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***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**

***D4.3 Final (optimized) version of Health Avatar PHR
iManageCancer Services***

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¹ **R** = Document, report (excluding the periodic and final reports), **DEM** = Demonstrator, pilot, prototype, plan designs

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

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1. Executive summary

Chronic cancer treatment places new demands on patients and families to manage their own care. The iManageCancer project actively supports this challenge and provides a cancer disease self-management platform designed according to the specific needs of patient groups and focusing on the wellbeing of the cancer patient with special emphasis on psycho-emotional evaluation and self-motivated goals.

The iManageCancer platform is designed on clinical evidence and in close collaboration of clinical experts, IT specialists and patients and will be assessed in clinical pilots with adult and paediatric cancer patients.

This document presents the final version of the avatar-based PHR for cancer patients.

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. In addition a patient is able to upload his data to the PHR and to use an eDiary visualization. Furthermore, the patient can enter all kinds 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 can enter the main data of his/her disease (passport screening) including treatment plan and other medications.

The Health Avatar scenario in iManageCancer demonstrates 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 supports the visualization of the behaviours and daily activities of the patients. It functions 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. It offers a range of tools for the self management of cancer in terms of lifestyle and physical activities. These tools are mainly designed to target patients with prostate cancers and help them to:

- Know their health status and performance by viewing their self-collected data
- Improve their knowledge about health and diseases by tailored information provision
- Raise their risk awareness and perceptions about diseases by personalised risk assessment
- Engage in health and fitness activities by recommending relevant programmes and courses
- Help look after weight, fitness, calories, emotion and sleep.

2. Introduction

2.1 *About the project*

Chronic cancer treatment places new demands on patients and families to manage their own care. The iManageCancer project supports this challenge and provides a cancer disease self-management platform designed according to the specific needs of patient groups and focusing on the wellbeing of the cancer patient with special emphasis on psycho-emotional evaluation and self-motivated goals.

The iManageCancer platform is designed on clinical evidence and in close collaboration with clinical experts, IT specialists and patients, and will be assessed in clinical pilots for adult and paediatric cancer patients.

The main objectives of iManageCancer listed in the DoW are summarised as:

1. **Empower patients and their relatives through an ICT based self-management service platform.**
2. Allow patients **to keep track of their health and disease status.**
3. Provide the patients with **personalized, context-sensitive, data driven information services.**
4. Help adult and young cancer patients through **serious games** to manage the impact of the disease on their psychological status.
5. Provide patients with **decision support and guidance through a knowledge base of formal care flow plans.**
6. Support patients and their doctors in **managing medications.**
7. Provide clinicians and patients an **interactive psycho-emotional health assessment instrument.**
8. Increase patients' safety by developing and incorporating **predictive models in the system for the early detection of severe adverse events during chemotherapy.**
9. **Support patients in following a healthy and active lifestyle.**
10. Provide the patient with an easy-to-use **interactive cockpit for disease self-management** on mobile platforms.
11. Incorporate an instrument in the platform for **data driven analysis services** on anonymised clinical information to be used for public health research.
12. Conduct and assess **three pilots**, two for adult cancer patients and one for children.
13. Design an innovative **ecosystem for the empowerment of cancer patients.**

2.2 *Purpose of the document*

This document presents the final version of an avatar-based PHR for cancer patients. More specifically it presents the technical implementation and the user interface of a) the iPHR platform and b) the MyHealthAvatar app for cancer patients.

2.3 *Structure of this document*

This document comprises the following five main sections:

- Summary of use scenarios
- Technical implementation
- Conclusion

3. Summary of use scenarios and requirements from D2.2 and D2.3

3.1. Scenario PHR and eDiary

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. The most important functionality 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 scanned clinical documents, electronic clinical documents (word, excel) and imaging data (DICOM, JPG).

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 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. and write his/her private notes in eDiary. 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 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 patient can always find everything he/she shares with whom. He can stop the sharing with specific people completely or for specific documents at any time.

For the sharing of health data with others the concept “**Companion**” is introduced. This is not a role in its own. Everyone can become a “Companion” of a patient by invitation of that patient to share data of the patient with the companion. If the Companion is not a registered user, an email invitation will be send to the requested Companion with a personalised link to the iMC registration page. After successful registration, the Companion has also a PHR and access to all services. In addition, he will find the Patient who invited him to share all or only specific health data with him/her in the list “My Invitations”. Read only access is given to the data that the patient wishes to share with his companion. The Patient finds the Companion’s name in the list “my Companions”. To invite a person to access and share the patient’s health information, the patient shall be able to search this person in the system by his email-address. If the person is not a registered user the patient can send him an email based invitation as described above.

In the case of children (proposed age: 16 or younger), an adult companion has to be invited with whom the whole PHR account is shared and the concept of “Guardian” is introduced. Optimally, this person is allowed to add or upload data in the child’s PHR. In this case it should be marked that this data has been added by the companion and not by the child. As soon as the child has exceeded the age limit, the rights of the companion will change to ‘read only’, and the child becomes a “normal patient” with the rights to enable or disable sharing with others.

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

As the patient may wish to share his data with a Physician, it shall be possible that one can register in iMC as a doctor (self-declared).

In addition, it shall be possible for the operator of the platform to register an **iMC Administrator**. It is a special default account on the system that shall be created when the system is launched for the first time.

The iMC administrator is able to register further iMC Administrators. An iMC Administrator is not allowed to see health data of patients. He/she is allowed to monitor the traffic on the platform through use statistics functions (number of (new) users, number of (new) entries, usage of each tool, etc.), to monitor the conversation in the forum and to terminate accounts. In addition, he/she is allowed to execute the eConsent tool to create automatically cohorts of consenting patients for research projects and to confirm accounts of research projects. (For the purpose of research on patient data, it shall be possible to analyse cumulative patient data on a project base. It would also be beneficial, if the administrator could send a HTML message to all or a subset of users (i.e. news, advertisements).

The corresponding workflows are the following:

Workflow for patient to use PHR

1. The patient enters the iManageCancer platform (iMC Portal).
2. A list of all available electronic clinical report form (eCRFs) categories is shown and visualization options are available to the patient.
3. The patient selects an eCRF category.
 - a. The previous records of this category appear.
 - b. The patient can select a previous record to examine all details.
 - c. The patient fills in the eCRF and/or uploads the corresponding clinical documents (scanned documents, electronic clinical documents, JPG images, DICOM images etc.).
 - d. After filling and saving the eCRF, a report is presented to the patient about the submitted eCRF.
 - e. As soon as the eCRF is submitted, the data is saved.
4. The patient is visualizing information.
 - a. The patient can select the appropriate visualization method of choice (timeline, chart etc.).
 - b. The data is visualized according to the selected visualization.
5. A patient is notified with an alert.
 - a. A patient is alerted visually and/or acoustically about a nearby clinical visit or a medication.
 - b. The patient can click to the notification to see the details of the notification.
6. The patient logs out from the iMC portal.

Workflow for registration of a patient/physician in the iManageCancer platform

1. A patient/physician enters the iManageCancer platform.
2. The patient/physician uses a link to create an account and fills in the data needed for creating an account (see the section 4.1.2).

3. The iMC server checks if the account with the entered identifier (the e-mail address) already exists in the system.
 - If yes, the server sends the message to the patient/physician's GUI that the user already exists and allows him/her to enter another email address or to log-in with the existing user account.
 - If no, the server sends an email to the patient/physician with a link to confirm his/her e-mail address.
4. The patient/physician sends a confirmation to the iMC Server.
5. iMC server receives the confirmation and generates a PHR account, in the case of the patient only, and gives access to all tools and services.
6. iMC server sends the account data for accessing the iMC platform to the patient/physician.
7. The patient/physician is requested to change his/her password when he logs into the system for the first time.

Workflow for data sharing with a physician/companion in the iManageCancer platform

1. A patient logs into the iMC portal and selects documents or other resources in his PHR, which he/she wants to share with a physician/companion or the whole PHR with or without private notes.
2. The patient can select sharing options
 - a. for structured data (i.e. Information entered through eCRFs): select to share all or nothing with physician/companion or researcher
 - b. for unstructured documents (i.e. documents and photos uploaded) he/she can use a select option for each document or share them all (also for future documents)
 - c. (optional) specify the time interval on which this decision will be valid
3. The patient will be prompted to enter the e-mail address as an identifier for the physician/companion with whom he wants to share the selected resources.
4. (Optional) The patient selects the physician/companion by searching the list of his companions.
5. The iMC server checks if the physician/companion is a registered user. If he is not registered, an e-mail invitation is sent to the selected physician/companion with a link that identifies the sharing request. He can now register with this link as described above. If he is already registered, he will receive a request on his mobile to take a look on data of this patient. (Optional) The physician/companion will receive this notification via e-mail, if he/she has previously configured in his profile that he wants to get notifications from this patient about new documents in the PHR. Otherwise the physician/companion can see an information about new documents in the PHR when he logs in in the iMC platform.
6. The physician/companion will find the patient who invited him/her to share all or only specific health data with him/her in the list "My Invitations" (for the companion) or "My Patients" (for the physician). Read only access is given to the data that the patient has shared with his physician/companion. (Optional) The physician/companion can configure subscribing for notifications about new documents in the PHR of the current patient.
7. The patient finds the companion's name in the list "My Companions" or "My Doctors". References to the shared documents are added together with an enabled check box that indicates that this document is shared with this person and a check box that indicates that

- the whole PHR with or without private notes is shared. Another check box shall allow the patient to stop data sharing with this person
8. The patient logs out from the iMC portal.

