patient about taking a drug

Support for medication management may comprise the following functionality:

1. The patient can create and manage his medication plan
  1. The patient can add a new drug to the *Medication Plan*
  2. The patient can edit data of drugs already included in the *Medication Plan*. He can manage a drug doses depending on symptoms and results of health assessment tools.
  3. The patient can delete a drug in the *Medication Plan*. The drug will be not really deleted, but marked as “deactivated”. In this case, it will be possible to use the available drug description for deciding to use or not to use it later according to a reason given for the “deleting” of the drug from the list.
2. The patient receives a reminder message for a drug taking and confirms it after taking the drug
3. Taking a drug will be documented in the *Drug Taking History*
4. The patient can access information about a drug (drug instruction leaflet), check for drug-drug interaction and drug contraindications in relation to their disease and comorbidities.

The provided functionality should be available without an internet access as well.

#### 4.6.3. End users and workflow

The intended user of the drug self-management mobile application is the patient. By using this tool, the patient can perform the following functionality provided as workflows. For execution of these workflows, the patient has to perform the following actions:

Step 1: The patient opens the drug self-management app

Step 2: The patient selects the *Medication Plan* in the app.

**Precondition:** the patient has already an account in iManageCancer.

##### *ADD DRUG Workflow*

**Step 1:** The patient adds a new drug, prescribed by his doctor, to the *Medication Plan* using one of the following possibilities:

- The patient enters a drug name manually.
- The patient selects the drug name from a provided list
- The patient scans a barcode on the drug package
- The patient extracts a drug name from the drug package picture
- The patient makes a voice entry (optional)

**Step 2:** the *Drug-Drug Interaction* and the *Drug Contraindications Checkers* will verify if the entered drug interacts with other drugs in the *Medication Plan* and if there exist contraindications for the patient depending on his diagnoses when taking this drug.

**Exception handling:** when detecting drug-drug interactions or contraindications, the patient will receive a corresponding message including a suggestion to contact his physician to clarify the situation.

**Precondition:** The *Medication Plan* includes already at least one drug.

**Precondition** for the *Drug Contraindications Checker*: diagnoses for the patient are already recorded in the app or it is possible to receive diagnoses from the PHR.

**Step 3:** The patient can enter additional data for the drug described in the section Data below.

**Step 4:** The patient enters dosage(s) for the drug for every drug taking time point: amount and a measurement unit, e.g. 1 tablet for the morning, 1/2 tablet in the evening

**Step 5:** The *Drug Dosage Checker* verifies if the entered drug dosage for the singular drug dose and for the daily dose is correct

**Precondition** for the *Drug Dosage Checker*: some data (e.g. age, weight, gender and other options (pregnancy, smoking)) for the patient are already recorded in the app or it is possible to receive these data from the PHR.

**Step 6:** The patient can enter a time point for a reminder for every drug taking time point

##### **Results of the workflow:**

- a new drug is included into the *Medication Plan*
- The recorded diagnosis for the drug is entered into the patient's profile too.

- The patient's profile and the *Medication Plan* will be synchronized with the PHR as soon as the internet connection is available.

### *EDIT DRUG Workflow*

**Step 1:** The patient selects a drug in the *Medication Plan* and edits drug's data described in the section Data below of the ADD DRUG Workflow above.

The date of the editing drug data in the *Medication Plan* will be included automatically.

**Step 2:** The patient edits dosage(s) for the drug

**Step 3:** The *Drug Dosage Checker* verifies if the entered drug dosage for the singular drug dose and for the daily dose is correct

**Step 4:** The patient can edit the time point for a reminder for every drug taking time point or he/she can delete the reminder functionality for the edited drug

#### **Results of the workflow:**

- updated drug data are stored in the *Medication Plan*
- updated diagnosis for the drug is updated in the patient's profile too
- the patient's profile and the *Medication Plan* will be synchronized with the PHR as soon as the internet connection is available

### *DELETE DRUG Workflow*

**Step 1:** The patient selects a drug in the *Medication Plan* and deletes it. He can enter a reason for the drug deleting.

The date of the deleting drug data in the *Medication Plan* will be included automatically.

#### **Results of the workflow:**

- the drug will be not really deleted, but it will be labeled as "deleted" with a possibility to use this drug again or to view the reason of the deleting action
- the diagnosis for the deleted drug will be deleted in the patient's profile too
- the patient's profile and the *Medication Plan* will be synchronized with the PHR as soon as the internet connection is available

### *VIEW DRUG INFORMATION Workflow*

**Step 1:** The patient selects a drug in the *Medication Plan* and selects the "View Drug Information" option.

**Alternative step:** The patient selects "View Drug Information" option in the app (not in the *Medication Plan* module). He can search for a drug by entering drug name using one of the possibilities described in the step 1 of the ADD DRUG Workflow above.

**Optional step:** The patient can select a word or multiple words in the drug information and requests for explanation to the selection.

#### **Result of the workflow:**

The *Drug Information Receiver* will provide a well-structured information about the selected drug.

#### *CHECK DRUG-DRUG INTERACTIONS Workflow*

**Step 1:** The patient selects *Drug-Drug Interaction Checker* in the app and enters at least two drugs using one of the possibilities described in the step 1 of the ADD DRUG Workflow above.

**Result of the workflow:**

The *Drug-Drug Interaction Checker* will provide an information about possible interactions for the selected drugs.

#### *CONFIRM REMINDER MESSAGE Workflow*

**Step 1:** The patient receives a notification from the *Drug Taking Reminder* for taking a drug. The patient has two options:

- he/she can take the drug and select the “Confirm” button on the app
- he/she can select the “Skip” button on the app if he/she has decided to skip taking the drug. In this case he can also enter a reason for the skipping the current drug intake.

**Results of the workflow:**

- The confirmation or the skipping of the drug taking notification will be entered into the *Drug Taking History*: the drug will be labeled as “taken” or “skipped” (with a possibility to enter a reason – see the VIEW/EDIT DRUG TAKING HISTORY Workflow below)
- The *Drug Taking History* will be synchronized with the PHR as soon as the internet connection is available.

#### *VIEW/EDIT DRUG TAKING HISTORY Workflow*

**Step 1:** The patient selects the *Drug Taking History* in the app. Drugs for today are shown to the patient. The patient can select another day as well. Drugs are labeled as “taken”, “skipped” or “upcoming”. The patient has the following possibilities:

- he/she can enter comments to the drugs (e.g. reason for skipping)
- he/she can confirm taking of a drug (if it was not confirmed when receiving a notification)

#### *VIEW/EDIT PROFILE Workflow*

**Step 1:** The patient selects the *Patient’s Profile* in the app

**Step 2:** The patient edits data in his profile: age, weight, gender and other options (pregnancy, smoking)

**Result of the workflow:**

- The patient’s profile is synchronized with the PHR as soon as the internet connection is available.

- Drugs in the *Medication Plan* will be checked if changing of the weight of the patient has an impact on the recorded dosage for the drugs.
- Drugs in the *Medication Plan* will be checked if they have contraindications according to changed data about diagnoses, pregnancy or smoking.
- The patient will be informed, if contraindications are detected or if the dosage for the drugs should be changed. In such cases the patient will be asked, if the affected drugs should be temporary deactivated in the medication plan until the patient clarifies the dosage changing or alternative drugs with his doctor.

#### 4.6.4. Data

Data for the *Medication Plan* shall be entered or gathered automatically in the app on a mobile device and shall be synchronized with the medication plan in PHR as well. Therefore, the data below are input and output data:

- Duration of the drug taking:
  - o start date (required)
  - o end date (optional)
- Frequency of the drug taking (required):
  - o daily
  - o every x days (x should be specified)
  - o weekly
  - o monthly
  - o OR selection of days in the week
  - o OR entering a particular date (for a singular action).
- time points of the daily drug taking (optional)
- selection of the diagnosis for which the drug is prescribed (required) – a list of diagnoses should be provided.
- reason for the drug is prescription (optional)
- who has prescribed the drug (optional)
- date of the drug prescription (optional)
- picture of the drug (optional)
- picture of the package (optional)
- entering or selection of the drug producer (optional)
- selection of the drug pharmaceutical form (optional):
  - o tablet
  - o sugar-coated tablet
  - o granules
  - o capsule
  - o solution

- lozenge
  - juice
- selection, how to take the drug (optional):
  - oral
  - inhalation
  - local (e.g. for ointment)
  - injection
- comment (optional)
- date of adding a drug into the *Medication Plan* (gathered automatically)
- date of the last editing a drug information in the *Medication Plan* (gathered automatically)
- date of deleting a drug from the *Medication Plan* (gathered automatically)

Data for the *Drug Taking History* (input and output):

- drug name
- status of the drug taking:
- date and time point of the drug taking/skipping
- comment (e.g. reason for skipping)

Data for the *Drug-Drug Interaction Checker* and for the *Drug Information Receiver* (input data):

- A public repository containing structured drug information (including drug-drug interactions). The repository should be available online as well as a copy on a mobile device for offline functionality of the *Drug-Drug Interaction Checker* and for the *Drug Information Receiver*.

Data for the *Drug Contraindications Checker* (input data):

- A public repository containing structured drug information (including contraindications for drugs) described for the *Drug-Drug Interaction Checker* and for the *Drug Information Receiver* above.
- Diagnoses of the patient available in the patient's profile in the app or requested from the PHR

Data for the *Drug Dosage Checker* (input data):

- A public repository containing structured drug information (including conditions for drug dosage) described for the *Drug-Drug Interaction Checker* and for the *Drug Information Receiver* above.
- A subset of data from the patient's profile in the app or requested from the PHR:
  - date of birth (only year and month for calculating age of the patient)
  - weight
  - gender

- pregnancy
- smoking

Data for the *Patient's Profile* (input and output):

- user name and password (encrypted) in iManageCancer platform
- date of birth (only year and month for calculating age of the patient)
- weight
- gender
- pregnancy
- smoking
- diagnoses

#### 4.6.5. Interaction with other user scenarios

The Drug Self-Management scenario will interact with the following other scenarios:

- SC1: PHR and eDiary - for synchronizing of the following data:
  - patient's profile
  - medication plan
  - drugs taking history

### 4.7. Scenario Decision aid to support patients' participation in consultation (IEO, FORTH)

#### 4.7.1. Tracking information

Scenario Identifier: SC7

Issue Date	Version	Changes Made
27.05.2015	1.0	Initial Version
19.07.2015	2.0	Final Version

#### 4.7.2. General description and goals

A decision aid tool for prostate cancer treatment choice will be developed, where patients' participation in decision making seems to be very low according to the interviews with clinicians and patients.

Here, patients are guided through pros and cons of the choice prior to consultation and, in parallel, emotions associated with each risk or benefit are elicited. At the end of the decision aid, patients can write up a list of questions to ask during consultation. Lists of important questions to a particular diagnosis or treatment situations could be created (i.e. questions around chemotherapy, questions around prostatectomy).

This information can be provided to the clinician in order to guide consultation based on themes that are relevant for the patient and to his family and social situation. Expected outcomes from using the decision aid would be greater information comprehension/understanding, increased

satisfaction with consultation (compared to control group), and greater choice satisfaction (i.e., reduced regret), and eventually higher empowerment and self-management abilities.

This should be combined with the patient desired participation role and, possibly with information about his family and social situation from the Psycho-emotional monitoring tool.

### 4.7.3. End users and workflow

#### *Patient user*

- Prior to consultation (at arrival in the hospital or 24 hours in advance) the system reminds the patient to perform a whole or a partial psycho-emotional assessment
- Data are computed and scoring is generated.
- Decision Aids tool is activated
- Patient is guided through different treatment options
- For each treatment risk or benefit, the patient is asked to assign a cognitive weight and to choose among associated emotions
- The patient can write up a list of questions or choose from a list of pre-compiled questions
- Data is computed and combined with patient state of activation, decisional preferences and health locus of control (from the Psycho-emotional monitoring Tool) and with Family Resilience Tool
- A profile is generated

#### *Clinician user*

- The doctor receives a notification that a profile is ready for a scheduled patient
- The profile contains indications on areas, which generate significant emotional activation, which areas are evaluated as cognitively relevant for decision, patient's preferences on decision style and self-management and family resources.

### 4.7.4. Data

- Data input on scheduled appointments is received from the calendar and activates the Tool
- Data input on Patient activation, Need for cognition, Decisional control preferences (passive, shared, active), Health Locus of Control (Internal, External, Powerful Doctors, Powerful Others), ALGA-P (Social abilities, Financial Problems, Sexual Problems, Body Image, Pain, Fatigue, Self-efficacy) are provided from the Psycho-emotional monitoring tool
- Data input on family resilience are provided from the Family Resilience tool may be combined
- Data entry on cognitive and emotional weights is provided from the patient
- Data entry on questions for clinicians is provided from the patient
- Data from the Tool:
  - Generate a feedback for the patient on subjectively relevant areas



- Are sent to clinicians to guide consultation for shared treatment decisions

#### 4.7.5. Interaction with other user scenarios

- SC1: PHR and eDiary
- SC2: Health avatar
- SC5: Personal health information recommender
- SC8: Psycho-emotional status and management
- SC9: Family resilience evaluation
- SC12: Data analysis and data mining

### 4.8. Scenario Psycho-emotional status and management (IEO, FORTH)

#### 4.8.1. Tracking information

Scenario Identifier: SC8

Issue Date	Version	Changes Made
27.05.2015	1.0	Initial Version
19.07.2015	2.0	Final Version

#### 4.8.2. General description and goals

iManageCancer will use standardized psycho-behavioural questionnaires in order to monitor psycho-emotional status of cancer patients and their individual resources in coping with cancer. This tool will allow to tailor information provision and services in accordance with patients' preferences and attitudes and to develop individualised self-management action plans. We expect these intermediate goals to ultimately allow a better fitting between the patient and the Avatar, thus increasing self-management abilities and patient empowerment.

The assessment will include:

- A patient profile based on ALGA-P measuring
  - Psychological aspects:
    - Anxiety
    - Depressive symptoms
    - Self-efficacy
  - Psychosocial aspects:
    - Social abilities
    - Financial problems
    - Sexual problems
    - Body image
  - Cognitive aspects:
    - Memory and attention
    - Rumination
    - Cognitive closure
  - Perceived health states:
    - General self-rated health (GSRH)

- Pain
- Fatigue
- Physical abilities
- Appetite
- Patient activation (disengaged and overwhelmed, becoming aware but struggling, taking action, maintaining behaviour)
- Need for cognition (high, low)
- Decisional control preferences (passive, shared, active)
- Health Locus of Control (Internal, External, Powerful Doctors, Powerful Others)

The whole assessment or part of it will be compiled prior to consultation and visits and periodically.

Alerts on the electronic devices will remind the patient to periodically provide input.

### 4.8.3. End users and workflow

**Case 1:** The patient has to visit the clinic for a scheduled consultation with a physician

*Patient user*

- Prior to consultation (at arrival in the hospital or 24 hours in advance) the system reminds the patient via email or some other system to perform a whole or a partial psycho-emotional assessment
- Data are computed and scoring is generated. Detection of significant variations from previous assessments
- Patient profile is generated based on scoring, and feedback is provided on his status
- If the consultation includes discussion on therapies, Decision Aids tool is activated
- Depending on scores in ALGA-P, Family Resilience Tool is activated
- Depending on scores in different areas, suggestions on actions are activated, e.g., suggest psycho-oncologic consultation if depression scores are elevated; provide indications on pain management and/or alert clinicians if pain is increased.

*Clinician user*

- The doctor receives a notification that a profile is ready for a scheduled patient
- Scoring on different areas is provided along with short feedbacks and suggestions based on the patient's situation

**Case 2:** Periodic monitoring

*Patient user*

- A periodic reminder reminds the patient to perform a whole or a partial psycho-emotional assessment
- Data are computed and scoring is generated. Detection of significant variations from previous assessments
- Patient profile is generated based on scoring, and feedback is provided on his status
- Depending on scores in different areas, suggestions on actions are activated e.g., suggest psycho-oncologic consultation if depression is scores are elevated; provide indications on pain management and/or alert clinicians if pain is increased.

- Psychological profile activates different patterns of information provision from the Personal Health Information Recommender

#### *Clinician user*

- If scores in certain areas are significantly elevated, an alert is sent to clinicians.
- Scoring on different areas is provided along with short feedbacks and suggestions based on the patient's situation

#### **4.8.4. Data**

- Data input on scheduled appointments is received from the calendar and activates the Tool
- Data entry is provided from the patient.
- Data regarding profile:
  - Activate suggestions on self-management actions
  - Are stored in the PHR
  - Modulate information provision from the Personal Health Information Recommender
  - Are fed to the Decision Aids Tool and to the Family Resilience Tool
  - May send alerts to clinicians

#### **4.8.5. Interaction with other user scenarios**

- SC1: PHR and eDiary
- SC2: Health avatar
- SC5: Personal health information recommender
- SC7: Decision aid to support patients' participation in consultation
- SC9: Family resilience evaluation
- SC12: Data analysis and data mining

### **4.9. Scenario Family resilience evaluation (IEO, FORTH)**

#### **4.9.1. Tracking information**

Scenario Identifier: SC9

Issue Date	Version	Changes Made
27.05.2015	1.0	Initial Version
19.07.2015	2.0	Final Version

#### **4.9.2. General description and goals**

From a psychological perspective, individual resilience can be defined as the ability to utilize resources to cope with adversity. Different studies have come up with different ways of

categorizing such resources<sup>14, 15</sup> Grothberg (1995)<sup>16</sup>, proposes to group the sources of resilience in 1) external support (family, friends, communities, etc.), 2) internal strength (feelings, attitudes, values) and 3) interpersonal skills (communication, problem solving, management of feelings and temperament, social relationships).

When a family member is faced with a terminal illness, the potential death presents a crisis and a challenge to the entire family as a system. As a parent, the fact that your child has cancer, is one of the worst situations to face. According to the family systems theory (e.g., Bateson, 1971)<sup>17</sup>, individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit (Kerr & Bowen, 1988)<sup>18</sup>. Families are systems of interconnected and interdependent individuals: what happens to one family member affects the other members.

The main goal for this scenario is to create a tool able to measure the family resilience in order to individuate the critical areas that can deplete the patient's resources and to foster interventions that empower the whole family system.

A tool will be created that will investigate the following areas on the patient and all the family members, accordingly with the aforementioned literature evidence:

- ◆ low self-esteem/self-efficacy
- ◆ negative thinking style
- ◆ emotional reactions
- ◆ attitudes and values
- ◆ personal sense of competence
- ◆ sense of agency
- ◆ health beliefs
- ◆ self-reliance
- ◆ communication and problem solving skills
- ◆ family disharmony instability or breakout

#### 4.9.3. End users and workflow

The end users of the tool will be both the clinicians, the patients and possibly the family.

##### *Patient (and family) user*

- The patient (and the family) periodically will be remind by an alert to perform the family resilience evaluation

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<sup>14</sup> Kumpfer, K.L. 1999. Factors and processes contributing to resilience: The positive resilience framework, in Resilience and development: Positive Life Adaptions, edit by M.D. Glantz and J.L. Johnson. New York: Academic/Plenum Publishers, 179-224.

<sup>15</sup> McWhiter, J. J., McWhiter, B. J., McWhiter, E. H., & McWhiter, R. 2007. At Risk Youth: A Comprehensive Response for Counselors, Teachers, Psychologists and Human Service Professionals. 4th Edition. Belmont, CA: Thomson.

<sup>16</sup> Grothberg, E. 1995. A guide to promoting resilience in children: strengthening the human spirit. Den Haag: Bernard van Leer Foundation.

<sup>17</sup> Bateson, G., A Systems Approach. International Journal of Psychiatry, 1971, 9, 242 – 244.

<sup>18</sup> Kerr, M.E., Bowen, M.. Family Evaluation: An Approach Based on Bowen Theory. New York: Norton & Co., 1988.

- Data are computed and scoring is generated. In the first assessment the scores will be compared with a normative sample, while variations from previous assessments will be analysed
- A feedback on family resilience profile in lay language is provided
- Depending on scores in different areas, suggestions on actions are activated. Whenever recommendations consist on small changes in the family dynamics they will be provided by means of the platform. When severe criticisms appear a suggestion to contact a health care professional will be suggested.
- The Family Resilience Profile activates different patterns of information provision from the Personal Health Information Recommender

#### *Clinician user*

- If scores in certain areas are significantly elevated, an alert is sent to clinicians.
- Scoring on different areas is provided along with short feedbacks and suggestions

#### **4.9.4. Data**

- Data input on scheduled appointments is received from the calendar and activates the Tool
- Data entry is provided from the patient.
- Data regarding profile:
  - Activate suggestions on self-management actions
  - Are stored in the PHR
  - Modulate information provision from the Personal Health Information Recommender
  - Are fed to the Decision Aids Tool and to the Psycho-emotional Tool
  - May send alerts to clinicians

#### **4.9.5. Interaction with other user scenarios**

- SC1: PHR and eDiary
- SC2: Health avatar
- SC5: Personal health information recommender
- SC7: Decision aid to support patients' participation in consultation
- SC8: Psycho-emotional status and management
- SC12: Data analysis and data mining

### **4.10. Scenario Health enquiry (FRAU, USAAR)**

#### **4.10.1. Tracking information**

Scenario Identifier: SC10

Issue Date	Version	Changes Made
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26.05.2015	1.0	Initial Version
13.07.2015	2.0	Final Version

#### 4.10.2. General description and goals

This scenario describes the usage of a generic tool, which allows clinical experts to dynamically create standardised questionnaires for the patients and their supporters (e.g. family members). These questionnaires can be integrated in a workflow in order to provide them to the patients as part of a care pathway through planned applications like the Psycho-Emotional and Health Assessment Tool, the Family Resilience Evaluation tool, or any other iMC app. According to this, the Health Enquiry tool should support creation of questions with a standardised input of answers (e.g. selections and choices). This ensures that user's answers are captured in a way that they can be stored as structured data in PHR and be further assessed by other components (e.g. the decision support) easily.

#### 4.10.3. End users and workflow

End users of the generic Health Enquiry Tool are clinical experts who create the questionnaires, which will be filled in by patients or their supporters (e.g. the family members) through associated applications.

##### *Clinical Expert workflow*

1. A clinical expert creates a care pathway using the designer component of the iMC Care Flow Engine.
2. The clinical expert adds an enquiry task to the flow.
3. The clinical expert defines a name of the task and marks it as executable by a patient.
4. The clinical expert creates a question item. This comprises
  - a. The label text of the question.
  - b. The data type of answers (e.g. text, number, date).
  - c. (Optional) Value range of the answers (e.g. list of selections).
5. The clinical expert annotates the value of the question in terms of the underlying PHR data model. For this, she/he can choose from the supported concepts of the data model (e.g. patient -> symptom -> pain -> intensity).
6. The clinical expert can add more question items.
7. The clinical expert can define a time-dependent expire behaviour for the task.
8. The clinical expert can finalise and store the care flow.
9. The defined care flow is available in the system for the execution.

##### *Patient workflow*

1. The patient signs up for the defined care flow.
2. The patient will be asked to fill in the questionnaire by the responsible client application.
3. The patient can open the questionnaire as a form.

4. The questionnaire displays each question according to the defined item (i.e. the associated data type of the answers).
5. The patient can enter values in order to answer the questions.
6. The patient can finalise the input by confirming the questionnaire.
7. The entered data will be stored in the patient's PHR.

#### 4.10.4. Data

In this scenario structured data will be collected from standardised questionnaire forms.

#### 4.10.5. Interaction with other user scenarios

This scenario interacts with

- SC1: PHR and eDiary
- SC4: Management workflows
- SC8: Decision aid to support patients' participation in consultation
- SC9: Psycho-emotional status and management
- SC10: Family resilience evaluation.

### 4.11. Scenario Life style and vital sign monitoring (FRAU, Philips, USAAR, IEO)

#### 4.11.1. Tracking information

Scenario Identifier: SC11

Issue Date	Version	Changes Made
15.04.2015	1.0	Initial Version
13.07.2015	2.0	Final Version

#### 4.11.2. General description and goals

Patients treated with chemotherapy often suffer from side effects, which are not life threatening but limit their life quality, as e.g. anorexia, gain of weight, diarrhoea or mucositis. Such symptoms can be improved and treated with a simple optimization of the patient's life-style, as e.g. healthy or appropriate nutrition or physical exercises. Unfortunately, most patients do not have the knowledge and/or the motivation for an appropriate change of their lifestyle and doctors have little time to support them. Therefore, the iManageCancer platform shall help these patients with personalized guidance according to their measurements and symptoms.

In order to provide recommendations towards the optimisation of patient's life style quantified information about physical parameters and activity can be exploited for a decision support. These data can be collected and monitored with the help of (off-the-shelf) sensors and medical devices. It comprises the measurement of the body weight and patient's vital signs (blood pressure, pulse, body temperature) as well as the tracking of patient's activity. Results can then be used in dependent scenarios such as patient self-management scenarios.

### 4.11.3. End users and workflow

End user: Cancer patient treated with chemotherapy, but also other cancer patients

Workflow:

The end user of this scenario is the patient. The workflow can be described by the following steps:

1. Ideally, every morning before the breakfast, the patient uses a scale that is connected to his smart phone app and measures his weight. His smartphone reminds him to do so. If his scale cannot communicate, he shall be allowed to enter the weighing result in the smart phone app.
2. Ideally, every morning before the breakfast, the patient uses an ear thermometer that is connected to his smart phone app and measures his body temperature. His smartphone reminds him to do so. If his thermometer cannot communicate he shall be allowed to enter the temperature result in the smart phone app. The same applies for blood pressure.
3. The patient tracks her/his activity using wearable devices or smartphone apps during the day and during night (sleeping habits). Once a day, preferable in the evening, the patient transmits the recorded data through his smartphone to his PHR. Relevant data are steps per day, recorded distance outdoor, sleeping hours and intervals, resting hours, consumed calories.
4. The tracking data will be stored in patient's PHR.
5. Thresholds and trends in all signals shall be monitored to detect a decrease of the physical condition, continuous weight loss, indolence, bad sleeping habits and sleep disorders.
6. The patient will be informed about any decrease or deterioration of a parameter, but also about a positive development of a formerly worse parameter. In case of critical signals, the patient will be advised to visit the doctor or the clinical as soon as possible.
7. The doctor will be warned about critical parameters and their trends.

### 4.11.4. Data

In this scenario patient's data from (off-the-shelf) sensors and medical devices will be collected.

### 4.11.5. Interaction with other user scenarios

- SC4: Management workflows

## 4.12. Scenario Data analysis and data mining (FORTH)

### 4.12.1. Tracking information

Scenario Identifier: SC12

Issue Date	Version	Changes Made
31/03/2015	1.0	Initial Version
15/06/2015	1.1	Updated version (based on discussion during the CM-Homburg)
13/07/2015	2.0	Final Version



#### 4.12.2. General description and goals

The data analysis and data-mining scenario aims to extract information from the diverse data of iManageCancer and transform it into an understandable structure for better knowledge and further use. Smart data analytics will provide mechanisms able to identify patterns or trends in data, screen pre-frailty states and provide different views of data for new management plans. The data mining scenario focuses on data discovery, identification and extraction of previously unknown interesting patterns and associations between available data and the patients in the iManageCancer platform. In order to advance data mining within the iManageCancer context objectives and goals, special efforts will be forwarded in the utilization of main data mining standards (e.g. PMML<sup>19</sup> - Predictive Model Mark-up Language) and open source environments and libraries like Weka<sup>20</sup>. Objective: Create tools able to mine raw data and use well-known data mining methodologies and standards

- attempt to hypothesize relationships within the data
- identify patients that require medical attention
- screen for pre-frailty states
- draw conclusions related to the usage of the self-management platform

#### 4.12.3. End users and workflow

End users of this scenario are physicians, data miners, statisticians and data managers. As shown in the following figure, data analysis and data-mining in iManageCancer is an iterative approach, which combines data from the semantic layer of iManageCancer, pre-processes the data, performs the analysis and provides the results for visualization. The loop closes with the interaction of the end user who can select/refine the results of an analysis and start a drill-down analysis to extract knowledge from cohorts with specific criteria.

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<sup>19</sup> Guazzelli, Alex, Michael Zeller, Wen-Ching Lin, and Graham Williams. "PMML: An open standard for sharing models." *The R Journal* 1, no. 1 (2009): 60-65.

<sup>20</sup> Hall, Mark, Eibe Frank, Geoffrey Holmes, Bernhard Pfahringer, Peter Reutemann, and Ian H. Witten. "The WEKA data mining software: an update." *ACM SIGKDD explorations newsletter* 11, no. 1 (2009): 10-18.

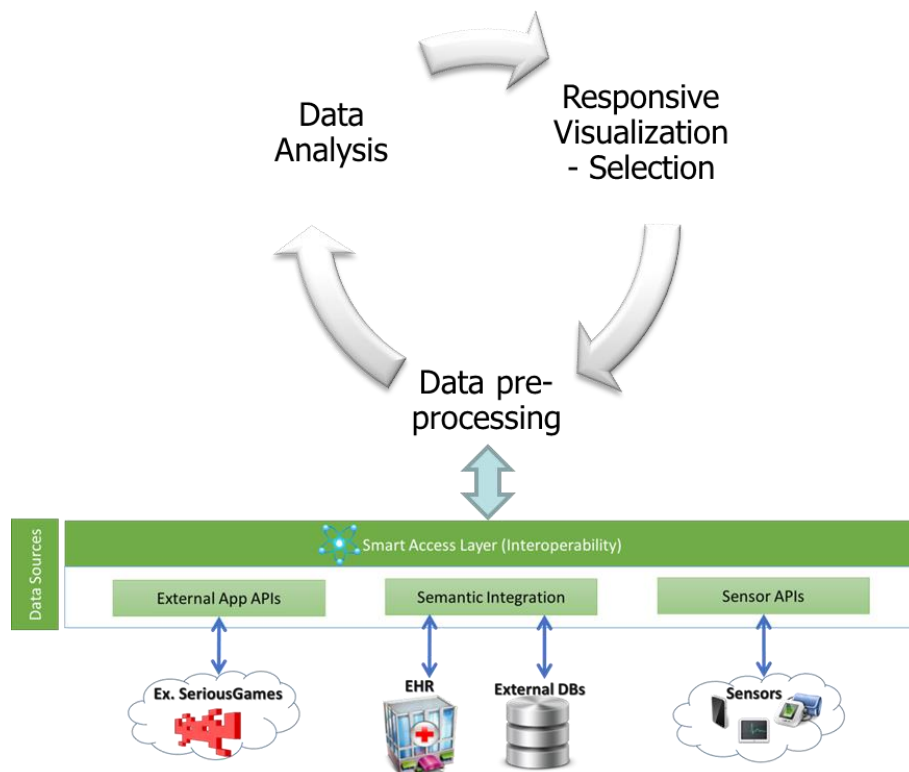


Figure 3. High-level architecture for data analysis and data mining.

The workflow for the data analysis and mining scenario consists of the following steps:

**Step 1: Overview of the data**

- The end user logs-in to the system
- An overview of the iManageCancer data for the whole population using various visualization techniques, such as charts, plots, bubble charts, parallel coordinates, is available.
- The user can view statistics for the active daily living and the frailty state of the iManageCancer population.

**Step 2: Create and analyse cohorts**

- The end user can select, using the interactive visualization techniques, specific features and set inclusion/exclusion criteria in order to create a new cohort, e.g. select only male patients and age >60. Alternatively, the user can select specific features, e.g. age and disease, and request from the system to propose new cohorts. The proposed cohorts will be extracted using clustering techniques along with feature selection algorithms for the identification of relationships in the data.
- Then the end user selects/approves one or more new cohorts and requests to analyse and view the results for these cohorts.
- The system applies data analysis for the new cohort(s) using machine-learning methodologies such as classification, regression, clustering and association rules.
- Analysis results are presented to the end user using the same visualization techniques as of step 1.