Then in D2.3 the following use-cases were generated:

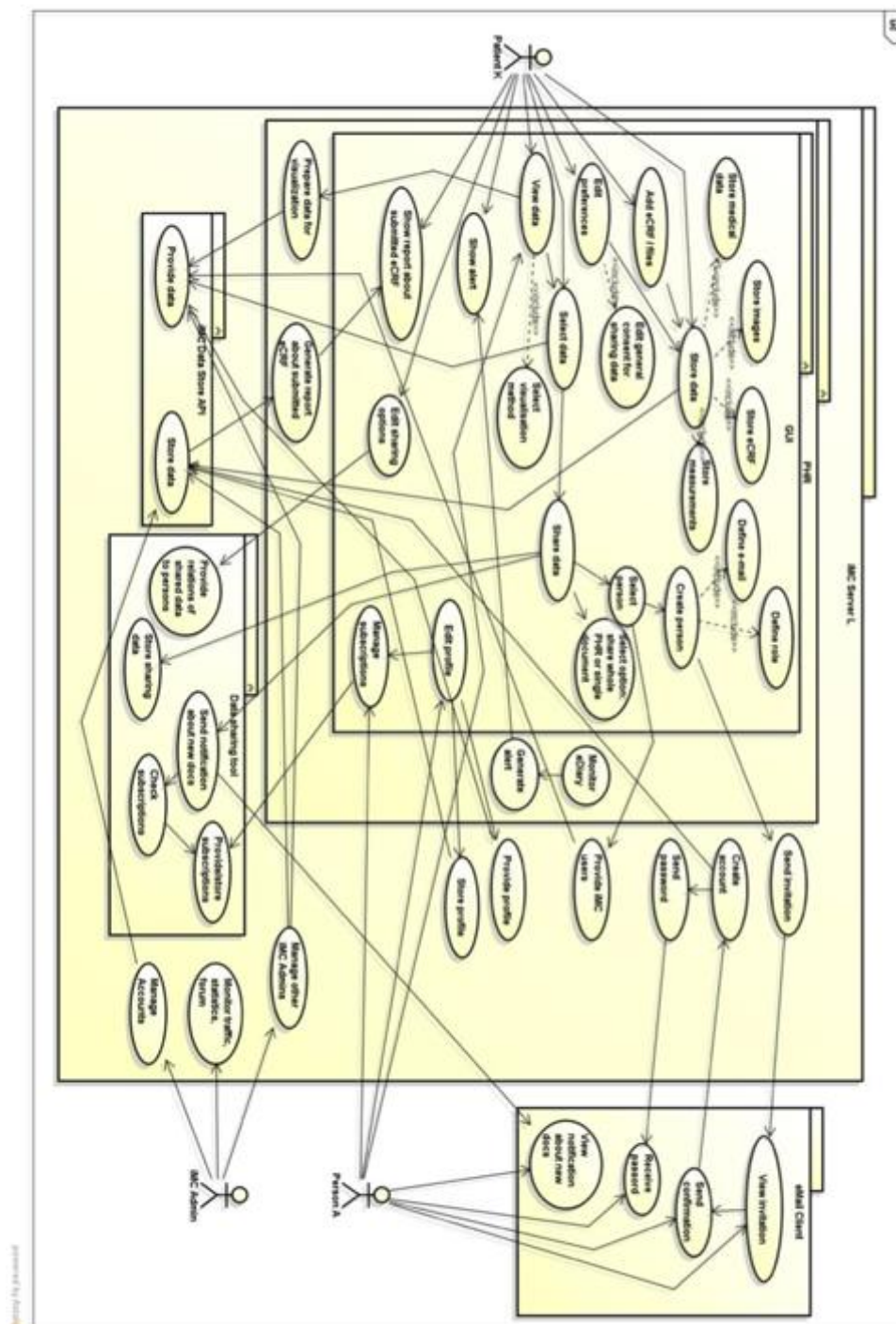


Figure 1: The use cases diagram of the PHR and eDiary scenario.

Use Case ID	UC.PHR.1	Priority	REQUIRED
Use Case name	Upload patient data and images to PHR and eDiary		
Scenarios	SC1		
Actors	Patient		
Brief description	Upload patient data and images. Use an eDiary for information organisation.		
Trigger	On actor's demand		
Pre-conditions	<ul style="list-style-type: none"> • Patient is registered to the iManageCancer platform. • Patient has a device such as a computer, laptop, tablet, mobile phone able to access the iManageCancer platform 		
Post-conditions	-		
Successful end condition	Data and images are successfully stored. Data is visualized using a diary/timeline mechanism.		
Fail end condition	Data and images cannot be uploaded or visualized.		
Relationships	Extends -	Includes -	
Basic flow	Step	Action	
	1	The patient enters the iManageCancer portal.	
	2	A list is shown of all available eCRF categories and visualization options available to the patient.	
	3	The patient selects an eCRF category. <ul style="list-style-type: none"> a. The previous records on this category appear. b. The patient can select a previous record to examine all details. c. The patient fills-in the eCRF and/or uploads the corresponding clinical documents (scanned documents, electronic clinical documents, jpg images, DICOM images etc.). d. After filling and saving the eCRF a report is presented to the patient about the submitted eCRF. e. As soon as the eCRF is submitted, the data is saved in the PHR database of the iMC Data Store. 	
	4	The patient is visualizing the information: <ul style="list-style-type: none"> a. The patient can select the appropriate visualization method of choice (timeline, chart etc.). b. The data is visualized according to the selected visualization. 	
	5	The patient is registering an event: <ul style="list-style-type: none"> a. The patient is selecting his/her calendar b. The patient selects a date to enter an event c. The title and the time of the event are entered and the event category as well d. The patient selects the alert types (there will be also preselected alert types according to the event category) 	
	6	The patient is notified with an alert: <ul style="list-style-type: none"> a. The patient is alerted visually 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 iManageCancer portal
Usage frequency	High	
User interfaces	PHR Client	
Notes and issues	-	

Use Case ID	UC.PHR.2	Priority	REQUIRED
Use Case name	User Registration/Role Management in iMC		
Scenarios	SC1		
Actors	Patient, Companion, Physician		
Brief description	Registration of the iMC users		
Trigger	On actor's demand or on a patient's invitation		
Pre-conditions	<ul style="list-style-type: none"> An actor has a device such as a computer, laptop, tablet, mobile phone able to access the iManageCancer platform 		
Post-conditions	-		
Successful end condition	An actor has an account in iMC platform and can use available resources according to his role		
Fail end condition	An actor has no account in iMC platform and cannot use the platform		
Relationships	Extends -		Includes -
Basic flow for patient/physician (self-registration)	Step	Action	
	1	An actor enters the iManageCancer portal and uses a link to create an account.	
	2	The actor selects the account type and registers.	
	2a	<p>A patient account is selected.</p> <p>The following basic information should be entered:</p> <ul style="list-style-type: none"> The email address as his/her identifier, First name, family name, Gender, Date of birth, Place of residence (just the city), Basic information on his/her cancer disease (optional), at least type of cancer disease, if any, to provide more personalized content, His/her preferences regarding the sharing of his data for research purposes through check boxes. <p>In the case of children (proposed age: 16 or younger), an adult <i>companion</i> has to be invited with whom the whole PHR account is shared (except of the private part of the e-diary). Optimally, this person is allowed to add or upload data in the child's PHR. In this case, it should be marked that this data has been added by the companion and not by the child. As soon as the child has exceeded the age limit the rights of the companion will change to 'read</p>	

		<p>only’ and the child becomes a “normal patient” with the rights to enable or disable sharing with others.</p> <p>Everyone can become a “Companion” of a patient on invitation of that patient to share data of the patient with the companion. Read only access is given to the data that the patient wishes to share with his companion. The patient finds the Companion’s name in the list “my Companions”. To invite a person to access and share the patient’s health information, the patient shall be able to search this person in the system by his email-address. If the person is not a registered user, the patient can send him/her an email based invitation as described above.</p>
	2b	<p>A doctor account is selected: The following information should be entered:</p> <ul style="list-style-type: none"> • The email-address as his/her identifier, • First name, family name, • Speciality, • Full name of his health organisation, • Full address of his organisation. <p>The system does not verify whether the user is a doctor or not, However it confirms the registration by sending an email with a confirmation link. The system shall allow to report misuse of an account and to block this account by an administrator.</p>
	2c	<p>An iMC administrator account is selected.</p> <p>The iMC administrator is a special default account on the system that is created when the system is launched for the first time. To be able to register as iMC administrator, an invitation should be pending from another iMC administrator. The following information should be entered:</p> <ul style="list-style-type: none"> • The email-address as his/her identifier, • First name, family name, • Username • Password
	2d	<p>A research project account is selected. The following information should be entered:</p> <ul style="list-style-type: none"> • A unique short name for the research project as the identifier of this account, • The email address of the researcher to confirm the account, • First name, family name of the principal investigator • Phone number (for the administrator only), • Full name of his affiliation, type of affiliation (Non-profit research organisation, for-profit organisation, governmental organisation, health insurer, others) • Position in his/her affiliation

		<ul style="list-style-type: none"> • Full address of his/her affiliation • A description of the research project he/she wants to carry out with the patients' data in layman's language including a statement about the type of data that is required for this research, • Inclusion criteria for patients that can be found in the system: Typically: Gender, Age, Type of cancer disease, any other structured information that is available • Minimum number of patients required for the research project • Duration in months (after account is provided)
	3	<p>The iMC server checks if the account with the entered identifier (the e-mail address) already exists in the system.</p> <ul style="list-style-type: none"> • If yes, the iMC Server sends a message to the patient's browser, that the user already exists, and allows to enter another email address or to log-in with the existing user account. • If not, the server sends an email to the actor with a link to confirm his e-mail address.
	4	The actor sends a confirmation to the iMC Server.
	5	iMC server receives the confirmation and generates a PHR account, in the case of the patient only, and gives access to all tools and services.
	6	iMC server sends the account data for accessing the iMC platform to the actor.
	7	The actor is requested to change his password when he/she logs into the system for the first time.
Usage frequency	High	
User interfaces	PHR Client	
Notes and issues	-	

Use Case ID	UC.PHR.3	Priority	REQUIRED
Use Case name	PHR data sharing		
Scenarios	SC2		
Actors	Patient, companion, physician		
Brief description	Share data with other members of the platform		
Trigger	On patient's demand		
Pre-conditions	<ul style="list-style-type: none"> • Patient is registered to the iManageCancer platform. • Patient has a device such as a computer, laptop, tablet, mobile phone able to access the iManageCancer platform 		
Post-conditions	-		
Successful end condition	Data is shared among iManageCancer members		
Fail end condition	Data cannot be shared		
Relationships	Extends -	Includes -	

Basic flow for patient	Step	Action
	1	The patient enters the iManageCancer portal.
	2	The patient selects documents or other resources in his/her PHR, which he/she wants to share with a physician/companion, or the whole PHR with or without private notes.
	3	The patient can select sharing options: <ul style="list-style-type: none"> a. For structured data: select to share all or nothing with physician/companion or researcher. b. For unstructured documents, he/she can use a select option for each document. c. (Optional) Specify the time interval on which this consent will be valid.
	4	The patient will be prompted to enter the e-mail address as an identifier for the physician/companion with whom he/she wants to share the selected resources.
	5	(Optional) The patient selects the physician/companion from the list of his companions
	6	The iMC server checks if the physician/companion is a registered user. If he/she is already registered, he/she will receive a request on his mobile to take a look on data of this patient. If he/she is not registered, the Alternative Flow 1 below is executed.
	7	The patient finds the companion's name in the list "My Companions" or "My Doctors". References to the shared documents are added together with an enabled check box that indicates that this document is shared with this person and a check box that indicates that the whole PHR with or without private notes is shared. Another check box allows the patient to stop data sharing with this person.
	8	The patient logs out from the iMC portal.
Basic flow for physician/companion	1	The physician/companion logs in into the iMC portal.
	2	The physician/companion will find the patient who invited him/her to share all or only specific health data with him/her in the list "My Invitations" (for the companion) or "My Patients" (for the physician). Read only access is given to the data that the patient has shared with his/her physician/companion.
	3	The physician/companion logs-out from the iManageCancer portal.
Alternative flow for physician/companion	1	The iMC server sends an e-mail invitation to the selected physician/companion with a link that identifies the sharing request.
	2	The physician/companion sends a confirmation to the iMC server.
	3	The iMC server creates an account for the physician/companion in iMC platform and assigns the shared documents to his/her account.

	4	The iMC server sends a confirmation email to the physician/companion.
	5	The physician/companion can now log into the iMC portal (see the basic flow for the physician/companion above).
Basic Flow for research project	1	The research project logs into the iMC portal.
	2	The research project identifies and uses the apps that can visualize information on the selected cohort.
Usage frequency	High	
User interfaces	PHR Client	
Notes and issues	-	

In consequence, D2.3 lists 7 important functional system requirements which were derived from these use cases. They are briefly listed in the following table.

ID	Name	Description
REQ.PHR.1	GUI for storing data, images and documents	The platform should provide a GUI for storing data, images and documents.
REQ.PHR.2	GUI for sharing data and images	The platform should provide a GUI for easily sharing data and images among iManageCancer members.
REQ.PHR.3	GUI for visualizing data using eDiary and Timeline	The platform should provide a GUI for easily visualizing data using eDiaries and Timelines.
REQ.PHR.4	API for storing data and imaging data	The platform should provide an API for storing, retrieving and updating data and images.
REQ.PHR.5	Secured access to PHR	The PHR should be secured by a user authentication mechanism.
REQ.PHR.6	GUI for user registration and management	The platform should provide a GUI for registration and management of users.
REQ.PHR.7	API for accessing system's user, roles and rights.	The platform should provide an API accessing user, roles and rights.

All of them have been realised in this demonstrator.

3.2. Scenario for Patient - Doctor and Patient - Patient Interaction

This scenario has to do with methods of communicating patients between themselves and patients and doctors. The iManageCancer platform will explore communication through the mechanism developed within the platform to enable information exchange among participants.

Workflow of patient to patient/doctor interaction.

1. A patient logs into the iMC portal and selects forum app from the menu.
2. The patient can select one of the available topics of the forum to check.
3. The patient can select to add a new post in the topic if needed.
4. The patient can select to send a private message. A new form opens where patient can select the receiver and add the message.
5. The patient can send a message through the chat app.

Use Case ID	UC.PDPPI.1	Priority	REQUIRED
Use Case name	Patient to Patient Interaction		
Scenarios	SC16		
Actors	Patient		

Brief description	Patients should be able to communicate using the iManageCancer platform	
Trigger	On actor's demand	
Pre-conditions	<ul style="list-style-type: none"> • Patient is registered to the iManageCancer platform. • Patient has a device such as a computer, laptop, tablet, mobile phone able to access the iManageCancer platform. 	
Post-conditions	-	
Successful end condition	A patient is able to communicate with another patient.	
Fail end condition	A patient fails to communicate successfully with another patient using the iManageCancer platform.	
Relationships	Extends -	Includes UC.PHR.1
Basic flow	Step	Action
	1	The patient logs-in to the iManageCancer platform.
	2	The patient selects to share some specific information using one of the following means <ul style="list-style-type: none"> • to share directly with another patient, • to publish some information in his connected social, network account like Facebook, Twitter etc., • to write something in a forum, • To write something in a chat room.
	3	The patient logs-out from the iManageCancer platform.
Usage frequency	High	
User interfaces	PHR Client	
Notes and issues	-	

Use Case ID	UC. PDPPI.2	Priority	REQUIRED
Use Case name	Patient to Doctor Interaction		
Scenarios	SC16		
Actors	Patient, Doctor		
Brief description	Patients should be able to communicate with doctors using the iManageCancer platform.		
Trigger	On actor's demand		
Pre-conditions	<ul style="list-style-type: none"> • Patient and doctor are registered to the iManageCancer platform. • Patient and doctor have a device such as a computer, laptop, tablet, mobile phone able to access the iManageCancer platform. 		
Post-conditions	-		
Successful end condition	A patient is able to communicate with a doctor.		
Fail end condition	A patient fails to communicate successfully with a doctor using the iManageCancer platform.		
Relationships	Extends -	Includes UC.PHR.1	
Basic flow	Step	Action	
	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: <ul style="list-style-type: none"> • to share directly some information directly with his doctor, 	

		<ul style="list-style-type: none"> 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.
Usage frequency	High	
User interfaces	PHR Client	
Notes and issues	-	

In consequence, D2.3 lists 7 important functional system requirements which were derived from these use cases. They are briefly listed in the following table.

ID	Name	Description
REQ.PDPPI.1	GUI for communication between patients	The platform should provide a GUI allowing the communication between patients
REQ.PDPPI.2	GUI for communication between patients and doctors	The platform should provide a GUI allowing the communication between patients and doctors

All of them have been realised in this demonstrator.

3.3. Scenario Health Avatar

The Health Avatar scenario in iManageCancer demonstrates the capacity of the iManageCancer platform in terms of lifestyle management support to 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 supports the visualization of the behaviours and daily activities of the patients. It functions 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 allows the patients to play a key role in the cancer care.

More specifically, by the use of the MyHealthAvatar app, we support the 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). We will also support personal behaviour interventions that allow planning and reminding services for daily physical exercises, calories control and medication. The app also sends reminder messages for calories, physical exercises, medical testing, medication and hospital visit, etc. Also, we consider offering programmes (e.g. weekly or monthly) for weight and life style control for the patients at certain conditions by delivering these programme materials to the patients in need.

The workflow of the use scenarios described in previous section is defined as follows: 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 from a number of available sensors/mobile apps; 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 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. weight 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 and the patient can share information with others by selecting the users and information she/he wants to share. She/he can stop the sharing at any time.

In D2.3, the following use cases were generated:

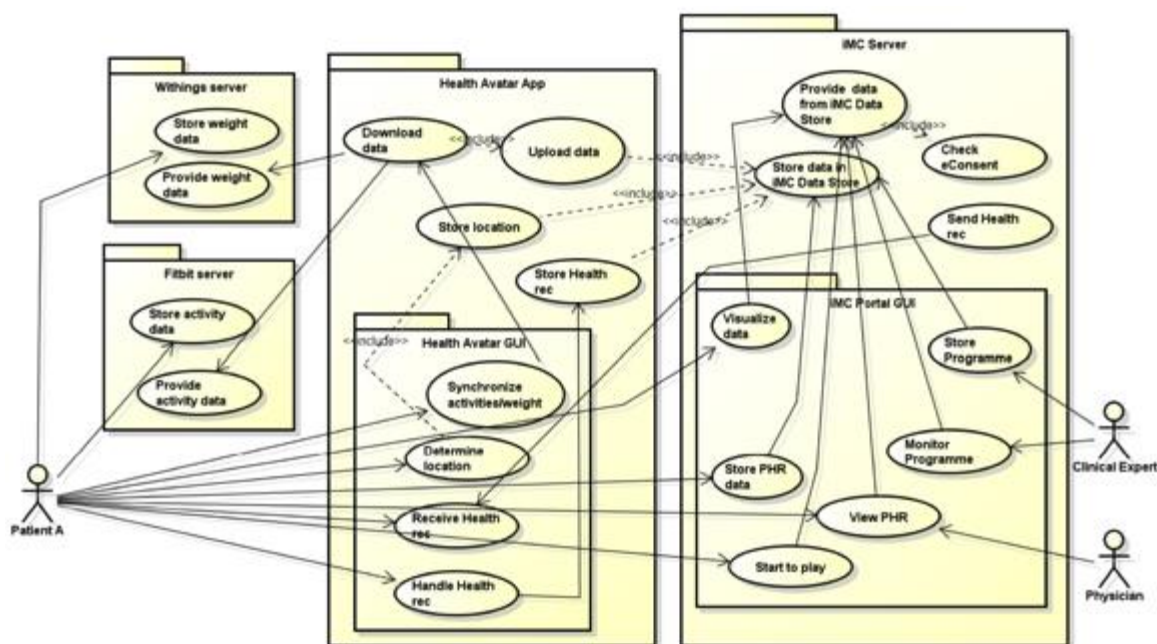


Figure 2: The use cases diagram of the Health Avatar scenario.

Use Case ID	UC.HAG.1	Priority	REQUIRED
Use Case name	Health Avatar GUI		
Scenarios	SC2		
Actors	Patient		
Brief description	The Health Avatar GUI provides a supportive environment for the patient's self-management of lifestyles for general health and wellbeing, enabling more effective care of cancer in terms of risk reduction through improving compliance with healthy lifestyle recommendation.		
Trigger	-		
Pre-conditions	<ul style="list-style-type: none"> • Patient has signed up to the system • Patient is engaged to the system. 		
Post-conditions			
Successful end condition	Patient uses the system for self-management on daily basis.		

Fail end condition	Patient fails to use the system to upload data, view data and follow instructions provided by the system	
Relationships	Extends	Includes -
Basic flow	Step	Action
	1	Patient uses sensors (Fitbit, Withings, Moves)
	2	Patient uploads his/her data to the external servers using the services provided by these external service providers (e.g. those from Fitbit, Withings and Moves).
	3	Patient synchronises the data into the avatar in the IMC platform
	4	Patient enters his/her PHR through
	5	The data is visualized through the IMC portal for patient to view interactively
	6	Physician may view patient's PHR if it is agreed by the patient
	7	Clinical expert can insert health programmes for the patient to follow
	8	There are games for the patient to play
Usage frequency	High	
User interfaces	Health Avatar GUI	
Notes and issues	-	

In consequence, D2.3 lists 7 important functional system requirements which were derived from these use cases. They are briefly listed in the following table.

ID	Name	Description
REQ.HAG.2	Linkage with external data sources	The system can be linked and be able to do data exchange with external data systems such as those from the sensors. The data upload should be as simple as possible to the patient.
REQ.HAG.3	Scalable and extendable data storage	The system (avatar) should be able to store a variety of data coming from different sources such as activities, events, PHR, and this needs to be scalable and extendable.
REQ.HAG.4	Patient's UI for Interactive data visualisation	Patient will need to be able to interactively view and select his data.
REQ.HAG.5	Data entering by patients	Patient will need to enter his PHR into the system which will be subsequently stored in the avatar. Easy data entering and data uploading should be made possible.
REQ. HAG.6	Assignment of health programmes to patients	Clinical expert should be able to assign health programmes to the patient to follow, and progress can be monitored by the expert.
REQ. HAG.7	Integration of games for health education	Patient can play their games for the health education purpose.

All of them have been realised in this demonstrator.

4. Technical implementation

4.1. System concept: *iPHR* and *MyHealthAvatar* app

The high-level architecture of the iManageCancer platform is shown in Figure 3. In the sequel we will analyse the iMC Portal iPHR and the MyHealthAvatar4iMC components.