**Step 3: Monitor specific patient**

- The end user can select one or more patients and:
  - View patient's statistics

- Plot patient's data in conjunction with average values of specific cohort(s), e.g. daily active living of population, frailty state of population, in order to highlight and identify deviations.

#### Step 4: Alerts

- The user can select and create a new alert for specific cohorts (from step 1 or 2) or specific patients (from step 3). The user will be able to select specific features (e.g. from a parallel coordinate UI) and add an automatic alert/indication. Such an alert could be to compare the side effects of two different treatments.
- The system will monitor the specific feature(s) for the specific cohorts and if significant differences appear, the researcher will be informed via email.

#### 4.12.4. Data

The iManageCancer platform collects multidisciplinary data covering areas from the medical, the environmental and the lifestyle domains. Data mining scenario will take advantage of all the available data in iManageCancer in row and structured format. Specifically, the available data and the handling for the data mining scenario are as follows:

- Medical data
  - Well structured, text (using ontologies) & images with rich metadata
- Environmental and sensor data
  - Medical sensors (e.g. blood glucose, temperature etc.): Intervals for normal-abnormal must be provided
  - Activity sensors: Numeric values will be used.
- Personal profile
  - Diary: Free text (not always in English). To use it we need NLP and annotations (could be used the system from the Personal Health Information Recommender)
  - Uploaded images. Could use only meta-data (if any).

The output of the scenario will be:

- Predicted values based on the selected model type(s) like accuracies, probability, standard error, confidence, support etc.
- Filtering of the data (sub-cohorts, features selection, different views) to be provided as input for visualization to the end user.

#### 4.12.5. Interaction with other user scenarios

- SC13: Visualization

### 4.13. Scenario Visualisation (BED)

#### 4.13.1. Tracking information

Scenario Identifier: SC13

Issue Date	Version	Changes Made
27.05.2015	1.0	Initial Version
19.07.2015	2.0	Final Version

#### 4.13.2. General description and goals

We define the visualization services provided by the platform as the engagement of individuals, in activities and practices that sustain and promote health and well-being by:

- Visualizing data from self-monitoring of own health-status including daily activities and symptoms.
- Visualizing individual risks and allowing for analysis of the impact of the behaviour to the risks

#### 4.13.3. End users and workflow

More specifically, we will implement the functionalities as follows:

1. Enhancing user experiences in behaviour monitoring, symptom reporting and facilitating their lifestyle management by allowing the monitoring of a wide range of data including their activities, movement, step accounts, diet and other health-related behaviours and events, and symptoms from sensors and mobile apps. This will be done through the visualization of the health status of the individual and their behaviours including their locations, movements, diet, quality of life, environment, mood, blood pressure, glucose, alcohol, smoking, and other symptoms, etc. Visual analytics will be used to display individual/aggregated data items to allow easy interpretation of the data of the patients. With the search bar of the system, the users can easily send queries about their activities, movements, diet, etc.
2. Visualizing individual risks and allowing for analysis of the impact of the behaviour to the risks
  - Visualization of the risk assessment outcomes by linking the personal diary with the behaviour prescription to show the underlying risk factors, demonstrating to the patients the relations between the outcomes of the self-management/treatment.
3. Supporting personal behaviour intervention modules that allow planning and reminding for daily physical exercise, diet and medication where necessary.
  - Supporting intervention: allowing for the visualization of “Behaviour prescription” including a set of targets in terms of daily activities, calorie intake and energy consumption, etc.
  - Education intervention: through visualization, help the users to interpret the educational materials to the patients in needs, for example, highlight the key messages and show the relationship between different materials to assist their reading.

#### 4.13.4. Data

The different types of input and output data have been illustrated in the description above.

#### 4.13.5. Interaction with other user scenarios

These are the relevant scenarios:

- SC1: PHR and eDiary - for data storage
- SC8: Psycho emotional status and management - for retrieving patient information for storage
- SC12: Data analysis and data mining - to discover useful information to patients
- SC4: Management workflows - to support management in the eDiary
- SC3: Chemotherapy - for clinical case
- SC6: Drug self-management - for the part of behaviour intervention

- SC5: Personal health information recommender - for education materials
- SC10: Family resilience evaluation - for social interaction
- SC11: Lifestyle and vital sign monitoring

#### **4.14. Scenario Patient – Doctor and Patient - Patient Interaction (FORTH)**

##### **4.14.1. Tracking information**

Scenario Identifier: SC14

Issue Date	Version	Changes Made
23.06.2015	1.0	Initial Version
13.07.2015	1.1	Final Version

##### **4.14.2. General description and goals**

This scenario enables patients to communicate between each other and with their doctors.

In general, there are two communication means, internal and external that will be explored by the iManageCancer project.

- *External communication* means are social platforms like Facebook, Twitter etc. that will be linked to the account of stakeholders in the iManageCancer platform and will allow publishing news, messages etc. through these platforms.
- *Internal communication* means are tools developed and controlled by the iManageCancer project such as chat rooms, forums etc. However, in such a case the chat rooms/forums etc. need to be moderated. Since internal communication means should be moderated, they impose restrictions on their sustainability since they demand continuous man-effort. However, we are going to investigate their usage by pilots and draw conclusions by this experience. Besides these options patients will be able to select specific data within a specific time-frame to be shared with their doctors and the doctors will be able to recommend specific web documents to patients directly.

##### **4.14.3. End users and workflow**

Patient to Patient

1. The patient logs-in to the iManageCancer platform
2. The patient selects to share some specific information using one of the following means
  - to share directly with another patient
  - to publish some information in his connected social account
  - to write something in a forum
  - to write something in a chat room
3. The patient logs-out from the iManageCancer platform

Patient to Doctor

1. The patient logs-in to the iManageCancer platform

2. The patient selects to share some specific information with his doctor using one of the following means
  - to share directly some information directly with his doctor
  - to write something in a forum for doctors
  - to write something in a chat room with his doctor
3. Then as soon as the doctor logs-in to his iManageCancer account a notification will be generated and he will be able to see the shared information
4. The doctor is able then to respond to the shared information publishing a comment/recommendation either directly as a message to the patient or via a chatroom or a forum.

#### **4.14.4. Data**

The demonstration will aim at patients that will exchange information and patients sharing their data with doctors.

#### **4.14.5. Interaction with other user scenarios**

These are the relevant scenarios:

- SC1: PHR and eDiary - for data storage
- SC5: Personal health information recommender - for education materials

## 5. Serious Games

### 5.1. Cell Attack (Working title) (SGS, USAAR)

#### 5.1.1. Tracking information

Game Identifier: G1

Issue Date	Version	Changes Made
20.04.2015	1.0	Initial Version
29.04.2015	1.1	Updated version
12.07.2015	2.0	Final Version

#### 5.1.2. General description and goals

In this serious game the patient fights against cancer cells inside of his/her body. He/she gains level and receives special attention (in particular in dire straits: operations, chemotherapy, etc.) from his/her relatives and friends, if declared even from strangers inside the game.

The relative, friend or stranger is able to do some good, in teams (or alone), by supporting the user (patient) in game and show him/her that they care and think of him.

All users can play different game modes and destroy cancer cells with their spaceship by e.g. drawing symbols at the cancer cells.

The game motivates the patient in fighting against cancer and shows the way how medicine works and how important the daily medicine is.

A great bandwidth of people will be addressed by the game by the medium tablet or smartphone and different game modes for all ages.

The patient will be supported by different people and the game will help the patient in the way, the user is not feeling lonely in hard times (e.g. lonely hours in hospital or during hard times at home when nobody of the friends is allowed to visit him/her).

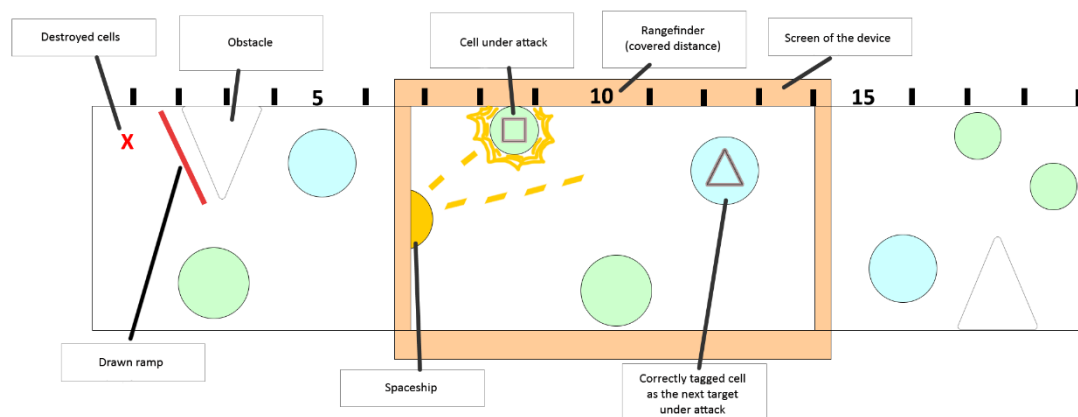


Figure 4: Mock-up of the graphical user interface of the game. Please keep in mind that the sketch is game designer's art and is only made to illustrate mechanics. Visualization will be part of the next design phase, when the core mechanics are settled.

#### 5.1.3. End users and workflow

This is a serious game for small children with cancer and their relatives, friends etc. and people who are interested in helping cancer patients. The workflow for the game is:

1. The user taps at a link from the iManageCancer platform or opens the app store from the mobile advice directly
2. The app can be downloaded at the used advice for free
3. The user starts the downloaded app
4. The user has to choose a nickname
5. He has to choose a game mode (explorer or supporter) and needs an account at the iManageCancer platform by playing as an explorer. This one has to be entered into the app.
6. A game menu will be shown
7. The user can decide between different areas (daily requests, daily login bonus, explorer mode, supporter mode action, supporter mode strategies, high score, my peer group, my supported explorer group, friends list, my actual explorer):
  1. The user taps at the button for daily requests:
    - A window will be opened with all daily requests.
    - The user is able to activate a daily request by tapping at the support button next the request.
    - The user is able to switch back to the game menu.
  2. The user taps at the button for daily login bonus:
    - A window will be opened with the daily login bonus.
    - The user is able to collect the bonus by tapping at the bonus icon. If the bonus was already collected, the field with the bonus icon will be empty.
    - The user is able to switch back to the game menu.
  3. The user taps at the button *Explorer Mode*:
    - A level map will be opened.
    - The user is able to choose a level by pressing this button.
    - The game starts
    - Or the user is able to switch back to the game menu.
  4. The user taps at the button *Supporter Mode Action*:
    - The user is able to choose between single or coop mode
      1. Single mode: the game starts.
      2. Coop mode: the user is able to choose between inviting a friend, playing an already started game or searching for another user in the internet:
        1. Inviting a friend:
          1. The user will be forwarded to his friends list and is able to choose a friend.
          2. The friend will get an invitation.
          3. After the friend accepted the invitation, the friend is able to start the first lap.
          4. After finishing this lap the user is able to play his first lap.
        2. Playing an already started game:
          1. The user is able to play his lap.
        3. Searching for another user:
          1. Another user who searches for another user too will be added to the game.
          2. After the other user is added, the user is able to play his first lap (the user who searched for another user first will be the second player).
      - The user is able to switch back to the game menu.
5. The user taps at the button for supporter mode strategies:
  - The game starts.
6. The user taps at the button for high score:



- The high score window will be opened.
  - The user is able to scroll the list of users, searching for somebody, inviting somebody to a coop supporter game or sending an invitation message for the friends list:
    1. Searching for somebody: the nickname or parts of it will be entered in a search text field and the search starts with tapping at the search button. All users with entered letters will be shown.
    2. Inviting somebody to a game: by tapping the invite button, an invitation will be sent automatically.
    3. Inviting somebody to the friends list: by tapping the invite button, an invitation will be sent automatically.
  - The user is able to switch back to the game menu.
7. The user taps at the button *My peer group*:
- A list with all users who supports the user will be opened.
  - The user is able to tap a button for deleting users from this list and one for collecting a special ammunition.
  - The user is able to switch back to the game menu.
8. The user taps at the button *My supported explorer group*:
- A list with all users who are supported by the user will be opened.
  - The user can choose and change the supported explorer(s).
  - The user is able to switch back to the game menu.
9. The user taps at the button *Friends list*:
- A list with all friends of the user will be opened.
  - The user is able to delete a friend or add a friend to the supported user list by tapping at the corresponding button.
  - The user is able to switch back to the game menu.
10. The user taps at the button *My actual explorer* (drop down menu):
- Here the user is able to choose an explorer from his explorer list by scrolling the nicknames of the explorers and choosing one by tapping.
8. The App will be closed like all other apps by using the back button at the advice.

#### 5.1.4. Data

- For the supporter: nothing.
- For the explorer: the data of the iManageCancer account.

#### 5.1.5. Interaction with other user scenarios

- SC1: Scenario PHR and eDiary
  - The account data of a user from the iManageCancer platform (check if the person has an account or not).
  - From the PHR: Event-Flag, if there is an important medical intervention.

## 5.2. Educational Game (BED, IEO)

### 5.2.1. Tracking information

Game Identifier: G2

Issue Date	Version	Changes Made
14.06.2015	1.0	Initial Version
19.07.2015	2.0	Draft Final Version
20.07.2015	2.1	Final Version: Updated to address comments from Serious Games meeting, 20.07.2015

### 5.2.2. General description and goals

#### Meta-targets of the game

- To create a game that educates patients (and individuals) to healthy behaviors while having fun
- Improve self-efficacy in self-management skills through mastery and vicarious experience of the Avatar in the Serious game

#### Concrete targets of the game

- Learn more healthy life-styles (balanced diet, appropriate physical exercise) and increase problem solving skills (adjustment-oriented self-management approach)

The driving idea with this structure is to make a game that is powered by exercise, positive action and thinking. The user's need to advance their avatar in the main game encourages engagement with other iMC units. The advantage of an ambiguous core module is that a wide variety of users can engage with the game, not just people who have existing medical issues. This wider appeal can help build a larger community, while supplying education about preventive life-styles. The patient can choose between an individual activity and a group activity. This choice possibility should always be open, in order to both give the opportunity to the patient to change his/her mind. Specific learning outcomes can be achieved by targeted mini-games.

### 5.2.3. End users and workflow

This game platform presents a modular design with a common core module which connects to more specialised modules, specialised content will change the focus from standard fitness activities to disease prevention or management.

### **Core Module**

The core game module stores an avatar, acquired items, resources and achievements, a complete player profile. This module communicates with multiple external data sources, which contain quantifiable data on user activities, this data is analysed and converted into resources for use in the game, for example:

The health avatar records steps taken, the game reads this data in and converts it into a resource such as physical effort points.

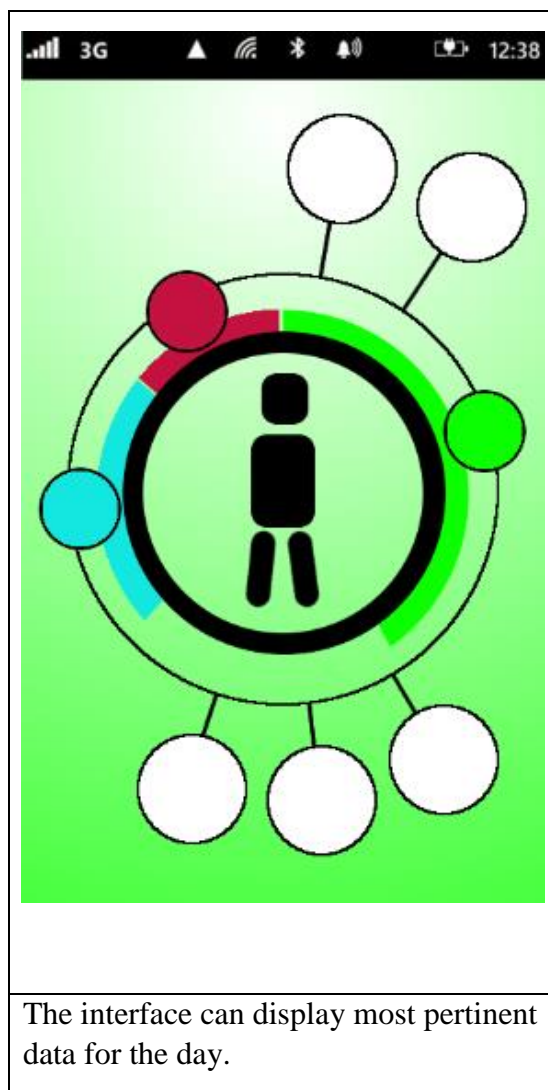
It is possible to link the serious game with other branches of the app (e.g., psychological profiles in WP6, or info from the PHR).