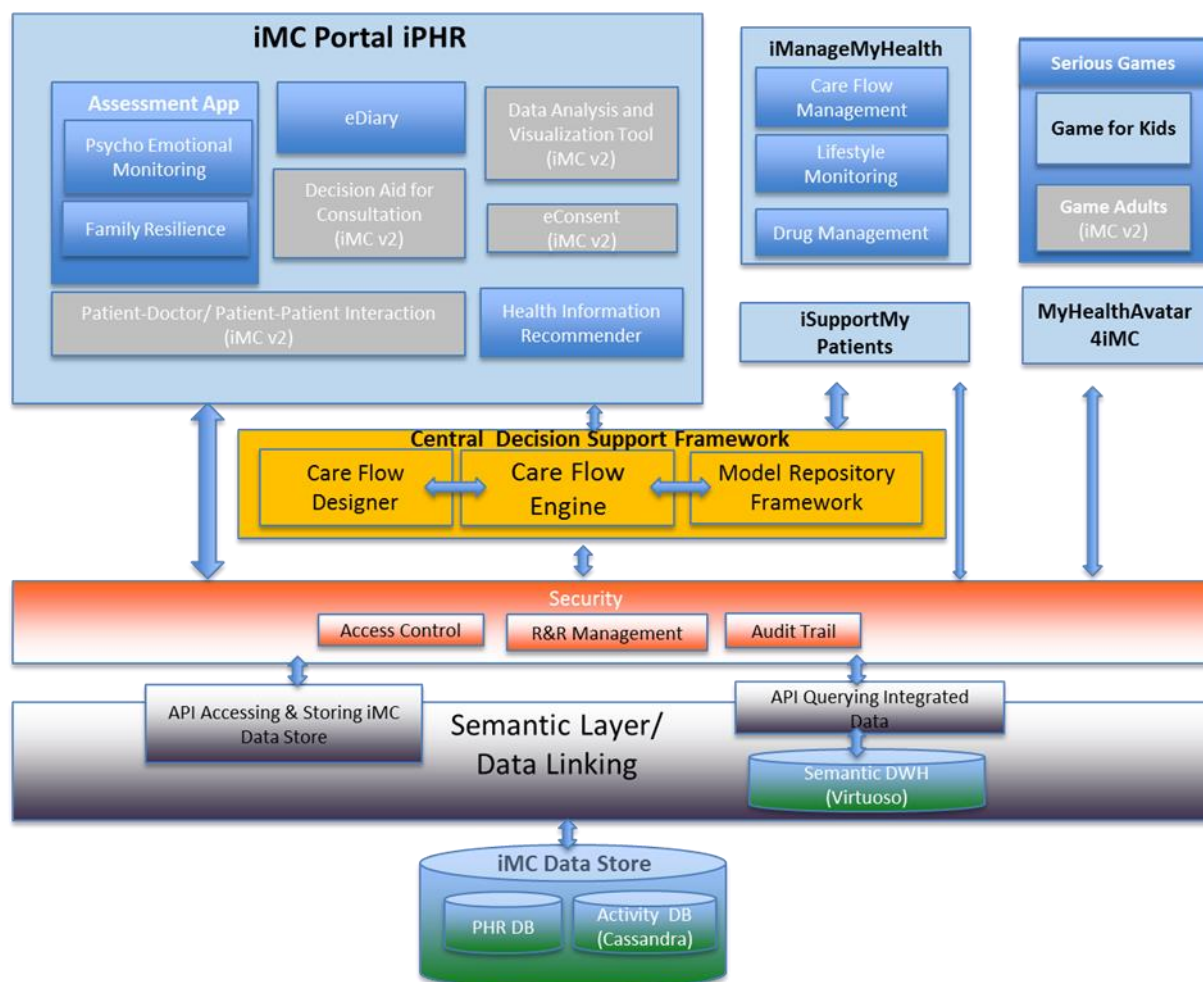


Figure 3: High-level functional view on iManageCancer platform.

4.2. *iPHR*

The intelligent Personal Health Record (iPHR) platform regularly monitors the psycho-emotional status of the patient and periodically records the everyday life experiences of the cancer patient with respect to the therapy side effects, while different groups of patients and their families share information through diaries and clinicians are provided with clinical information. The iPHR extends Indivo PHR [1] and moves beyond the current state of the art among others in the following directions:

GUI: It provides an attractive, user-friendly, graphical user interface that is platform independent and optimized for mobile devices (laptops, tablets, mobile devices etc.).

Sharing & interoperability: Multiple roles are supported such as patients, health professionals, companions and researchers allowing the secure and seamless sharing of selective information,

enhancing the patient/doctor and patient/patient interaction and communication and enabling researches to access statistical information.

e-Diary: If further optimizes interactions of the participants using e-diaries, allowing the patients to enter and to view their activities and behaviours across different period of time

Multiple apps: Besides legacy apps for managing and recording the individual health status (i.e. problems, allergies, medications, procedures, laboratory results etc.), novel apps have been implemented focusing on psycho-emotional monitoring of the cancer patient, providing intelligent services (e.g. drug interactions and recommendations, alerts, patient profiling etc.) and managing medical documents.

Advanced data management: The users are able to be connected through their iManageCancer account to external data sources such as activity trackers, sensors, social media and hospital information systems. To this direction, a novel big-data infrastructure has been designed and implemented allowing the uninterrupted addition of future data sources.

Involve stakeholders in the design and development process: Right from the beginning of the development process all involved stakeholders were heavily involved in the development process. Besides the requirements elicitation phase where more than two hundred possible end-users were contacted, earlier versions of the system have already been evaluated by a diverse set of physicians at three different places and time points and the results have been used to further improve the system.

The iPHR can be accessed using the following URL <https://iphr.ics.forth.gr/>. A user can register and get an account. For demonstration purposes, we use also the username *diana* and the password *12345678A*. A detailed tutorial showing all available functionality can be found in an online tutorial³. As such in this chapter we will provide only a high-level description of the provided iPHR functionality.

The goal of the presented iPHR system is to provide an innovative ecosystem for enhancing the self-management principle of patients through the involvement of all stakeholders participating in the therapeutic process. This chapter focuses on the patient, the doctor and the administrator side whereas the added-value services for the researchers (e.g. smart analytical services for cohort statistics, create project requests for data etc.) are currently being built on top of these functionalities and will be presented in a following deliverable. To the best of our knowledge the developed system is currently the only platform available implementing all the aforementioned functionality.

4.2.1. The access management layer

The iPHR has been customized to allow users to connect through an easy-to-use interface. Patients can access the iPHR functionalities from any kind of device (desktop, tablet, smartphone) by just using a web browser. A screenshot of the interface is shown in Figure 3. By using this interface, the patients can access the intelligent apps offered by the apps layer, that will be presented in the sequel, enabling them to manage their data from anywhere with an active internet connection. The interface is automatically adapted to the screen analysis of the device and appropriate information is automatically hidden or visualized to optimize user experience. In addition, the interface is translated into four languages (English, German, Italian and Greek) whereas adding a new translation is only matter of translating a single text file.

³ <https://iphr.ics.forth.gr/apps/procedures/static/Tutorial.pdf>

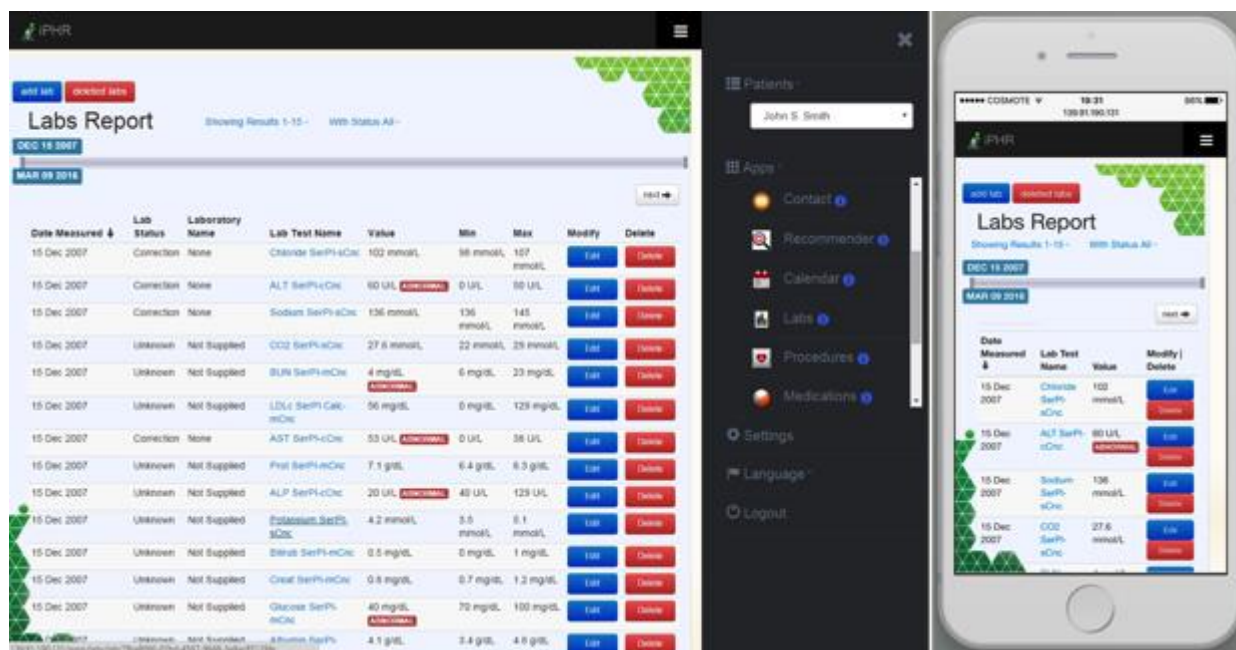


Figure 4: The desktop and the mobile iPHR view.

Furthermore, this layer serves the logical security of the whole infrastructure since patient information should be secured and accessible only by authorized users. The iPHR security system supports authentication methods for connecting to the system and authorization methods for accessing applications and/or data. The security layer uses OAuth 2.037 and SSL and supports five roles: patients, companions (family members, parents, friends, supporters etc.), guardians (for children), health professionals, researchers and administrators. The GUI is adapted according to the selected role. A patient can share selected data with companions and health professionals. Administrators can perform platform monitoring and maintenance. Currently the functionalities with respect to the researcher are under implementation and will be presented in a following deliverable. To this direction, researchers will generate requests and administrators will review the researcher's requests, identify whether there are sufficient patients for the requested project and if so, generate the e-consent to be further signed by the patients that will participate in the research projects. As soon as the required number of patients give their consent the corresponding API functions will be enabled providing access to statistic information. The researchers will not have direct access to patient data but only through the statistical APIs to ensure individual patient's data protection. The administrator's console is already implemented shown in Figure 5

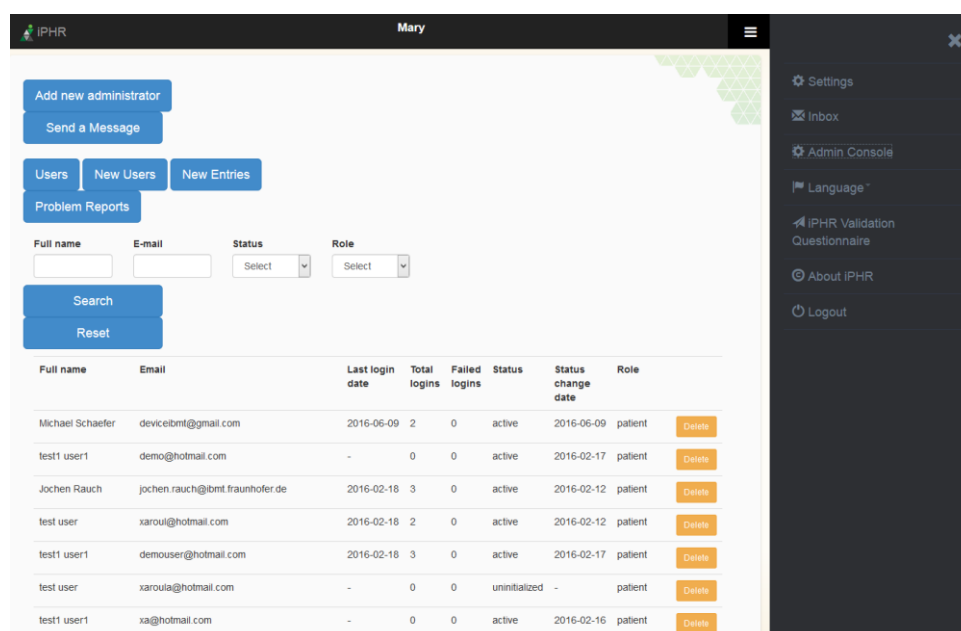


Figure 5: Administrator Console

4.2.2. The apps layer

The apps layer allows patients to view, gather and manage their medical information in an accessible and secure method. The Platform is designed to encourage the patient to take a more active role of their health management, enhance clinician-patient communication, maximize compliance to therapy and produce intelligent recommendations.

There are currently four apps categories which we analyse below:

General health monitoring apps: In this category there are app for recording and visualizing all health related information (e.g. the *allergies*, the *measurements*, the *medications*, the *procedures*, the *immunizations*, the *vital signs*, the *diagnoses*, the *problems* and the *laboratory results* app). Example screenshots of the measurements app are shown in Figure 6 and Figure 7. Data entry is supported by auto-complete mechanisms whenever possible. In addition, all data entered are annotated behind the scenes with three different ontologies (LOINC, SNOMED-CT and RxTerms) using NLP techniques in order to assign meaningful information on the entered data. In addition to these general-purpose apps specifically for cancer patients a *Psycho-emotional Status app* and a *Family resilience app* have been implemented. The apps use standardized, validated psycho-behavioral questionnaires to monitor the psycho-emotional status of cancer patients and their families and their individual resources in coping with cancer.

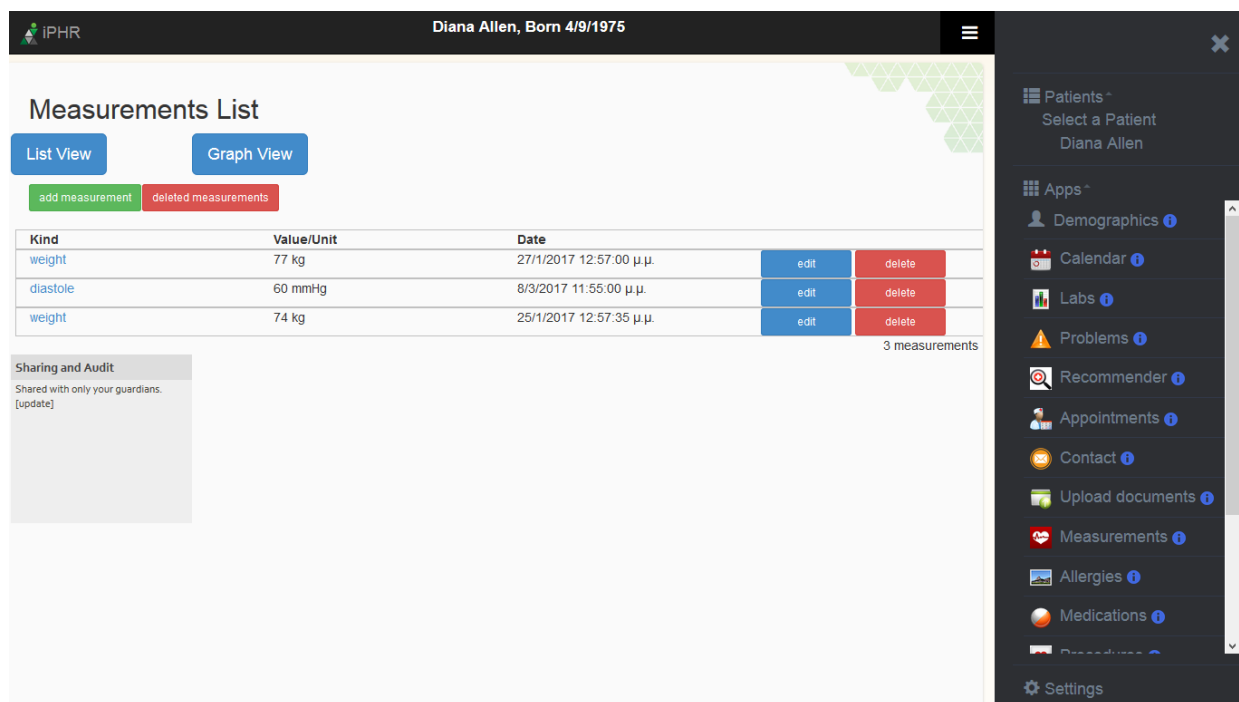


Figure 6: Measurements list view

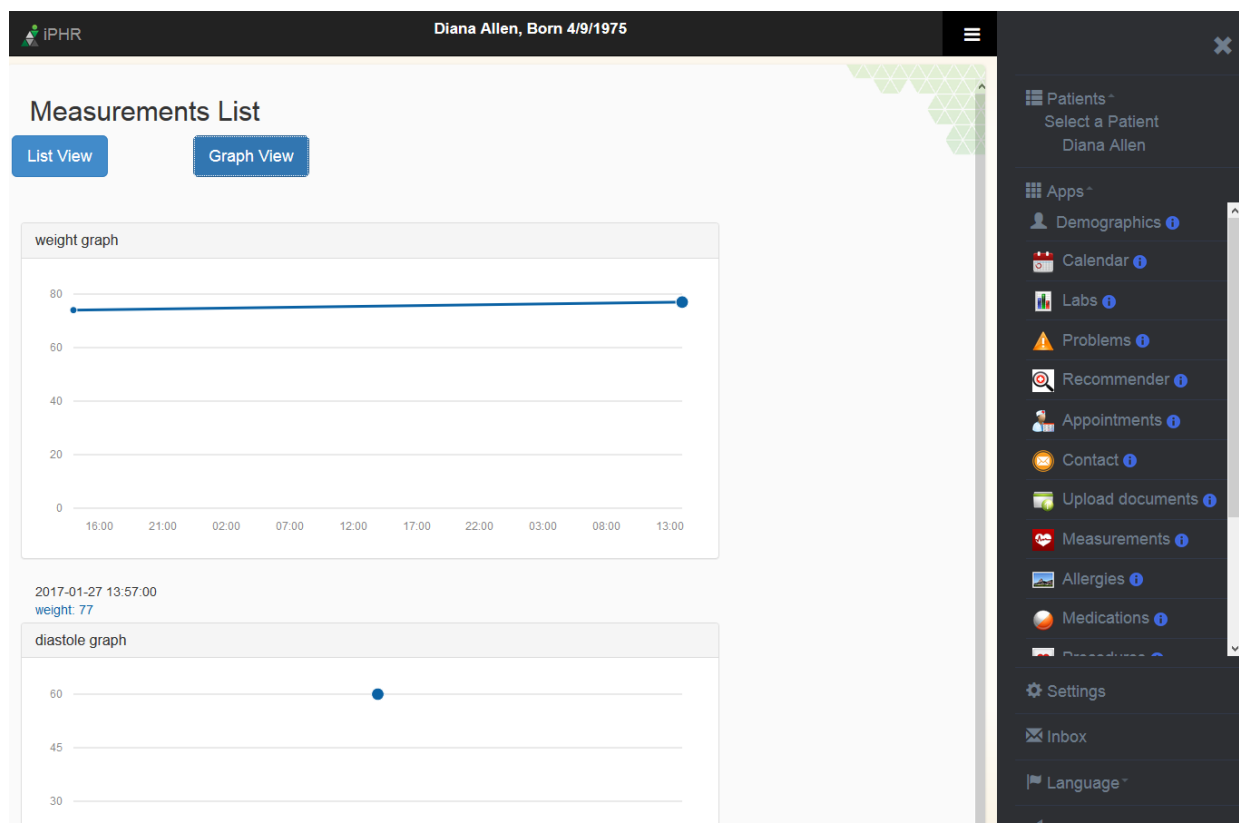


Figure 7: Measurements graph view

Imaging/document repository apps: In this category, there are apps allowing the *upload* and *management* of *medical documents* such as discharge letters and images. These documents can

also be linked to records within the general health monitoring apps. A screenshot of the corresponding app is shown in Figure 8.