This approach allows us to add or remove linkages to other modules in the project dynamically making the resource gathering scalable and dynamic.

The core module then provides access to other modules.

Examples of possible modules:

- Social (Lobbies or communal communication tools)
- Competition/Challenge/Primary Game (Effects avatar status, achievements, rankings & rewards).
- Shop (Spend rewards earned in Competition).
- Passive Resource gathering (Draws data from other apps and converts them to resources).
- Active Resource Gathering. (Simple educational mini-games that earn resources)



### **Social Module**

This could take the form of a lobby/town themed space. An example of a social lobby would be the Wii U's plaza.

The user's avatar would join other players avatars in an open space, these other avatars could be added by pre-defined social groups or by encounters in events.

Chat and group forming could occur here, social interactions earn social points. Players can show off costumes and achievement medals/ribbons here, there is also an option to add player holdings such as a small plot to host



rewards and vanity items. A user can build up their holding to show off status and achievement, a mechanic of holding degradation if plot is left idle for a length of time would make any publically displayed items degrade, not to the point of loss, but enough to encourage a user to interact with them to return them to a pristine and shiny state. An example of the degradation mechanic at work is Farmville, where crops spoil if left unattended, and yield is reduced.

Here in the Lobby patients or individuals can select people they want to play with. Additional resources may be earned by “expert” users involving naïve users in their team. Team members can also send a certain amount of resources to each other.

### **Shop**

The shop allows the user to expend their rewards from the main game to purchase costume pieces or items for their social plot. The shop could also provide the interface for equipping items. Many contemporary games employ this feature, allowing players to customise their avatar to create a stronger bond with the avatar, other motivations include showing off progress to peers through the wearing and display of rare or exclusive items.



*Figure 5: Shop mock-up.*

### **Competition/Challenge/Primary Game**

This module can be any compelling game that utilises the resources gathered through the core module, this game can also use the user’s avatar as the protagonist(s). As we wish for our user to engage with this game for some time, we will need to generate content/challenges procedurally to ensure the user never feels they have completed (finished) the game.

A simple example is an Olympic themed game with sandbox features, a narrative can be established as part of the main games story, which could include a backstory of an underdog fictional team up against the best the world has to offer in an international sporting completion. The user and friends work together to best Artificial Intelligence (AI) teams to progress through the story. The user however can at any time compete against other players and player teams in an open-ended competition.

The competition is filled with events such as marathons, cycling races and rowing, effort related resources gathered from the core module are traded to push the user’s avatar, or a group champion avatar along the course. In the open world competition there will be multiple automatically generated events happening in parallel, but not limited to running races or cycling races, meaning there is always one to join. Players receive rewards and feedback upon completion (e.g. currency for the store).

Consideration for users who consistently do poorly must be a priority, the intention is to provide competition and challenge, but we may end up demoralising the losers of events. An approach to result reporting could be developed to promote the positive aspects of their participation. An example of this type of approach would be when a team of 5 people complete an event, only the top contributor gets a special notification or reward, while people's specific contributions are not quantified, this anonymises poor performers. People who did not get the special reward for best contribution will get other motivational notifications and rewards such as for personal bests, highest ever score or personal goal completion.

The process of locating and joining events will be simple and intuitive, filters will help players find a suitable event that still has available places. Other features will include a filter to show any open event with a friend in it. Once the race begins, the app will visualise the player's progress as either a simple percentile bar or a more elaborate mini map with a player position icon.

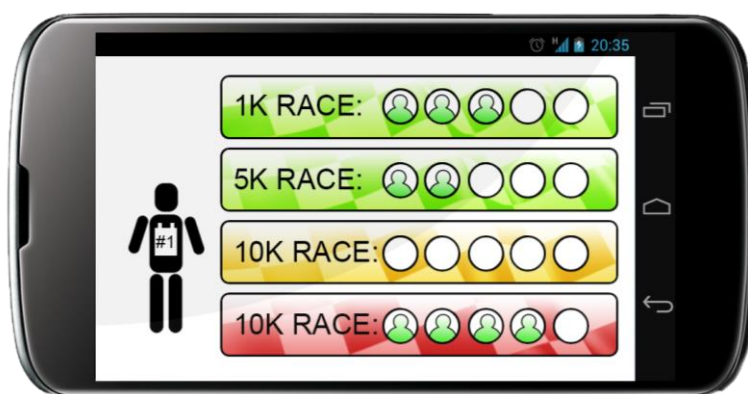


Figure 6: Mock-up of ranking system.

There will be a ranking system with multiple awards, this may be broken down by country or region so more participants can win in their category. Some are for cumulative scores, but most should be based on a set time period, e.g. who walked the furthest, who walked the fastest, who completed the most events, who earned the most rewards in March. This method allows many chances for users to succeed at something, and negates the situation where a user has a bad week/month that brings down their overall average.

“You were the fastest walker in England this month!”

### **Resource Gathering**

This is an active process where users can select mini-games, which offer resource rewards. This provides an opportunity for users to gather resources they have not earned through other modules such as MHA and iMC. The games can all be aimed at promoting healthy/positive lifestyle choices, games such as match3 games where you are trying to destroy cancer cells, an infinite runner where the user jumps and ducks to avoid junk food, which makes their avatar fat and hit health food, which slims them down.

Designing the mini-games component to be modular we can add in new games as the old ones loose popularity, greatly increasing the life cycle of the platform. These games are intended to be very simple in design, quick to play and un-ranked.

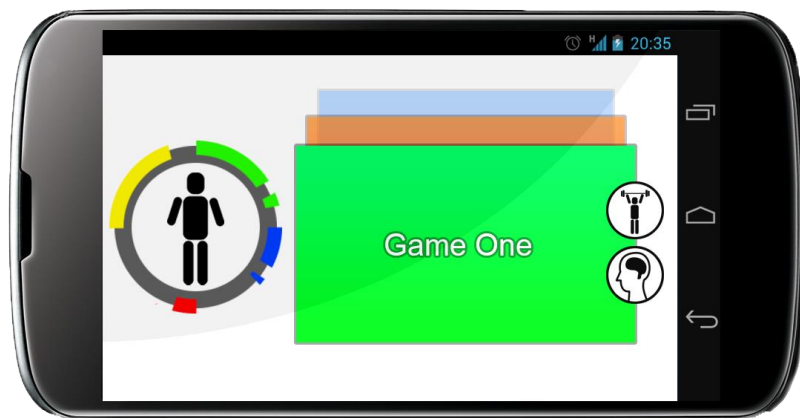


Figure 7: Mock-up with overview of collected resources.

The mock-up above shows how the game gives an overview of resources already collected, so that the user can choose a mini-game to supplement a resource that is lacking, for instance the user may flip through games until they find one with social rewards, indicated by resource tags. An example of a game or activity that generates social points would be any activity that requires cooperation. Social points are allocated simply for participating in social activities, and not as rewards for specific responses to avoid influencing people's interaction and responses.

#### 5.2.4. Mini Games Examples

The Mini Games described in the following sections are examples that might be build or not. During the lifetime of the project it will be discussed, which of these Mini Games can be build according to the resources of the project. The listing of these examples does not imply that all these Mini Games will be developed.

### 1. Infinite Runner

#### *1.1 Diet Dash, design!*

##### *Summary:*

Diet dash is an infinite runner game the user's avatar (hopefully imported from IMC platform) is participating in a running event. There is no backstory to this event.

The objectives of this game are to condition the user to associate unhealthy diet options with weight gain and energy loss. The user is motivated to beat their old best distance, or beat a friend's best distance.

##### *Gameplay*

The user's goal is to achieve the longest run they can. The runner moves at a constant speed through an infinite level with jumping platforms (procedurally generated). The run continues while the player still has energy, which diminishes over time. The player can replenish energy by running over items of food.

Food comes in various forms, healthy through to very unhealthy. Healthy food adds energy and less weight (fat) to the runner's energy and weight bars. Unhealthy food adds energy but considerably more weight. The energy loss rate is affected by the runner's weight (more weight, faster energy loss).

The player must quickly react to the random terrain and the choices of diet along those paths while moving at speed.


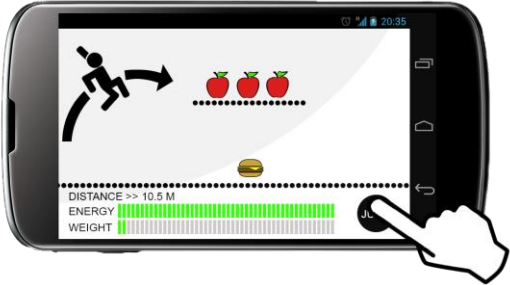
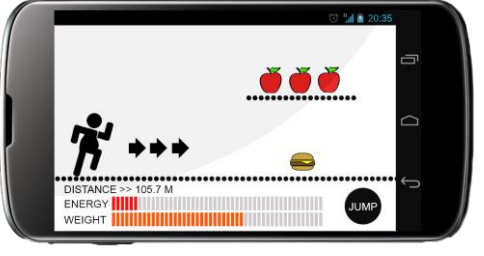


### Mind-set

The player has to make quick reaction judgments of path finding and diet, the player should be feeling challenged and be under pressure to react quickly and well. This game is not designed to elicit many emotional responses other than pride at achieving a new high score or beating a friend's high score.

## 1.2 Technical specifications

### Screen shots

	
<p><i>Figure 8: Player (fixed to left of screen) sees options coming in from the right. The player asses their options.</i></p>	<p><i>Figure 9: Player reacts to the situation, pressing the jump button to attempt to land on the raised platform.</i></p>
	
<p><i>Figure 10: The player is low on energy and high in weight, the avatar is visually fatter and energy is draining faster.</i></p>	

### Controls

The in-game controls (excluding menu UI) for this game are a single jump button located onscreen. The touch screen of the mobile device allows the user to interact with this button. The button has a single action, to cause the player to jump by a fixed height (Fig 10).

### Mechanics

**Weight and energy balance**, this is achieved by having running decrease energy and weight (slower for weight). To ensure there is a chance to keep running, healthy food always provides more energy than it takes to run off the weight it adds, some foods will be neutral and others will leave an overall energy loss. Eating while at full energy will simply add extra weight (adding more challenge)

**Infinite world**, this mechanic is achieved by procedurally adding food items and platforms. This mechanic can also be modified to gradually ramp up difficulty by adding less good food or simply less food overall.

**Competition and ranking**, this can be achieved by logging distances into an offline high score table and letting users enter their initials to tag their run. This kind of scoring encourages users to hand their mobile device to a friend and say “beat that” but could be augmented by an online high score system later if resources allow.

## **2. Puzzle**

### ***2.1 Food Finder, design***

#### *Summary:*

The user’s avatar is a waiter at a restaurant, a queue of hungry customers arrives, each with a list of requirements and looking for a recommendation from the menu.

The objectives of this game are to subtly educate users on nutritional content of common foods and meals while at the same time providing a fun and challenging activity with visually compelling mechanics and characters.

#### *Gameplay*

The user’s goal is to make as much money from tips given by happy customers as they can during the round.

The user achieves their goal by selecting from the menu a meal that matches as many of the current customer’s requirements as possible (Fig 2.2) and then dragging and dropping the item onto the customer (Fig.2.3) to receive feedback and rewards (Fig 2.4). The user then moves on to the next customer. The round is timed and there are an infinite number of potential customers.

The customer’s requirements are displayed on screen and come in the form of “Likes and Dislikes”. In this example six of these requirements are generated, three “likes” and three “dislikes” (Fig 2.1). The customer will respond positively for a menu selection that meets their “likes”. In this specific example the customer likes food that contains the colour red, is under 500 calories and is low in carbohydrates. The customer will react negatively to food that is soft, has tomatoes and is sweet.

The user is scored on the amount of tips they receive in the allotted time, the happier a customer the more they will tip the player. Their character smiling or frowning, giving simple and easy to understand visual feedback represents customer’s happiness. Bonuses may be earned from the restaurant for getting runs of happy customers e.g. five very happy customers in a row earns the player £100 employee of the month reward.

The user can be ranked on multiple conditions, highest ever amount of money earned in a round, most happy customers ever in a round, longest extremely happy/moderately happy/satisfied customers streak etc.

#### *Mind-set*





The player is being helpful, decisive and knowledgeable. The player is put in a position of responsibility for their customer’s happiness as well as their own financial success; the player is rewarded for being mindful of the happiness of the customer, hopefully fostering positive



emotional responses. The player may also experience guilt at failing to please a customer, which it is hope will motivate them to think more before making a decision in the future.

2.2 Technical specifications

Screenshots

	
Figure 11: A new customer is active (larger, cantered) and has 6 requirements.	Figure 12: The user uses their finger to select a salad.
	
Figure 13: The user drags the salad onto the active customer.	Figure 14: Positive matches are highlighted with stars, negative matches remain visible. (subject to change)

Controls

The in-game controls (excluding menu UI) for this game are a simple touch screen drag and drop. The user uses their finger to select an item of food from the active menu and drags it to the active customer, releasing their finger to confirm the action. If the menu needs to be larger (adds search mechanic), a scrolling horizontal swipe action will be used to move the menu left and right, then a horizontal swipe action to push the central item (in this specific UI layout can change if needed) down onto the active customer to make the selection.

Mechanics

**Difficulty and reward:** difficulty can be changed by altering the balance of “likes” to “dislikes”, either adding more “likes” to reduce the chances of a negative result or vice versa. More difficult customers will give better rewards if satisfied.

**Customer requirements:** this mechanic can be achieved by randomising the menu items (food) on display, and then picking one of those items at random and selecting a variable number of its properties (based on difficulty) to be the customers “likes” requirements, then randomising the “dislikes” requirements while making sure none of them are properties of the selected menu item. This method ensures one perfect menu choice.

**The menu:** the menus is simply a database of meals, a picture of the meal to be displayed then a list of properties such as calories, salt content, fat content, texture, sweetness or colours.

### **3. Connect 3 Cell Game**

#### ***3.1 Pop Culture (pun on cell cultures), Design***

##### *Summary*

The player is a doctor fighting cancer (or infection) inside a patient's body. The player has an arsenal of targeted drugs to fire at the invading cells in order to destroy them. The player can also charge up a super weapon (radiotherapy?) to kill even more invading cells.

The objective of this game is simply casual gaming fun, there are no meaningful learning outcomes to be had unless we can squeeze in some science.

This particular type of game is extremely common: there is nothing unique about this version.

##### *Gameplay*

The player must complete a course of treatment to win the level. There are a fixed amount of invading cells per level, the cells simply move in from the left side and slowly move towards the right. The player loses if the invading cells get all the way across (see Fig 15 to Fig 17).

To prevent the advance of invading cells, the player attacks them with their anti-cancer drugs located on the right side of the screen. The player launches coloured pills at the invading cells to kill them, when a pill of a certain colour hits the cells it slots into the incoming mass, if there are three or more cells of the same colour joined together, then all cells in that colour chain are destroyed. After firing a pill a new pill moves down a conveyor into the firing position ready for the next shot. Play continues until all invading cells are destroyed or the player loses the game.

Further development may see the introduction of special cells and power ups such as the radiotherapy beam; special cells may become resistant to pills and need to be broken free by destroying cells around it etc.