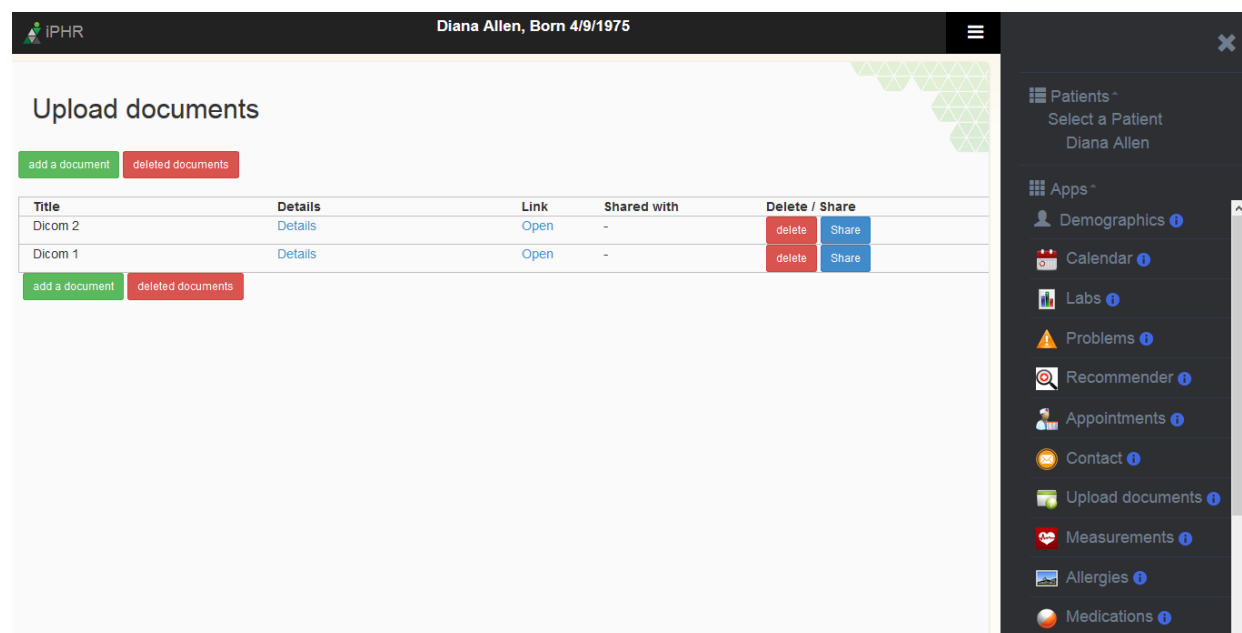


Figure 8: Upload documents application

Management apps: In this category, there is an app for linking and importing *sensor* and *activity* data from external devices (Fitbit, Moves, etc.) and an app for *exporting* all or partial profile information in XML and JSON formats. An additional app is provided for *sharing information*. Using this app, each user can formulate groups, add other accounts to these groups and select which information is shared with which group. For example, a patient can select to share his/her entire medical profile with his/her medical doctor and later he/she can update this choice at will. Beside sharing information with specific group or people, an *e-consent app* will allow patients to give their consent for providing access to statistical information over their profile for individual research projects. Patients will be able to identify the reasons that these projects are requesting access and can electronically give or withdraw their consent at will. Finally, there is an *appointment app* in this category which patients can use to set their future appointments with their doctors.

Intelligent services apps: In this category, there are apps allowing access to the integrated information and offering added value services. An *e-Diary* collects and visualizes all relevant information helping patients to better understand their health information, offers a complete track of their health status and notifies them about important events such as appointments or taking medications. To this direction, *alerts* are also shown to the patients either for reminding an appointment, or a medication. An example alert is shown in Figure 9.

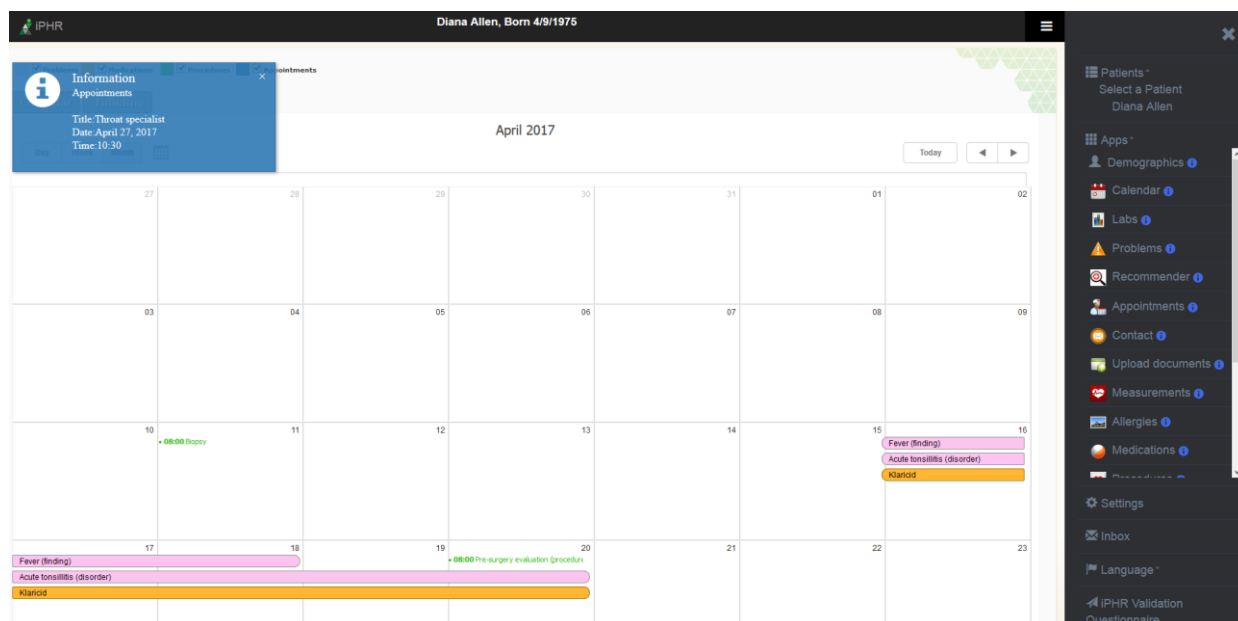


Figure 9: e-Diary calendar view and alert

Finally, the *information recommender* app is a semantically-enabled, intelligent mechanism that empowers patients to search in a high-quality set of web documents for relevant medical knowledge. The documents are high quality documents in the cancer domain, identified by the clinicians and indexed using NLP techniques. The indexed documents are matched automatically with the patient profile and his/her input queries to automatically provide intelligent and personalized recommendations, according to the individual preferences and medical conditions. The recommendations can be textual web pages, documents (pdfs/docs) and videos. The user has the option to rate the results of the app for each question.

Information exchange & communication apps: In this category, there apps that enable information exchange among participants. The patients can use the *forum* app in order to ask a question that corresponds to some of the specified topics or answer to another user's question. Topics that are irrelevant or can be offensive in any way can be reported from users. The administrators are responsible to remove the reported posts and even close the user account. Private messaging among users is also an option through the *forum* app. The *chat* app is another communication app for a more explicit communication. Screenshots of the aforementioned apps are shown in Figure 10.

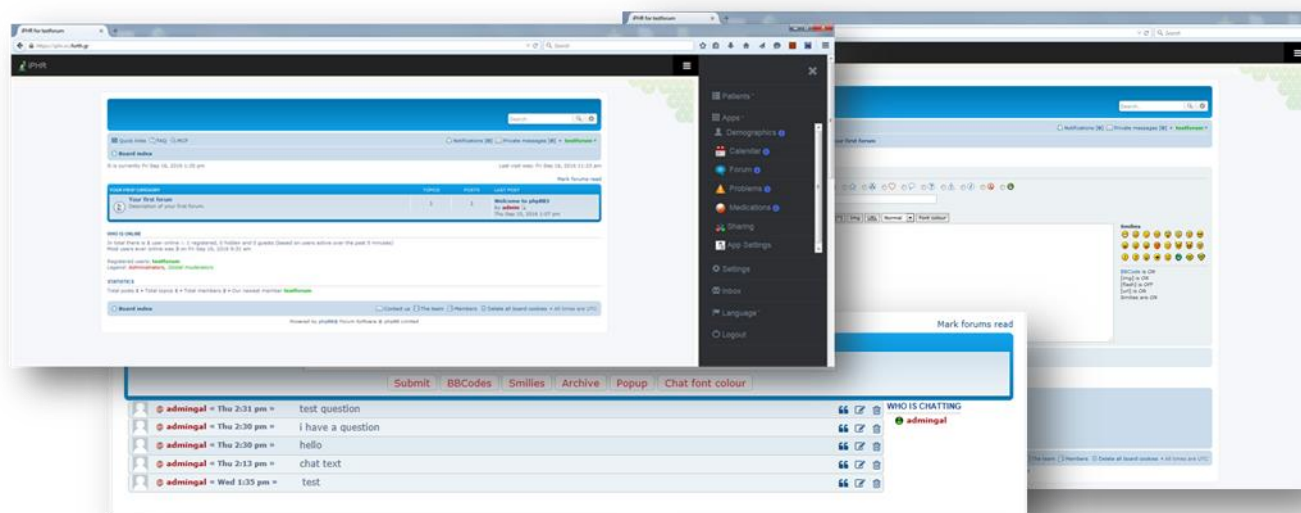


Figure 10: Communication & Information Exchange apps

Apps for health providers: Although this chapter focuses on the functionality of the iPHR for patients, there are already developed apps for clinicians and more are yet to come till the end of the iManageCancer project. The clinicians can select the patients that share their data with them and visualize the shared data through tables and diaries. In addition, the *Information Recommender Annotator app* allows clinicians to enter and update high quality documents that are automatically indexed and made available through the Information Recommender app to their treating patients. Another app, the *psycho-emotional profiler app* analyses the patients' answers to the psycho-emotional questionnaire and creates their psycho-emotional profile in real-time. The results are visualized using various visualization methods such as tables and bar-charts. The scores for each factor included in the questionnaire ('global self-rated health', 'perceived physical health', 'anxiety', 'self-efficacy', 'cognitive closure', 'memory', 'body image', and 'sexual life') are automatically calculated and scores that deviate from the average population are represented using different colours. The average population can be a sample of breast cancer patients or a sample of healthy subjects, depending from the need and the interest of the physician. When one or more of the patient's scores deviate from average, one or more recommendations are provided to the physician together with a short explanation of the corresponding factor(s). As more of the tools become available, new visualization methods will be implemented to help clinician quickly identify the patient profile and optimize his/her communication with the patient. Another application available for clinicians is *clinical assessment app*, which provides a questionnaire for adding detailed information about patient's cancer diagnosis such as treatments, diagnosis, age of diagnosis, karnovsky index etc. A screenshot of the cancer clinical assessment tool is shown in Figure 11.

New Questionnaire

Patient name
-- select an option --

Age at diagnosis

Gender
Male

Diagnosis
ALL

Initial diagnosis
Initial

Treatment (select treatments)

Chemotherapy Intensity: High Duration: lesser than 3 months

Surgery Intensity: High Duration: lesser than 3 months

Radiotherapy Intensity: High Duration: lesser than 3 months

Karnovsky Index
100 – Normal, no complaints, no evidence of disease.

Expected outcome
Greater than 90% survival probability

Computer skill of the child
Very good

Figure 11: Clinical assessment app

A screenshot of some of the apps is shown in Figure 4 whereas the apps appearing in the menu can be selected according to patient's interests.