##### *Mindset*

The player is looking for a simple colourful distraction, he is challenged by the pace of the ever-moving mass of cells but never stressed out, there is little to no intended emotional investment in this scenario. There is a chance of frustration if we have fixed level design that gets progressively harder, a player may become stuck on one level, this may also motivate them to keep playing until the challenge is bested or cause them to quit due to frustration.

#### ***3.2 Technical specification***

##### *Screenshots*



Figure 15: Cells beginning their advance to the right.



Figure 16: Cells Moving further right.



Figure 17: Cells reach the far right, game over!



Figure 18: User taps screen to set target vector for pill.

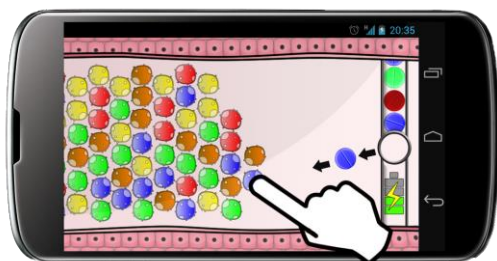


Figure 19: Pill is launched towards player's target tap.

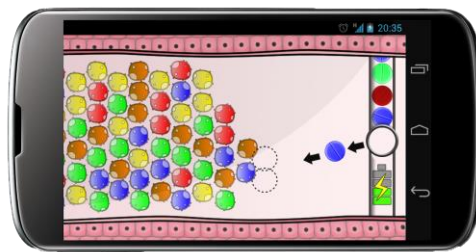


Figure 20: The pill will join the advancing grid: there may be more than one suitable slot. If after collision pill is equidistant from both points, choose by random.

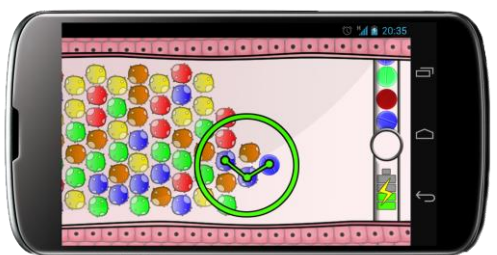
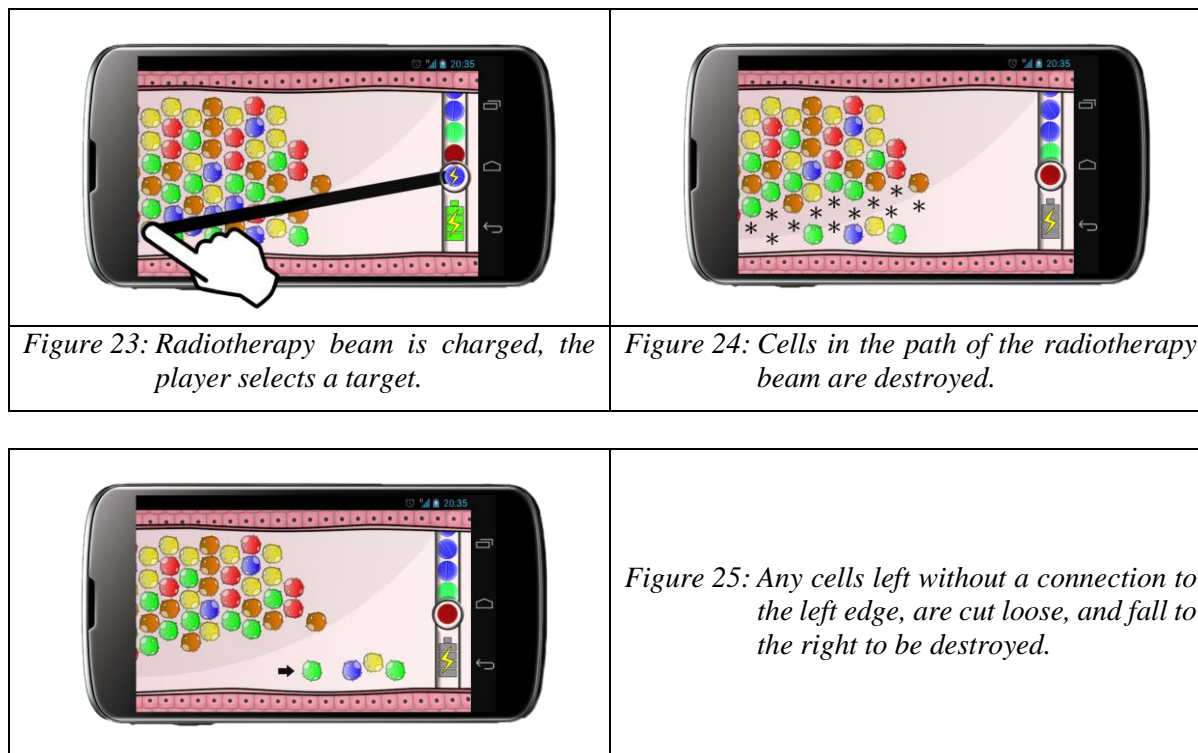


Figure 21: The pill joins the grid and makes a 3+ chain.



Figure 22: Cells in a 3+ chain are destroyed.



### Controls

This game uses a touch screen and single click interface (excluding menu UI). To fire a pill a user simply single taps the screen where they would like the pill to go. Once the tap event occurs, the pill is launched on a vector that will move it in the direction of the tap event from its start point.

### Mechanics

**Level design:** to keep the game from becoming repetitive, we can implement levels and we can then use one of two techniques to design levels. Either we explicitly define levels, which will give us a finite number of levels and mean a sizable workload to design and test these levels. The other method is to design levels procedurally. There are many approaches to procedural design but it would be feasible to create a set of rules and patterns that could make a challenging level of varying difficulty.

**Cell destruction:** once a pill hits and fits into the grid of cells and pills it queries its neighbours to find out, which have the same colour as it, those cells or pills then do the same, every cell of that colour is stored, if the number is above two then all cells in the chain are destroyed. Any cells left without a connection back to the far left of the screen, are cut loose and fall faster off to the right, where they are simply destroyed.

**Radiotherapy beam (optional):** many games have power ups, the radiotherapy power up charges a little each time you fire a pill, once fully charged it unleashes a powerful focused beam that destroy all standard cells and pills in its path.

## 4. Who wants to be healthier?

The aim of this mini game is to promote interest in health topics and increase knowledge in a funny way.

Quiz game similar to who wants to be a millionaire. Questions are of increasing difficulty and can regard general health or be focused on specific topics of self-management for patients on a time-limited basis. A link to the Personal Health Information Recommender can be inserted at the end of each question (e.g., when you answer wrong or when you take a long time to answer). Participants can ask 3 times for help (50%-50%, consult an article in the PHIR before answering, ask a team member or random participants).

## **5. Food tournament**

Participants can choose whether they want to play for a single meal (and choose a meal) or for a whole day plan (5 different levels with breakfast, morning snack1, lunch, snack2, dinner) or special meals to move to the next world (e.g., Christmas meal or Easter meal).

Each session has a certain duration. Ingredients move on the screen. There are different indicators (e.g., grains, proteins, good fats, bad fats, vegetables, fruits, calories). The number of calories and nutrients can be set up depending on the recorded physical activity of the player, or on therapies for patients, or on the disease, otherwise they will be set on a standard.

Special indicators may be set up in case of special diet (e.g., avoid bloating or increase particular vitamins). The player must touch moving foods in order to reach a minimum level of the indicators and keep it within a maximum indicator before the session ends.

When the player plays well, he can earn bonuses, which can only be sent out to team members and on a limited amount. In this way, we favour players grouping in teams and interacting. Best teams of the day, week or month get extra bonuses or can play with special facilitation (e.g., play a session with more healthy foods). Examples of bonuses can be bad fats neutralizer bonus, vitamins boost bonus, omega3 power caps, de-bloater bonus, crunchy fibres tab, which they can use at the end of the game to compensate for indicators which are above or below the desired range.

Difficulty can be increased e.g., by increasing the number of ingredients and indicators, building up weekly meal plans based on single sessions played over time.

Indicators can also be used on a global game basis and can be modulated by physical activity recorded (or TBD sports hours manually entered). E.g., physical activity burns fats in the fat indicator or extends tolerance in the grains indicator.

### **5.2.5. Data**

- From the participants of the platform

### **5.2.6. Interaction with other user scenarios**

This will be used as a means

- For the account data of a user from the iManageCancer platform (check if the person has an account or not).
- From the PHR: Event-Flag, if there is an important medical intervention.
- For behaviour monitoring and recommendations for behaviour changes. Due to the limited amount of behaviour data, recommendations will need to be generalised and anonymized to avoid giving incorrect direction to a user. For example, a user displaying low activity usage, may receive an informative notification about increased risks for people with low activity lifestyles, but not explicitly indicating the user.

## 6. Ethical, legal and privacy constraints

The vision of iManageCancer is to provide a platform to patients with cancer that will help them to manage their disease more actively. Such a platform needs to deal with personal data of patients. For the processing of such data, the Data Protection Directive and its national transposition will be applicable as long as the upcoming Data Protection Regulation does not substitute the Data Protection Directive. At that time new regulation may occur. Nevertheless, data protection issues have to be considered both from a legal as well as from an ethical perspective.

### 6.1. Collaboration with MyHealthAvatar

There will be a close collaboration with MyHealthAvatar (MHA) project. MHA is a research project funded under FP7 by the European Commission. MHA is proofing the concept for the digital representation of patient health status. The platform is designed as a lifetime companion for individual citizens that will facilitate the collection of, and access to, long-term health-status information. The promises are to acquire population data to support clinical research and to support innovative medical care. In addition to data access, it also gives access to integrative models and analysis tools, utilizing resources already created by the Virtual Physiological Human (VPH) community. Overall, MHA will contribute to individualized disease prediction and prevention, and support healthy lifestyles and independent living. In this respect, there is a close linkage to iManageCancer and the possibility of exploitation of MHA within iManageCancer.

Part of the exploitation is the legal and ethical framework developed within MHA and described in D11.1 of MHA (The ethical and legal framework of MyHealthAvatar)<sup>21, 22</sup> This deliverable provides an overview of the applicable European data protection framework and relevant ethical guidelines. In addition, guidelines for patient-specific computer-based models are presented in this deliverable. It provides “an important reference for medical professionals to make personalized clinical decisions without compromise ethical and legal issues that might be raised or come to pass throughout the development of the models or in the treatment of patients. The possibilities to find, retrieve, and reuse all of the data, information and knowledge of patients and their physiological attributes have a clear potential to engage legal and ethical concerns.”<sup>23</sup>

The following bullets give a summary about the possibilities to find, retrieve, and reuse all of the data, information and knowledge of patients and their physiological attributes as given in this deliverable of MHA.

1. The processing of sensitive personal data is prohibited, except if there is a legal basis such as Article 8 (4) of Directive 95/46/EC or the data subject has given informed consent, which is also an ethical doctrine.
2. The Data Protection Directive sets the onus upon the data controller to meet the requirements of the need for a fair processing, which includes the need for limited retention, de-identification of data and data minimization.
3. Data security must be ensured.
4. Legal and ethical analysis of the scenarios and use cases need to be done.

As a consequence, the legal and ethical framework of iManageCancer needs to adhere to the 4 given bullets, exploiting the corresponding framework of MHA. In chapter 6.2 of this deliverable the specific requirements for the different scenarios are given.

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<sup>21</sup>

[http://www.myhealthavatar.eu/wp-content/uploads/2015/03/MHA-Deliverable\\_D11.1\\_Legal\\_and\\_ethical\\_framework\\_final\\_version.pdf](http://www.myhealthavatar.eu/wp-content/uploads/2015/03/MHA-Deliverable_D11.1_Legal_and_ethical_framework_final_version.pdf)

<sup>22</sup> MHA: D11.1 The ethical and legal framework of MyHealthAvatar

<sup>23</sup> MHA: D11.1 The ethical and legal framework of MyHealthAvatar, chapter 7: conclusion



Consent forms for uploading (participating) and for processing data are provided in Appendixes 3 and 4 of this deliverable. In addition, in D11.2 of MHA<sup>24</sup> a survey was carried out to analyze the strengths and weakness of the data protection framework in supporting the patient scenarios of MHA. Patient organizations, regulatory authorities, researchers, consumers and industry associations gave answers to this questionnaire. In summary “stakeholders in general welcome an overhaul of the current data protection framework and the potential for harmonisation a regulation would bring. However, they also warn that some issues need to be considered, e.g. the issue of broad consent and (administrative) obligations for data controllers that could be seen as detrimental to research and not necessary for data protection purposes”<sup>25</sup>. The heat map shown in the figure below is agreed by MHA.

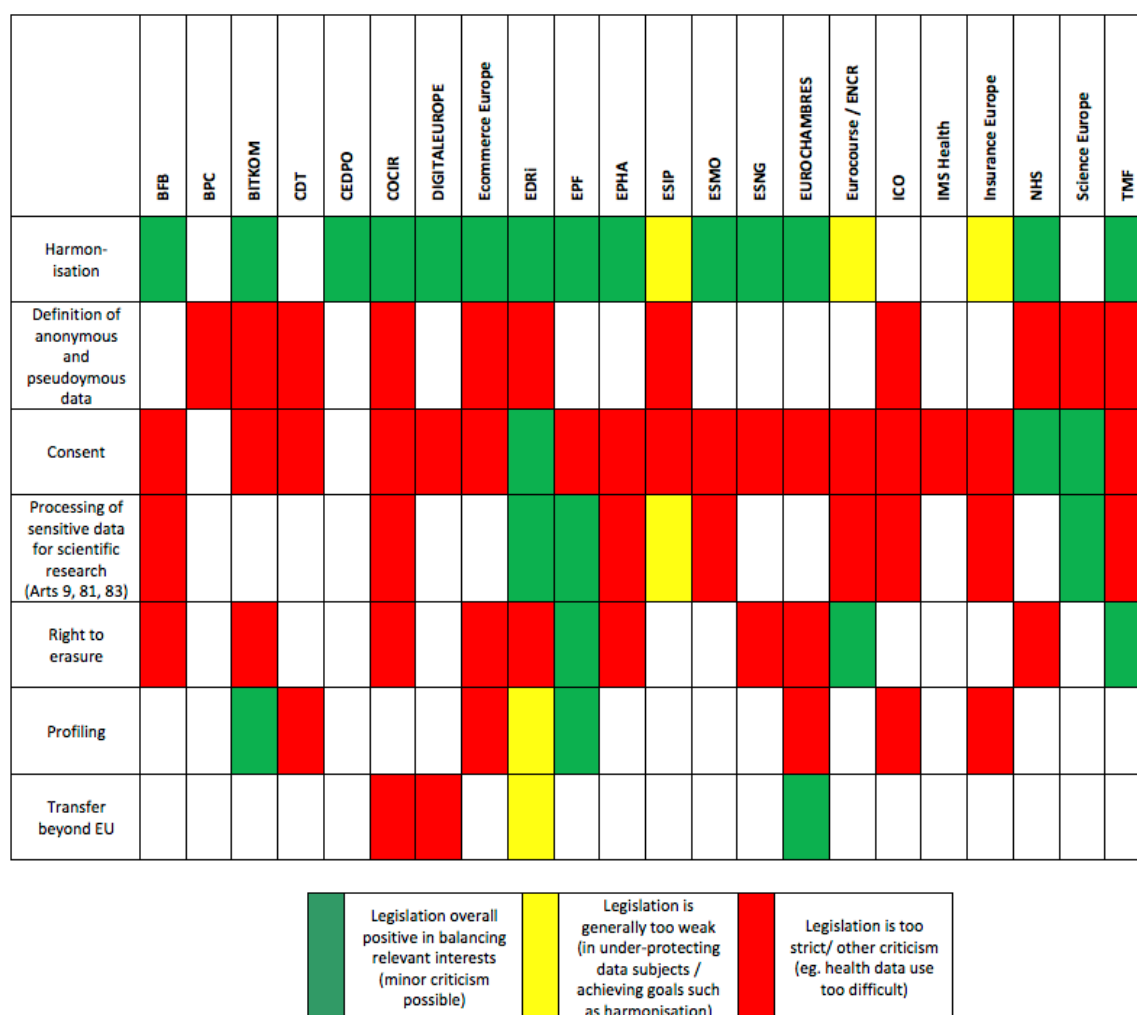


Figure 26: Heat map of stakeholders' position. (figure, taken from MHA: D11.2 - Survey on strengths and weakness of the European data protection framework in supporting the patient in scenarios like MyHealthAvatar)

<sup>24</sup> MHA: D11.2 Survey on strengths and weakness of the European data protection framework in supporting the patient in scenarios like MyHealthAvatar

<sup>25</sup> MHA: D11.2 Survey on strengths and weakness of the European data protection framework in supporting the patient in scenarios like MyHealthAvatar, chapter 1: executive summary

iManageCancer will follow as closely as possible the legal and ethical framework developed within MHA and described in D11.1 of MHA since the main issues are common in the two projects. Some of these issues that will be handled in iManageCancer include:

*Privacy and confidentiality:* iManageCancer will respect patient privacy and will design all technological elements based on respecting the patient's ethical right to control their health information<sup>26</sup>.

*Equity:* The project will ensure that if helpful, most cancer patients, even those with low computer literacy, will be able to use this technology and enjoy the benefits. This will also be taken into consideration in the design phase.

*Integrity:* While patients will have obviously control over their data input, they will be well informed at the same time, that accurate and complete information is critical in order to achieve the goals of the platform in assisting the self-management of cancer as to improve the patient-clinician communication.

In the following section more legal and ethical issues are discussed in the context of the individual scenarios of the iManageCancer project.

## **6.2. Scenario specific ethical, legal and privacy constraints**

In addition to the general description of the ethical and legal framework, the following paragraphs describes for each of the scenarios specific requirements, if necessary.

### **6.2.1. Scenario PHR and eDiary**

The PHR is a central element of the iManageCancer platform. A patient using the PHR has the ability to run different applications that are defined within this deliverable. A most important tool is to upload data to the PHR and to use an eDiary. Every patient registered to the platform can upload all kind of data into his PHR. As these data are private and sensible, specific requirements for data protection need to be installed. These requirements are as follow:

1. A roles and rights management system is installed that controls access to the iManageCancer platform.
2. Secure upload of data via https protocol.
3. Data need to be stored in an encrypted way.
4. The patient has full control about his data. He can upload, edit and delete his data at any time without giving a reason.
5. The uploaded data belong to the patient.
6. Secondary usage of data is only possible after anonymization of the data.
7. Contracts between the patient (data provider) and the data user need to be signed for secondary usage of anonymized data.

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<sup>26</sup> Matthew Wynia and Kyle Dunn, Dreams and Nightmares: Practical and Ethical Issues for Patients and Physicians Using Personal Health Records, The Journal of Law, Medicine & Ethics, Volume 38, Issue 1, pages 64–73, Spring 2010.



8. The patient can share his data with other people at any time for a pre-determined time. These people are not allowed to download, edit or delete the data. They gain only the allowance to read the data after signing a contract with the patient.
9. An audit trail needs to be installed. The patient will be able to see at any time who did do what and at which time with his data.
10. eConsent needs to be part of the platform to allow these functionalities.
11. iManageCancer guarantees the storage of the data for the lifetime of the project.

The following figure explains the control of data by the patient.

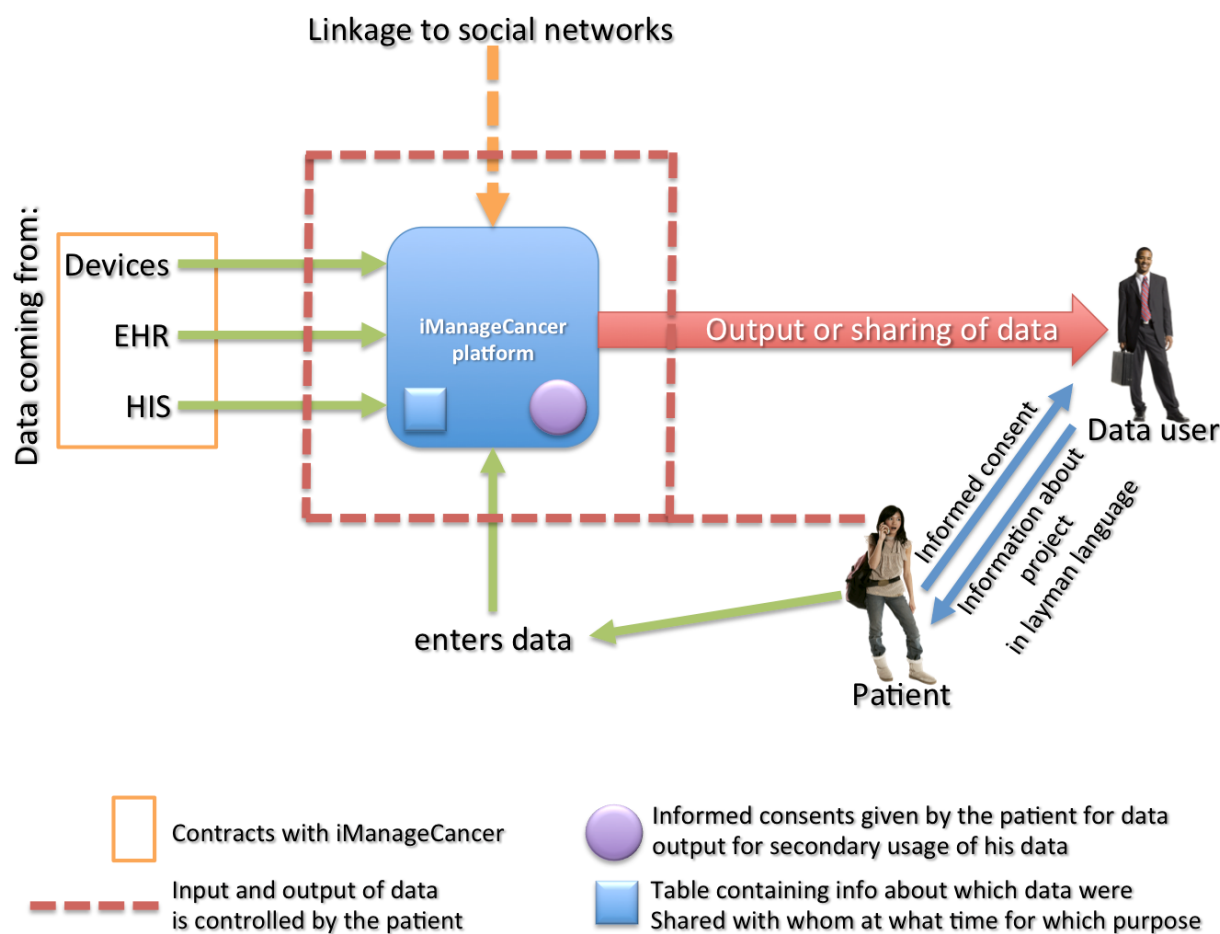


Figure 27: Schematic view of data control by the patient.

### 6.2.2. Scenario Health avatar

The health avatar scenario is a perfect complement to the PHR scenario. It offers a one-stop service for the patients in terms of data collection, and self-management services, such as monitor, record, and education. The system will support the visualization of the behaviours and daily activities of the patients. It will function as a supportive environment to empower the patients in looking after their own health, raising their self-awareness of any potential risk of developing diseases while encouraging their healthy lifestyles in terms of doing routine daily exercise, stopping smoking and controlling their diet.

From an ethical perspective this scenario will empower patients by giving them a role of monitoring and managing their own health. Legally this scenario needs to take into account that patients will use private data stored in the iManageCancer platform. For that purpose, the same requirements written in the PHR and eDiary scenario need to be respected. Specifically the patient has full control about his data. He can upload, edit and delete his data at any time without giving a reason to do so. It must be assured that data upload from devices and apps will be correctly linked to the specific patient. They will be encrypted and only accessible to the patient, as long as he does not allow sharing or secondary usage of the data. The developed tool allows only the usage of the patient's specific data. It is not possible to analyse data from other patients. This is controlled by the roles and rights management system of the platform.

Patients need to get informed that the supporting intervention, the education intervention and the risk assessment are done within a research project and that the researchers of iManageCancer are not responsible for the recommendations given as long as the tool is not validated and certified according to the medical device law.

### **6.2.3. Scenario Chemotherapy management**

The main goal for this scenario is to produce prototype predictive model(s) able to stratify patients into low and high-risk groups with respect to serious adverse event(s) such as febrile neutropenia. It is envisioned that, following appropriate clinical validation, the risk score(s) produced should improve the clinician's ability to intervene before such an event occurs, as well as increase patient awareness with respect to their disease state.

The same requirements for data safety and security as given for the PHR apply for this scenario. In addition, patients need to get informed that the predicted risk is provided within a research project and that the researchers of iManageCancer are not responsible for consequences the patient takes based on the predicted risk score as long as the tool is not validated and certified according to the medical device law.

### **6.2.4. Scenario Management workflows**

The main idea of this scenario is that patients will be guided through specific aspects of the disease management by the application and receive support in decision making at certain points.

The same requirements for data safety and security as given for the PHR will also apply for this scenario. Patients need to get informed that the recommendations given by the tool are provided within a research project and that the researchers of iManageCancer are not responsible for consequences the patient takes as long as the tool is not validated and certified according to the medical device law. In comparison to the chemotherapy management scenario, the risk within this scenario is lower as there is always feedback to supporting people that can influence the decision taken by the patient. To allow this, the patient needs to give consent that his/her supporters are allowed to get information about his/her decision.

### **6.2.5. Scenario Personal health information recommender**

The Personal Health Information Recommender is targeted at improving the opportunities that patients have to inform themselves in the internet about their disease and possible treatments, and providing to them personalized information and recommendations.

Most important from the legal perspective is the need to inform patients about the restrictions of answers given by the tool as long as the tool is not validated and certified.

### **6.2.6. Scenario Drug self-management**

A mobile application for drug self-management will be developed in the iManageCancer project as a patient-centered approach. This app will enable patients to successfully manage an increasing number of prescriptions and avoid dangerous drug interactions and side effects.

From a legal perspective, it is important that nobody can access the medication plan of a patient without having allowance by the patient given by eConsent. All changes of the medication plan, including drugs and dosages, will be recorded in the audit trail of the platform.

In case of detecting drug-drug interactions or contraindications, the patient will receive a corresponding message including a suggestion to contact his physician to clarify the situation. He will be notified to do this immediately and not changing the medication plan by himself without feedback from his treating physician.

### **6.2.7. Scenario Decision aid to support patients' participation in consultation**

Here, patients are guided through pros and cons of the choice prior to a consultation with their physicians and, in parallel, emotions associated with each risk or benefit are elicited. Prior to the consultation, the system reminds the patient to perform a whole or a partial psycho-emotional assessment. At the end of the decision aid, patients can write up a list of questions to ask during consultation.

Data that are stored as a result of the psycho-emotional assessment, are very sensitive data and all requirements given in the PHR scenario need to apply here. If the patient wants to share this data with his physician, he/she can do this by using the eConsent tool.

### **6.2.8. Scenario Psycho-emotional status and management**

iManageCancer will use standardized psycho-behavioural questionnaires in order to monitor the psycho-emotional status of cancer patients and their individual resources in coping with cancer. This tool will allow to tailor information provision and services in accordance with patients' preferences and attitudes and to develop individualised self-management action plans.

Data that are stored as a result of the standardized psycho-behavioural questionnaires are very sensitive data and all requirements given in the PHR scenario need to apply here. If the patient wants to share this data with his physician, he/she can do this by using the eConsent tool. Even if the questionnaires are validated, the results may cause psychological problems by the patient and psychological support might be needed for the patient. To use the tool the patient needs to be informed beforehand about this possibilities and he/she should get the advice to ask for psychological support in such a case.

### **6.2.9. Scenario Family resilience evaluation**

The main goal for this scenario is to create a tool that is able to measure the family resilience in order to individuate the critical areas that can deplete the patient's resources and to foster interventions that empower the whole family system. Within this scenario data of the patient and the whole family will be investigated. To make this possible, sharing of data between members of the family must be allowed by all of them. This can be done by the usage of the eConsent tool. It must be stated that this sharing of such sensitive data will only be allowed for usage by this tool. All legal requirements concerning data safety and security as given for the PHR scenario does apply.

Depending on scores in different areas, suggestions on actions are activated. Whenever, recommendations consist on small changes in the family dynamics, they will be provided by means of the platform. When severe criticisms appear, a suggestion to contact a health care professional will be shown.

#### **6.2.10. Scenario Health enquiry**

This scenario describes the usage of a generic tool, which allows clinical experts to create dynamically standardised questionnaires for the patients and their supporters (e.g. family members).

This tool per se is from a legal and ethical perspective not critical. Only in case the developed questionnaire is used to collect data and uploading them to the iManageCancer platform, the same legal requirements need to be fulfilled as described in the PHR scenario.

#### **6.2.11. Scenario Life style and vital sign monitoring**

In order to provide recommendations towards the optimisation of patient's life style, quantified information about physical parameters and activity can be exploited for a decision support. These data can be collected and monitored with the help of sensors and medical devices. It comprises the measurement of the body weight and patient's vital signs (blood pressure, pulse, body temperature) as well as the tracking of patient's activity. Results can then be used in dependent scenarios such as patient self-management scenarios.

As within this scenario, data are collected, all legal regulations given in the PHR scenario do apply. The usage of thresholds and trends, provided by patients' data, may cause fear or makes the patient anxious. For that reason, it is necessary to inform the patient to contact his treating physician for consultation. If the tool is used to automatically warn the doctor about critical parameters and their trends, the patient needs to allow this beforehand by using the eConsent tool.

#### **6.2.12. Scenario Data analysis and data mining**

The data analysis and data mining scenario aims to extract information from the diverse data of iManageCancer and transform it into an understandable structure for better knowledge and further use. Smart data analytics will provide mechanisms able to identify patterns or trends in data, screen pre-frailty states and provide different views of data for new management plans.

This scenario needs to use data from many patients. For that purpose every patient, who allows the usage of his/her data in this scenario, needs to explicitly agree and give his consent by using the eConsent tool. Data will be anonymized before the developed tool can use them. Results of the analysis and data mining might be send to the patient, if he wants to be informed about such results.

#### **6.2.13. Scenario Visualisation**

The services provided by this scenario will visualize data from self-monitoring and interpret them by visualizing individual risks.

From a legal perspective, all legal regulations for data security and safety do apply that are described in the PHR scenario. The visualization of individual risks by the data may cause fear or makes the patient anxious. For that reason, it is necessary to inform the patient to contact his treating physician for consultation if he uses this visualization scenario.

All intervention recommendations should be regarded as research and the patient needs to be informed about this fact, meaning that nobody from iManageCancer will take responsibility for consequences taken by the patient that are based on such a recommendation.

#### **6.2.14. Scenario Patient – Doctor and Patient – Patient Interaction**

This scenario has to do with methods enabling patients to communicate between each other and with their doctors. There is the possibility of external communication with other social platforms like Facebook and the possibility of internal communication within the iManageCancer platform.

In case of linking to external social networks and sharing data between iManageCancer and such platforms, the patient needs to be informed that iManageCancer cannot take responsibility for data security and safety for his/her data and that the patient him-/herself is the only responsible person for data safety and security of his/her data. iManageCancer is unable to qualify and quantify the risk of such a linkage.

In case of internal communication between members of the iManageCancer platform, all legal regulation need to be taken into account that are described in the PHR scenario.

#### **6.2.15. Conclusion**

Most important for all the different scenarios is that the legal framework of the PHR and eDiary scenario as described above needs to be respected by all other scenarios. In this context eConsent is an important tool that allows the user to adhere to the legal framework. Therefore, this tool is one of the most important ones in the iManageCancer platform to allow a smooth run of all scenarios described for the iManageCancer platform.