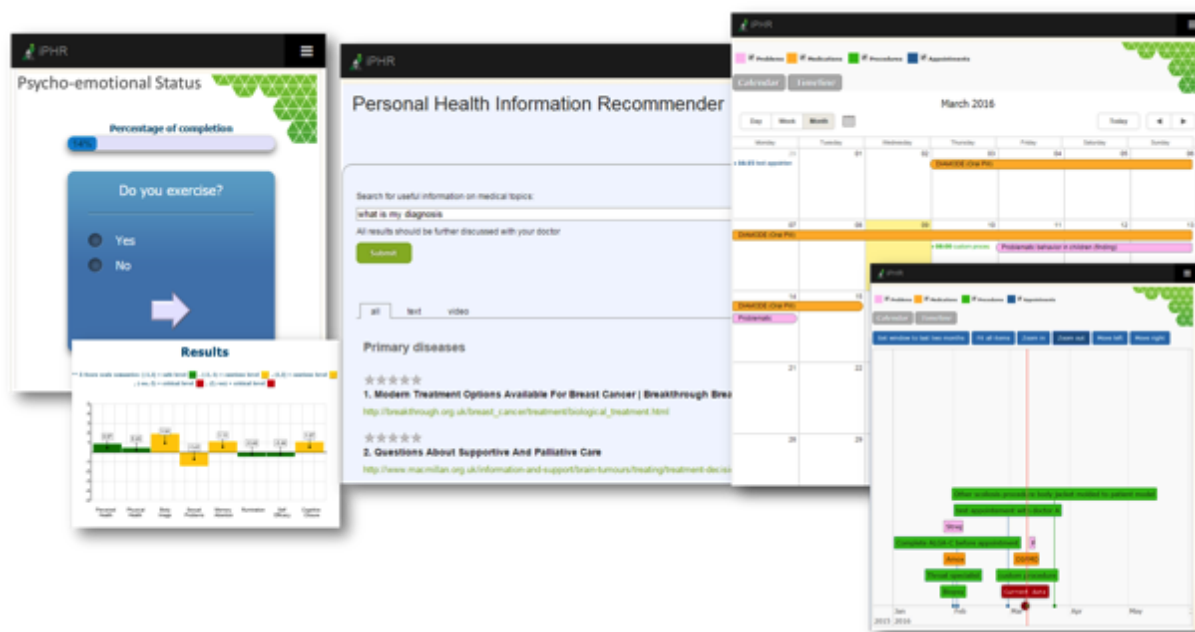


Figure 12: Some of the iPHR apps (psycho-emotional status, profiler, personal health information search engine, e-diary)

4.3. MyHealthAvatar

The MyHealthAvatar app in iManageCancer provides a unique platform that empowers patients in terms of supporting their life management and healthy lifestyles for the management of cancer.

4.3.1. Relevance to cancer management

The MyHealthAvatar app helps weight control, calories control and promote physical exercises.

A healthy lifestyle can give you more control over your health and help you to improve it. Lots of things can affect your health, including body weight, calories and physical activity. There is a strong evidence that weight problems can increase the risks of affecting treatment of many different types of cancers, for example, the prostate cancer - a healthy weight means the cancer is less likely to spread after surgery or radiotherapy; Hormone therapy may also be more effective if the patients stay a healthy weight. Many side effects from the treatment are much easier to cope after the surgery under a healthy weight. On the other side, being underweight is also problematic, and affect the health of the patients significantly. Therefore, it is very important for cancer patient to stay at healthy weight.

Maintaining a healthy diet is an important approach for weight control and hence reduce the risk of many health problems. A healthy weight can be improved progressively and steadily by making changes to the diet and by being progressively engaged in a reasonable amount of physical exercises.

Engaging in physical activity is another important means of weight control. It can also help the patients cope with some of the side effects of the treatment, and help release their feelings of anxiety and depression. There is also some research that suggests that physical activity may help slow down cancer growth.

4.3.2. User interface summary

Logging in: Using this login interface, users can sign up or log into the MyHealthAvatar for iMC mobile application. The page itself is presented in a standard login form, two text fields to receive the username and password, a “Remember me” check box and two large user-friendly buttons to initiate the login or alternatively begin the registration process.

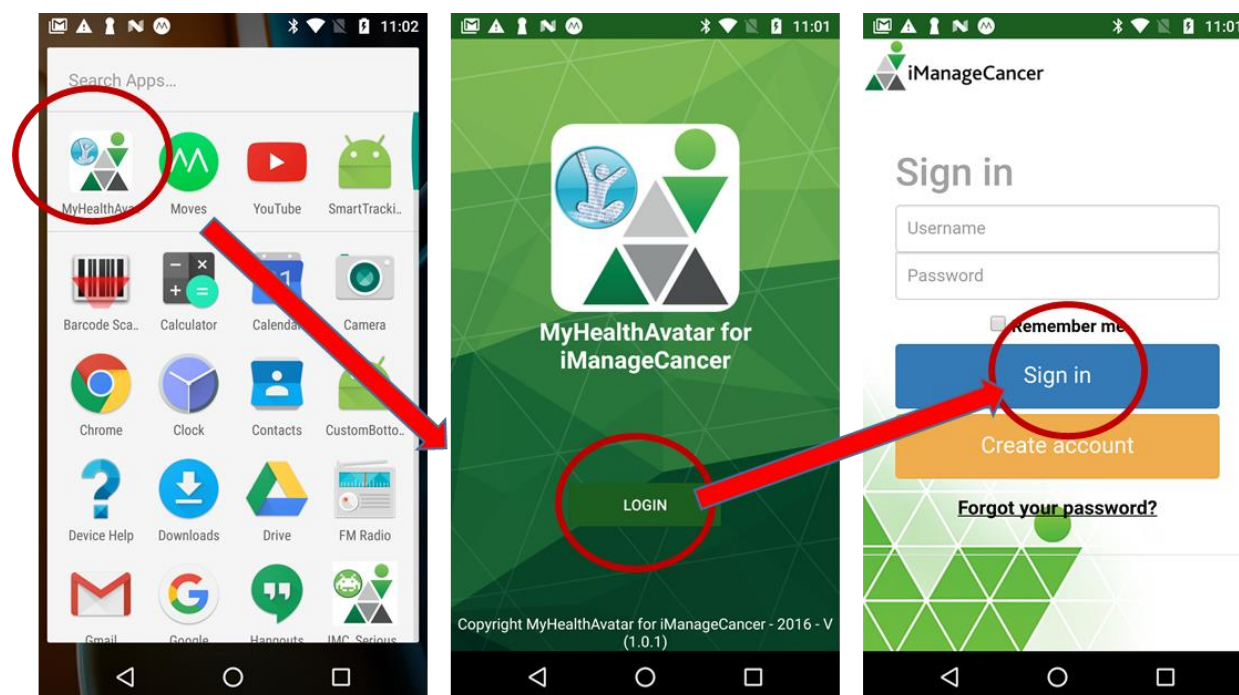


Figure 13: MyHealthAvatar login page

Accessing the navigation menu: The sliding navigation panel is a fragment view within the Android application. It is gesture activated and implements standard single touch event triggers to facilitate application feature navigation.

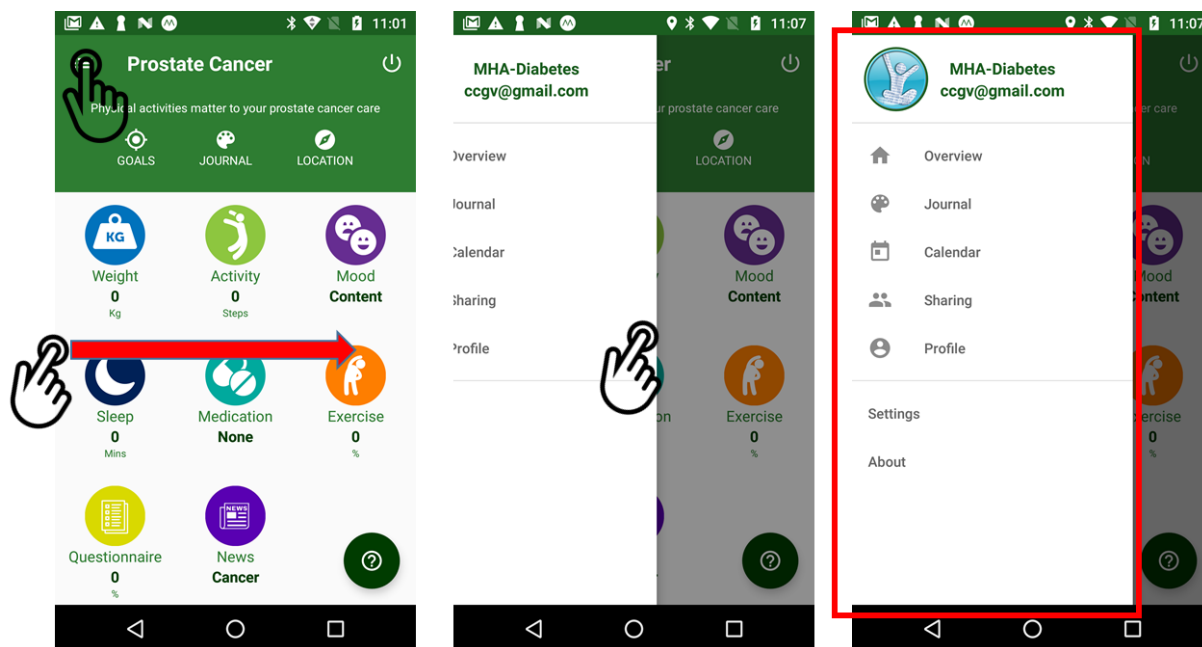


Figure 14. Sliding menu navigation.

Overview: The Overview page provides quick access to suites that relate to the user's cancer condition. The page also provides quick access to goal setting, journal and the location. The overview's purpose is to collect together suites that are most relevant to the user's condition and present them in an easy to use grid for easy access.

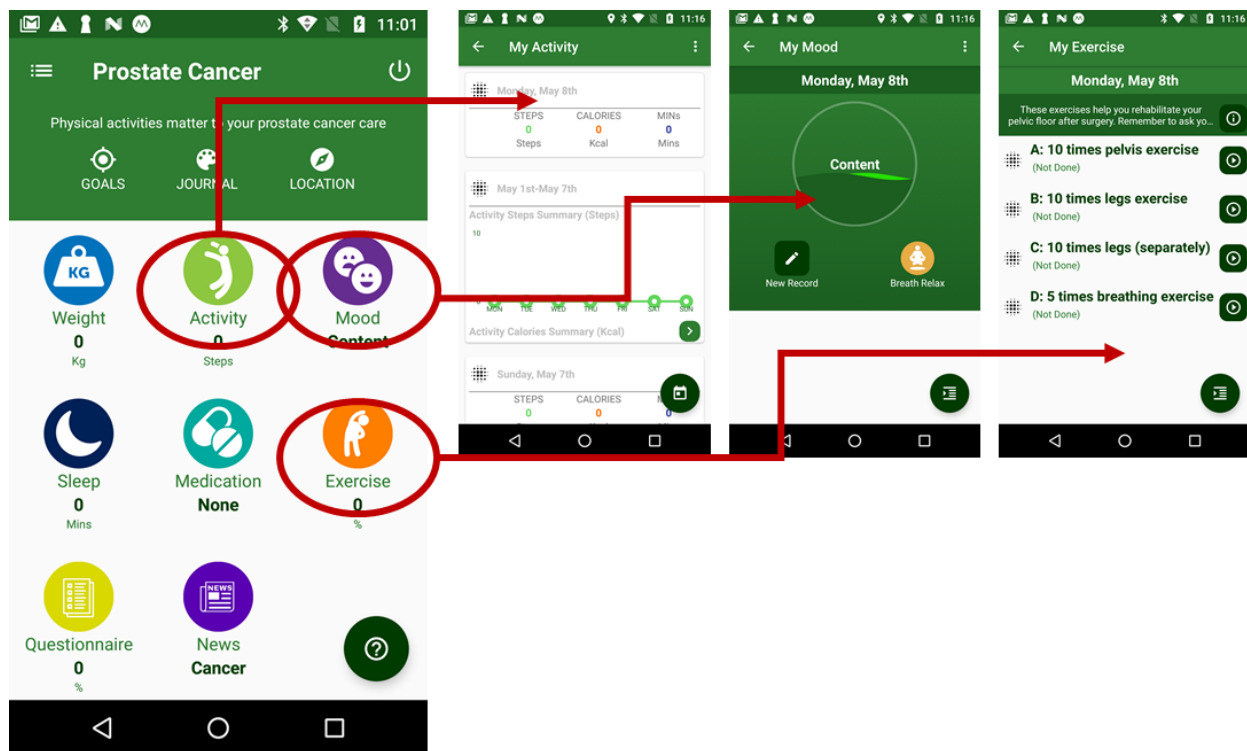


Figure 15. Overview page.