In addition, transparency of the platform for citizens and patients is of utmost importance. The users need to know what happens with their data and they need to be convinced that they themselves are the owner of the data and that they can upload, edit, destroy or share them as they want to do. For that purpose, a good description of the platform needs to be disseminated and easily accessible through the website of iManageCancer.

## 7. Conclusions

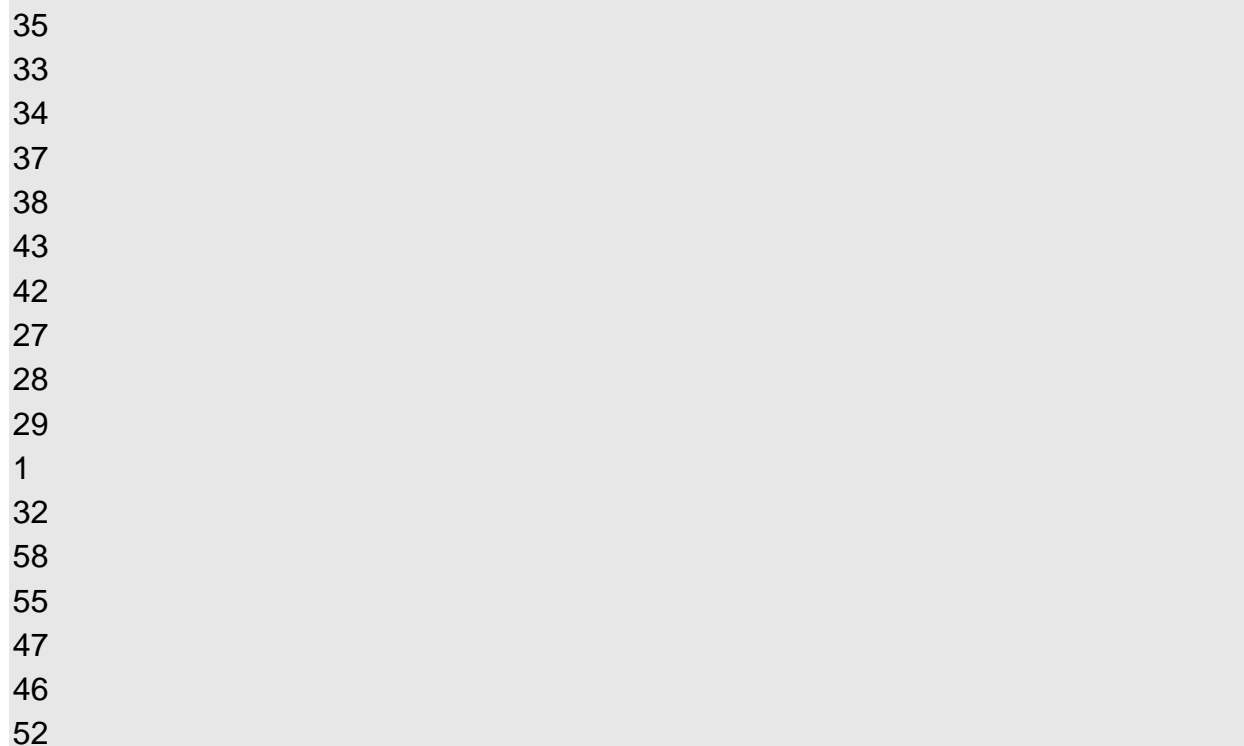
We describe in this deliverable 14 scenarios and 2 serious games that are the basis of iManageCancer. These scenarios and serious games were selected according a methodology of a survey, White Papers from ‘PatientView’ and project workshops. By selection of these scenarios and serious games, we are convinced that the iManageCancer project will provide a cancer disease self-management platform designed accordingly to the specific needs of patients with cancer. All scenarios will be translated in use cases and build as tools/apps. The legal and ethical framework is illustrated and based on the ethical and legal framework of the MyHealthAvatar project. The adaptation of the legal and ethical framework of MyHealthAvatar shows the close collaboration of these two European projects and will result in a more concrete approach for the scientific community. The described legal and ethical framework will keep data privacy at the highest level and protects all data by technical and contract measurements to avoid misuse of them. For the part of the developed tools, the medical device law applies. During the iManageCancer project it is not possible to certify these tools within the lifetime of the project, as there are no resources of time and money to do so. This certification needs to be addressed in the exploitation of the platform and the developed tools after the completion of the project. In addition, the platform and tools will be developed in a way that it will be easy to adapt it for usage by patients with other diseases than cancer as well.

## 8. References

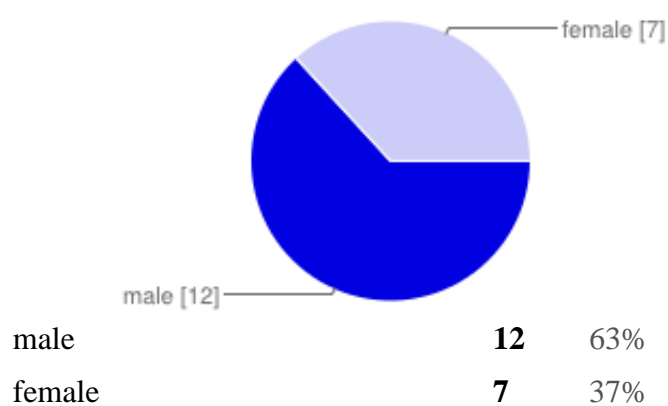
References are given as footnotes within the text.

## Appendix 1 – Answers to the initial questionnaire by participants of the kick-off Meeting

What is your age?

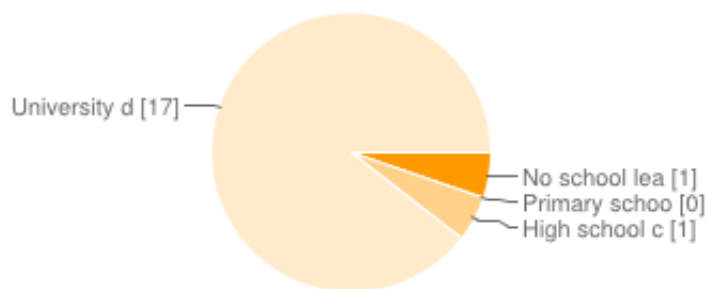


What is your gender?



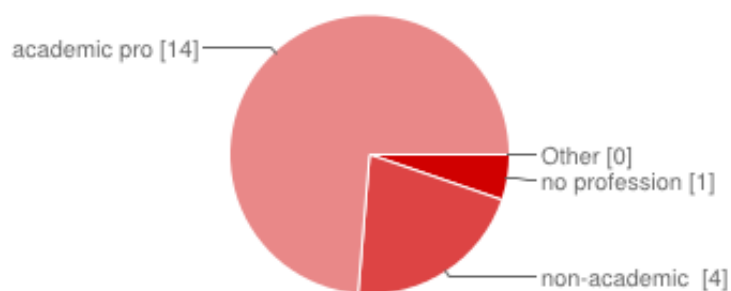
What is your highest educational status?





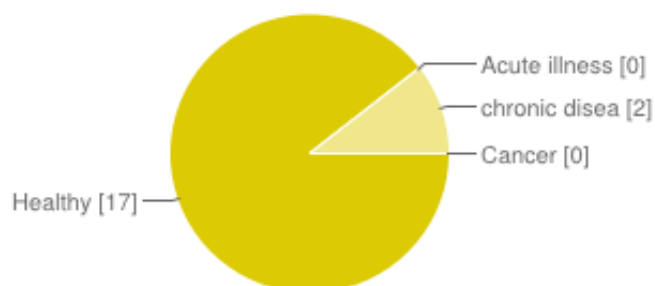
No school leaving certificate	1	5%
Primary school certificate	0	0%
High school certificate	1	5%
University degree	17	89%

### What is your profession?

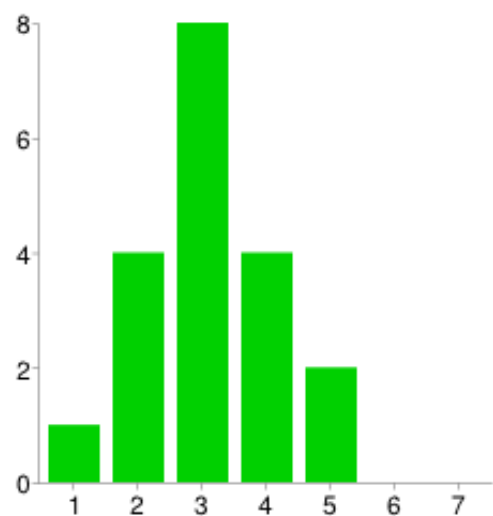


no profession	1	5%
non-academic profession	4	21%
academic profession	14	74%
other	0	0%

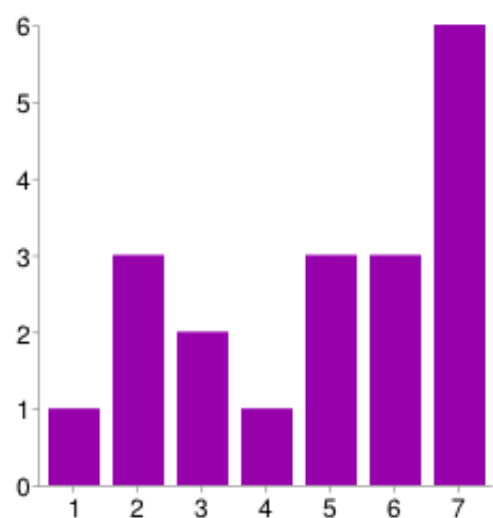
### What is your health status?



Healthy	17	89%
Acute illness	0	0%
Chronic disease	2	11%
Cancer	0	0%

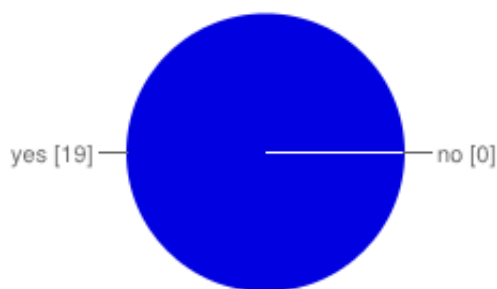
**What is your attitude to the health care system?**

1 1 5%      2 4 21%      3 8 42%      4 4 21%      5 2 11%      6 0 0%      7 0 0%

**What is your attitude to your physician?**

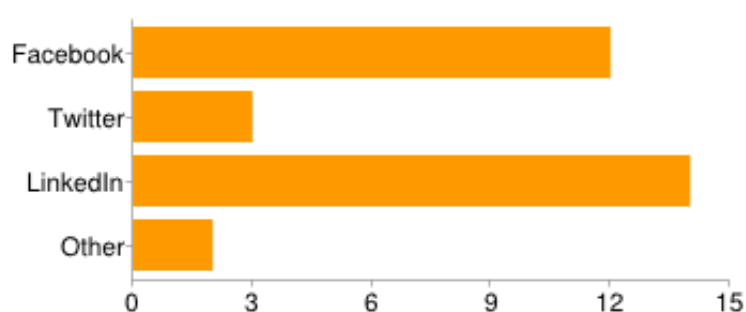
1 1 5%      2 3 16%      3 2 11%      4 1 5%      5 3 16%      6 3 16%      7 6 32%

**Are you a member of social network?**



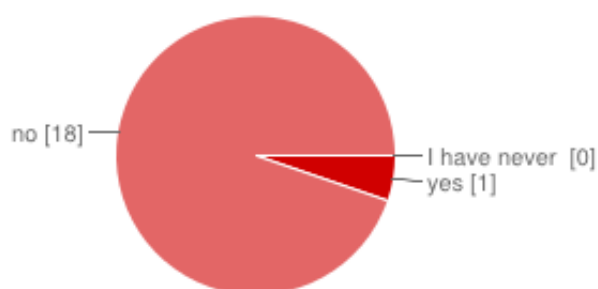
yes	19	100%
no	0	0%

### Which of the following social media are you using?



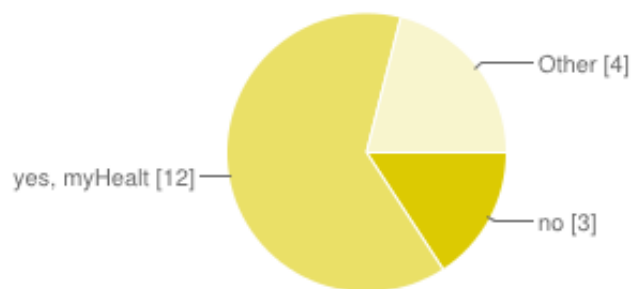
Facebook	12	63%
Twitter	3	16%
LinkedIn	14	74%
Other	2	11%

### Do you use a PHR (Personal health Record)?



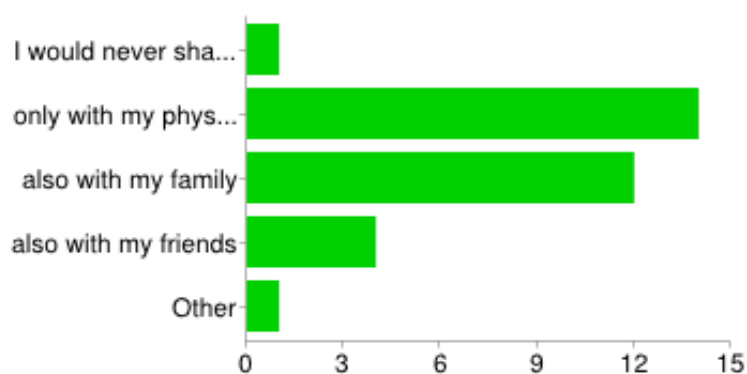
yes	1	5%
no	18	95%
I have never heard about PHR	0	0%

### Do you know platforms for patients?



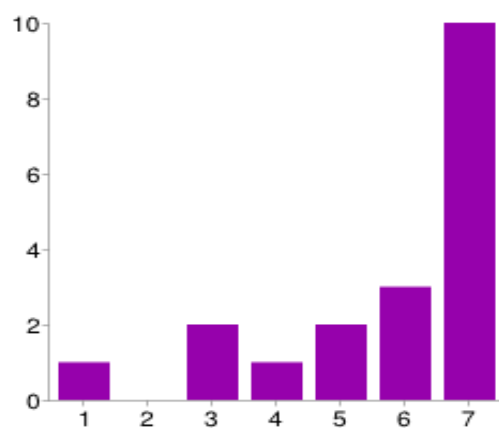
no	3	16%
yes, myHealthAvatar	12	63%
other	4	21%

### With whom could you imagine to share your health data via a secure webpage?



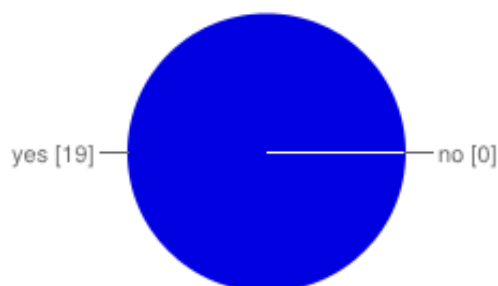
I would never share my health data via the internet	1	5%
only with my physician	14	74%
also with my family	12	63%
also with my friends	4	21%
other	1	5%

### How important are data security and privacy issues by sharing your health data?



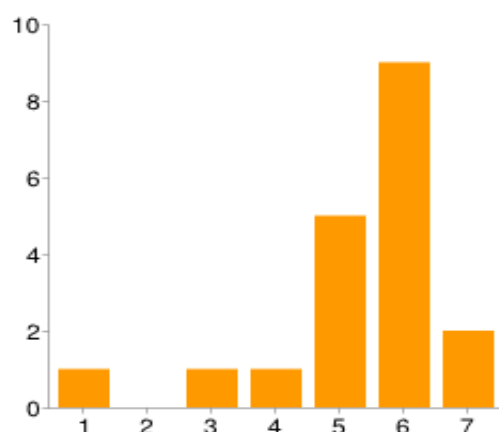
1 1 5%      2 0 0%      3 2 11%      4 1 5%      5 2 11%      6 3 16%      7 10 53%

### Are you doing online banking?



yes	19	100%
no	0	0%

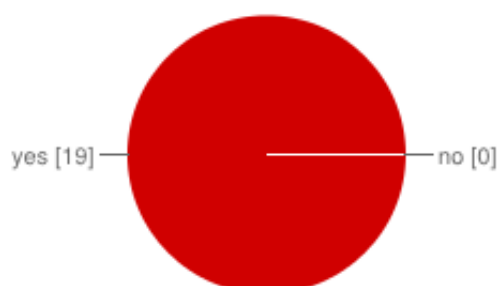
### How secure is online banking in your mind?



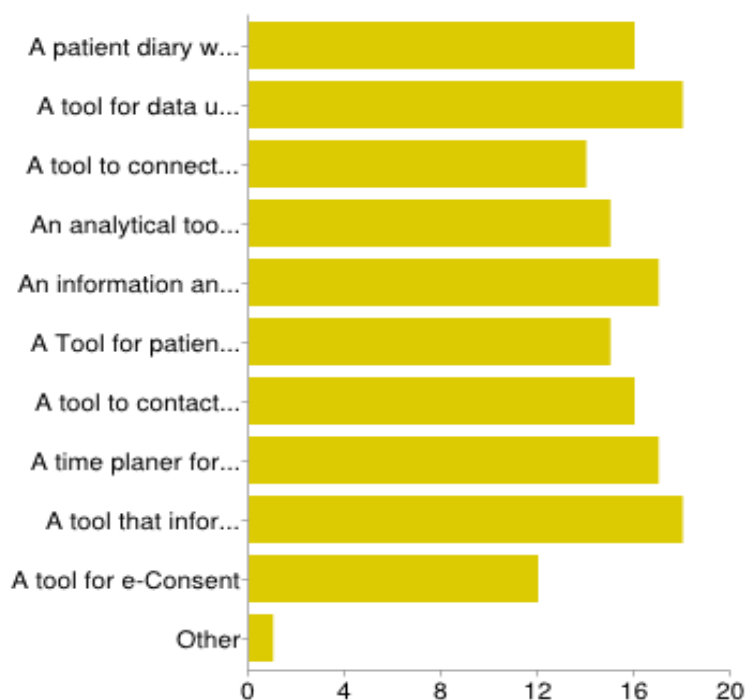
1 1 5%      2 0 0%      3 1 5%      4 1 5%      5 5 26%      6 9 47%      7 2 11%

### If you could get tools for analyzing your health data at home, would you use such tools?

Here is a list of tools one can think about that might be helpful for patients. Which of them would you like to have?

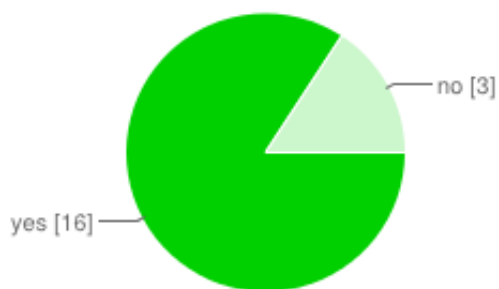


yes	<b>19</b>	100%
no	<b>0</b>	0%



A patient diary with imaging functionality	<b>16</b>	84%
A tool for data upload and sharing with your Doctor	<b>18</b>	95%
A tool to connect to wearable devices	<b>14</b>	74%
An analytical tool for uploaded data	<b>15</b>	79%
An information and recommendation browser	<b>17</b>	89%
A tool for patient education and information	<b>15</b>	79%
A tool to contact and interact with your treating physician	<b>16</b>	84%
A time planer for drugs and clinical visits/appointments	<b>17</b>	89%
A tool that informs you about drug interactions	<b>18</b>	95%
A tool for e-Consent	<b>12</b>	63%
Other	<b>1</b>	5%

**Do you have heard about serious games?**



yes	16	84%
no	3	16%

### Can you tell me a name of a serious game?

No

Duolingo

Re-mission

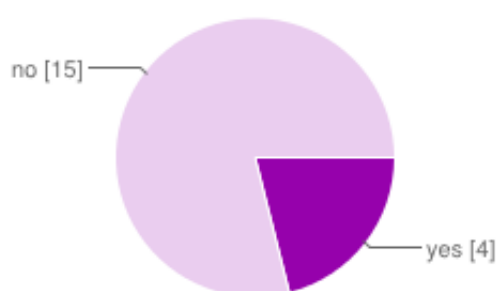
Don't know one

Emergency

Cancer fighter

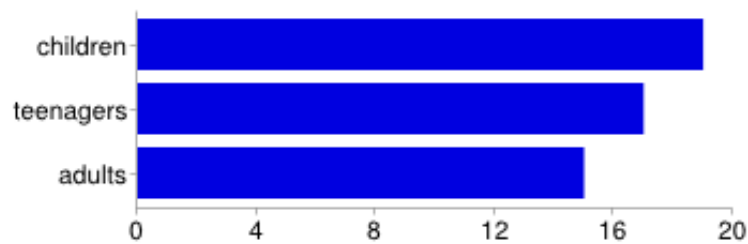
Re-Mission 2

### Do you have played a serious game?



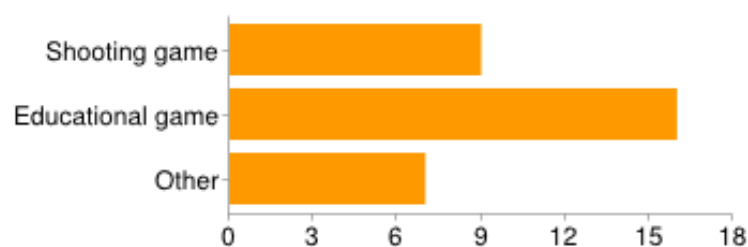
yes	4	21%
no	15	79%

### For whom do you think are serious games helpful



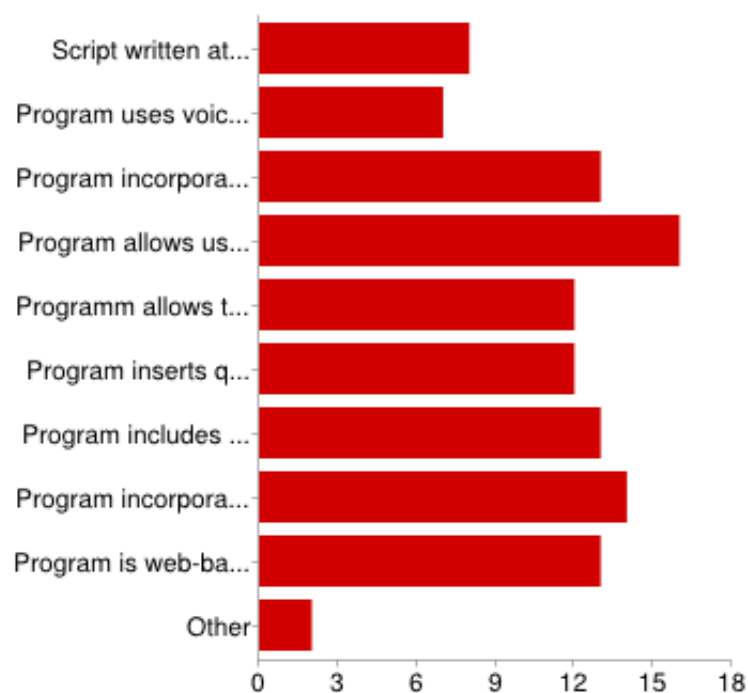
children	19	100%
teenagers	17	89%
adults	15	79%

### What should be the topic for a serious game for patients



Shooting game	9	47%
Educational game	16	84%
Other	7	37%

### What should be features of serious games?



Script written at or below 8th grade reading text

8 42%



Program uses voice-over to reinforce script messaging	<b>7</b>	37%
Program incorporates multimedia features including videos and animations	<b>13</b>	68%
Program allows user control	<b>16</b>	84%
Program allows to choose varying levels of information	<b>12</b>	63%
Program inserts questions and gives correct answers on demand	<b>12</b>	63%
Program includes a self-check or quiz	<b>13</b>	68%
Program incorporates features like touch screen	<b>14</b>	74%
Program is web-based for easier access	<b>13</b>	68%
Other	<b>2</b>	11%

## Can you tell a story for a serious game?

No

Test your knowledge on your condition

Marc is dealing with his cancer. Fear and anxiety are frozen his comprehension, decisions and actions

A little girl fights cancer with her friends and other kids with cancer and the more intensively she fights the more flowers appear on the screen

I am too tired now to think about a story

A game where the patient can take both the role of the clinician and the patient for specific conditions such as cancer

## Appendix 2 – Answers to the final questionnaire

The results of the survey are given in section 3.2.3. Here are only additional answers listed for questions related to ‘others’.

### Other social networks used:

	UK	Germany	Italy	Greece
	Numbers mentioned			
Pinterest	1			
XING	2	7	1	
Tumblr	5			
Fetlife	1			
Making Light	1			
Livejournal	1			

Ravelry	1			
Instagram	1		10	
TSN		1		
Researchgate			2	
GMail				1

### **Other helpful tools**

<b>UK</b>
Predictive models for treatment testing
A care pathway to which I, family and carers contribute
A dietary and exercise tool
Personal experiences of others with this condition, support sites, *A style systems
Properly anonymized, I'd love to share my health records for research.
Honestly I'd be happy if I could just email my doctor instead of calling, because anxiety and audio processing issues.
A tool to discuss experiences with fellow sufferers

<b>Germany</b>
Community Finder um gleichartige Patienten zu finden
Ein Programm um mich anonym mit anderen Betroffenen auszutauschen
eigener Befundsave für mich und meine Familie

<b>Italy</b>
None specified

<b>Greece</b>
None specified

**Ideas for serious games:**

UK
Anti cancer Plants V Zombies
Following the story of a character with the disease or diagnosing diseases through the symptoms
Explanation of disease underlying mechanisms, next actions...
A day in my life
Follow my medication - how it works in my body
Playing a person with a disease, but in a really beautiful, cartoon-like game, which made the disease seem manageable and less threatening. Maybe by being able to picture the illness somehow (just as with depression you can visualize the illness as a black dog).
Anything except playing as a character with chronic pain / depression / etc. If I wanted to interact with depression, I'd just turn the game off and stare at a blank screen.
I'm actually too low on health to think of a topic, but lemme say that the Sims and their energy/hunger/etc. meters would be a great thing to include. I feel like I measure my pain/tolerance/health on similar meters.
Immersive game such as "That Dragon: Cancer"
Anything allegorical. I'd rather educate through analogy to help distract.
Getting into the body to see how diseases work and fight them.

Germany
Beantwortungen mit unbestimmtem Ende
Visualisierung nach Simonton
Ritter bekämpfen Krebszellen mit ihren Lanzen
Funktion des Körper (Es war einmal der Mensch(Fernsehsendung))
Eine mit Happy End
Dokumentarisch spielen
Immunabwehr
Über spielen mehr informieren
Kriegsveteranen auf Entzug bringen

Italy
Come funziona la finanza (How does the finance?)
Qualcuno che guarisce alla fine (Someone who heals the end)
Greece
Ένας παίκτης που κινείται μέσα σε ένα κόσμο με δράκους, φανταστικά πλάσματα κτλ και θα πρέπει να κάνει κάποια βήματα για να ολοκληρώνει quests (A player who moves in a world with dragons, fantastic creatures etc and you have to make some steps to complete quests)
Θεατρική παράσταση (theatrical show)
A game demonstrating the optimistic side of life and the meaning of enduring pain and keeping on our efforts
Κυττάρα (cells)

## **Appendix 3 – Consent form for uploading data / participating in iManageCancer**

I, the undersigned \_\_\_\_\_, born on \_\_\_\_\_, the \_\_\_\_\_, in \_\_\_\_\_ and resident at \_\_\_\_\_ / \_\_\_\_\_ (address), reachable via \_\_\_\_\_ (e-mail-address), declare by the present consent form my agreement to the processing of my personal health data on the iManageCancer platform for the purposes of scientific development and validation of the European research project iManageCancer (Grant agreement no: 643529) (<http://imanagecancer.eu/>). In addition, users have the option, if they wish, directly to input further health-related information into the platform via a textbox: any such text data would be processed only by the institutions participating in the project (as listed on the project website) and not disclosed to any third parties.

The iManageCancer project is a feasibility study that aims in the future to propose a solution for access, collection and sharing of long-term and consistent personal health status data through an integrated environment, which will allow more sophisticated clinical data analysis, prediction, prevention and treatment simulations tailored to the individual citizen. At the present time, as part of the technical development of this environment, the iManageCancer project wishes to use the data in exploring different options for presenting it in an efficient and user-friendly manner. The intention is to allow the data collected to be linked within the iManageCancer platform only, and accessible to each user in a timeline.

I am aware that all necessary state-of-the-art security measures are incorporated in the platform to protect my data against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access or any other misuse.

I understand and agree that all data that I collect and provide to the project by using the above mentioned services may for the project duration be stored and used by the institutions participating in the project in a public cloud that may use servers located outside the EU/EEA (and may provide a level of privacy protection lower than that offered by EU data protection legislation).

I understand that at the moment, unless I opt to share my data with other users of the demo platform, the institutions participating in the project are the only entities, which have access to the data, which I have uploaded to the platform.

In case of any change to the above position, and in particular if the functions of iManageCancer will change, if additional apps, devices and other services will be linked to the iManageCancer platform, or if it is planned to make the demo platform public or use the data for any other purposes than those mentioned, the project will inform me by using my address or e-mail-address (as specified by me) for additional consent.

I have been given the opportunity to ask questions about the processing of my data and I have had these answered satisfactorily.

I am aware that my participation is voluntary and that I will not suffer adverse consequences for refusing to grant consent. I understand that I have the right at any time to withdraw my consent to the processing of my data on the platform without giving any reason. In the event of wishing to do so or having other concerns, I may contact the coordinator Stephan Kiefer (stephan.kiefer@ibmt.fraunhofer.de) at Fraunhofer IBMT, St. Ingbert, Germany.

In this case, my uploaded data will be permanently deleted from the iManageCancer platform.

A copy of this agreement will be sent to my address/e-mail-address (as specified by me) and another copy will be retained for record keeping by the project.

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Date, Name

## **Appendix 4 – Consent form for processing data in *iManageCancer***

I, the undersigned \_\_\_\_\_, born on the \_\_\_\_\_, in \_\_\_\_\_ and resident at \_\_\_\_\_ / \_\_\_\_\_ (address), reachable via \_\_\_\_\_ (e-mail-address), employee of \_\_\_\_\_, declare by the present consent form my agreement to the processing of my personal health data on the iManageCancer platform for the purposes of scientific development and validation of the European project MyHealthAvatar (Grant agreement no: 600929) [<http://imanagecancer.eu/>]

I understand and agree that all data that I collect and provide to the project by using the above mentioned services may for the project duration be stored and used by the institutions participating in the project [as listed on the project website] in a public cloud that may use servers located outside the EU/EEA (and may provide a level of privacy protection lower than that offered by EU data protection legislation).

I understand that at the moment, unless I opt to share my data with other users of the demo platform, the institutions participating in the project are the only entities, which have access to the data, which I have uploaded to the platform. In case of any change to this position, and in particular if it is planned to make the demo platform public or use the data for non-project purposes, the project will inform me by using my address or e-mail-address (as specified by me) for additional consent.

I have been given the opportunity to ask questions about the processing of my data and I have had these answered satisfactorily. I am also aware that my participation is voluntary and that I will not suffer adverse consequences for refusing to grant consent. I understand that I have the right at any time to withdraw my consent to the processing of my data on the platform without giving any reason. In the event of wishing to do so or having other concerns, I may contact the project coordinator Stephan Kiefer ([stephan.kiefer@ibmt.fraunhofer.de](mailto:stephan.kiefer@ibmt.fraunhofer.de)) at Fraunhofer IBMT, St. Ingbert, Germany.

A copy of this agreement will be sent to my address/e-mail-address (as specified by me) and another copy will be retained for recordkeeping by the project.

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Date, Name