User can also access to the goal setting page, the journal page and the location from the overview page – see the three figures below.

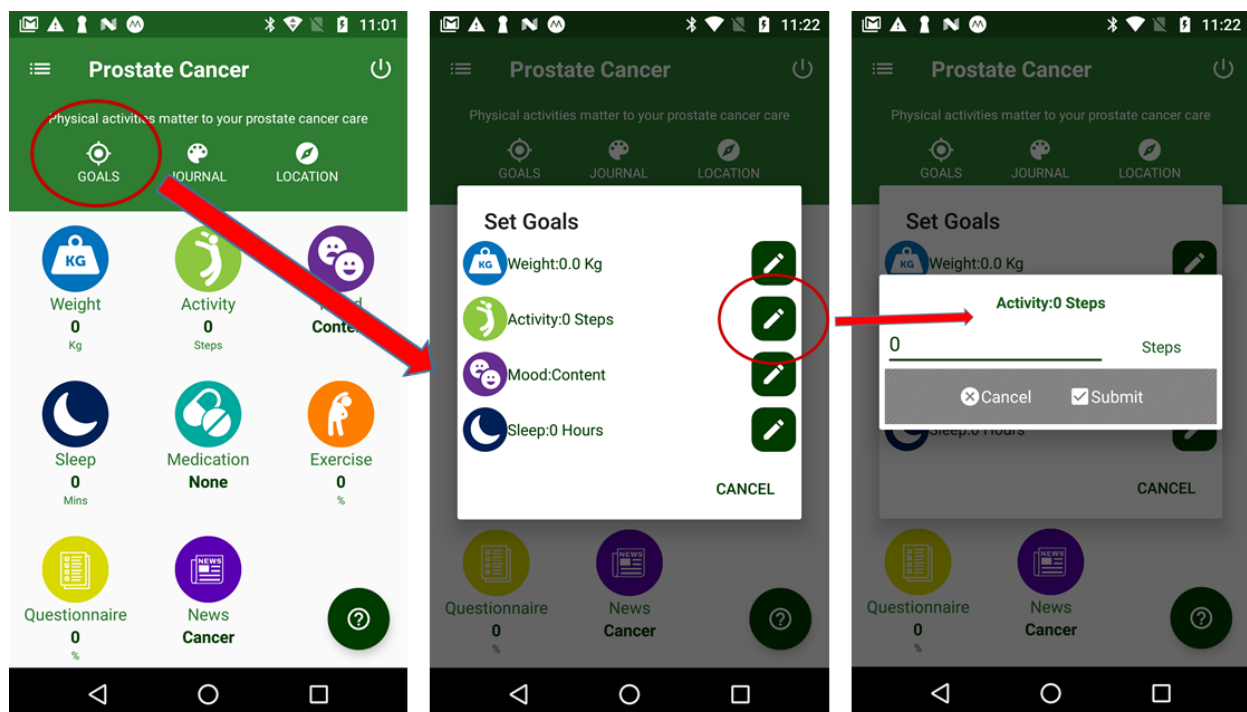


Figure 16. Overview: goals

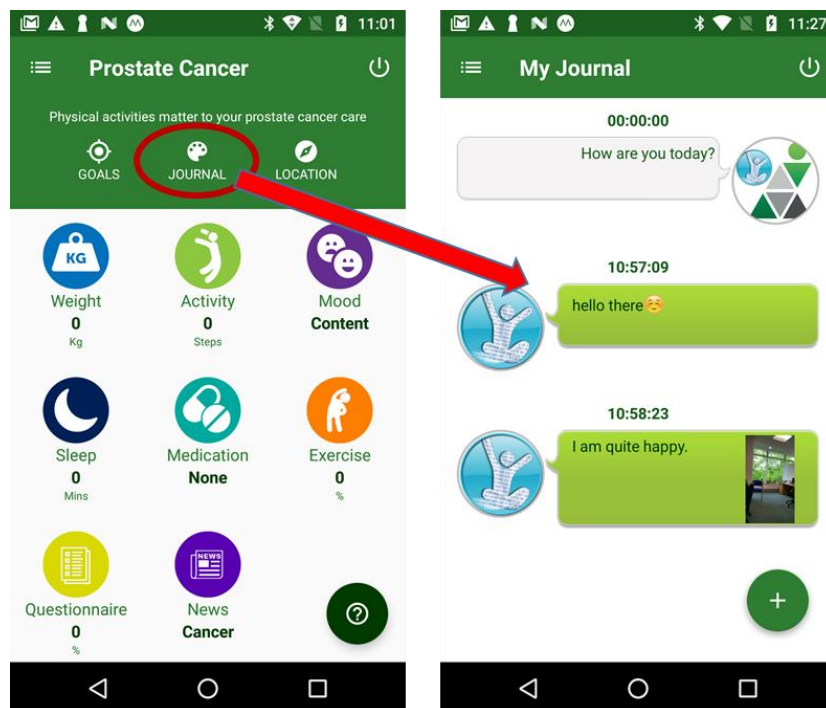


Figure 17. Overview: Journal.

Location: The Location feature provides place and activity information to users through a list. It can monitor the calories burnt and also provides information about the location. The user can also navigate backwards through historical records by the left and right arrow buttons, or click the calendar to choose the specific date. The interface also provides quick access to the location control menu. Users can choose to turn on/off the location tracking and the accuracy level. Utilising higher accuracy will result in higher power usage. The lower accuracy setting will yield lower quality activity tracking results.

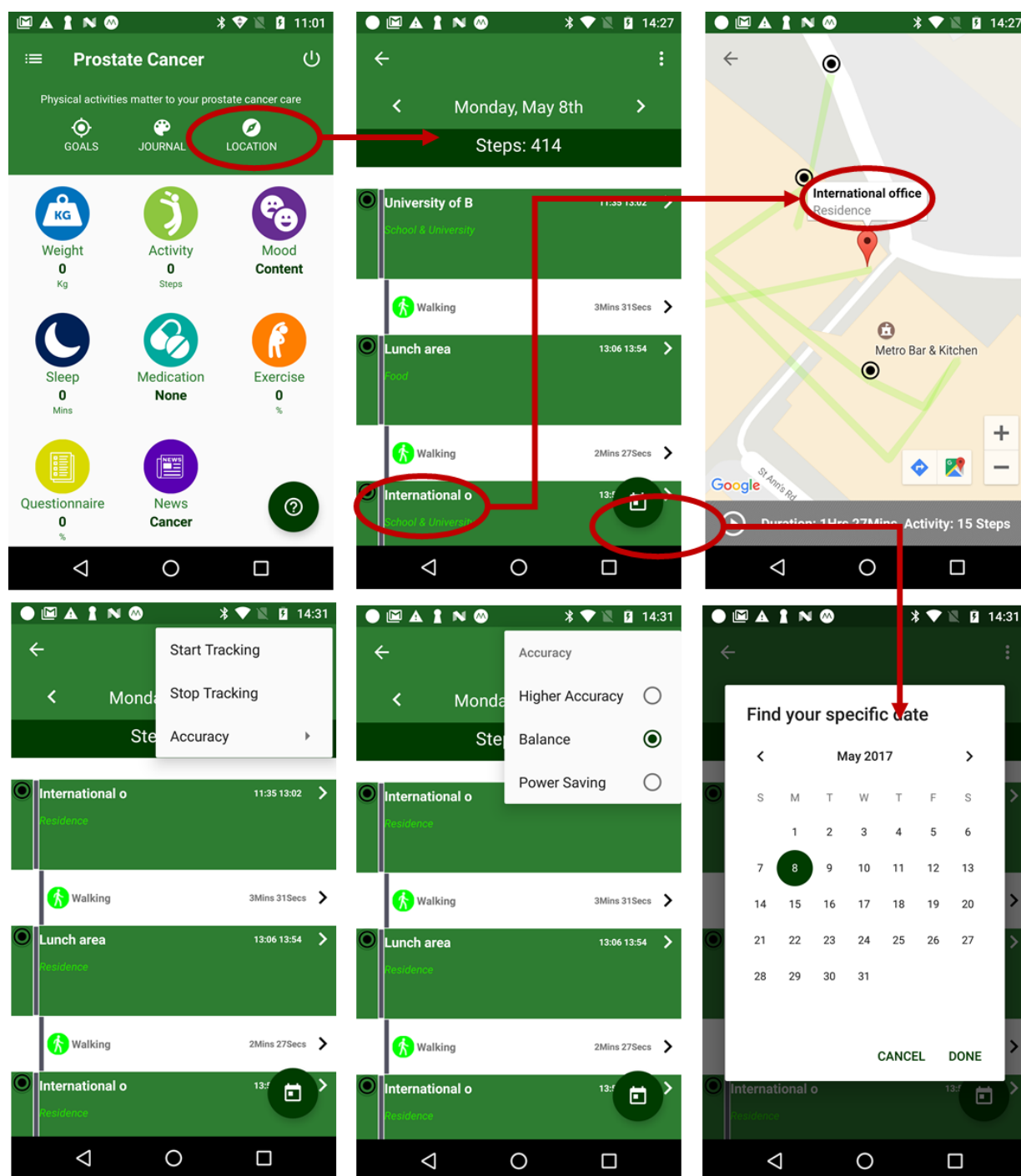


Figure 18. Overview: Location.

Journal: The Journal is presented in the style of a chat interface, with the MHA logo acting as an agent who provides reminders, motivation and information to the user. The journal allows the user to view and input a number of events and measurements throughout the day. This provides a mechanic for the user to log their daily activities in line with automatically generated content in a scrollable chronologically ordered list. It also provides feedback opportunities for the user to interact with – see Figure 19. Journal page access and use, and Figure 20.

BMI level has higher risk. The user can also navigate backwards through historical records by swiping up and down or click the calendar to choose the specific record. The interface also includes a summary on every Sunday and the last day of every month. The interface also provides quick access to the goal editing page.

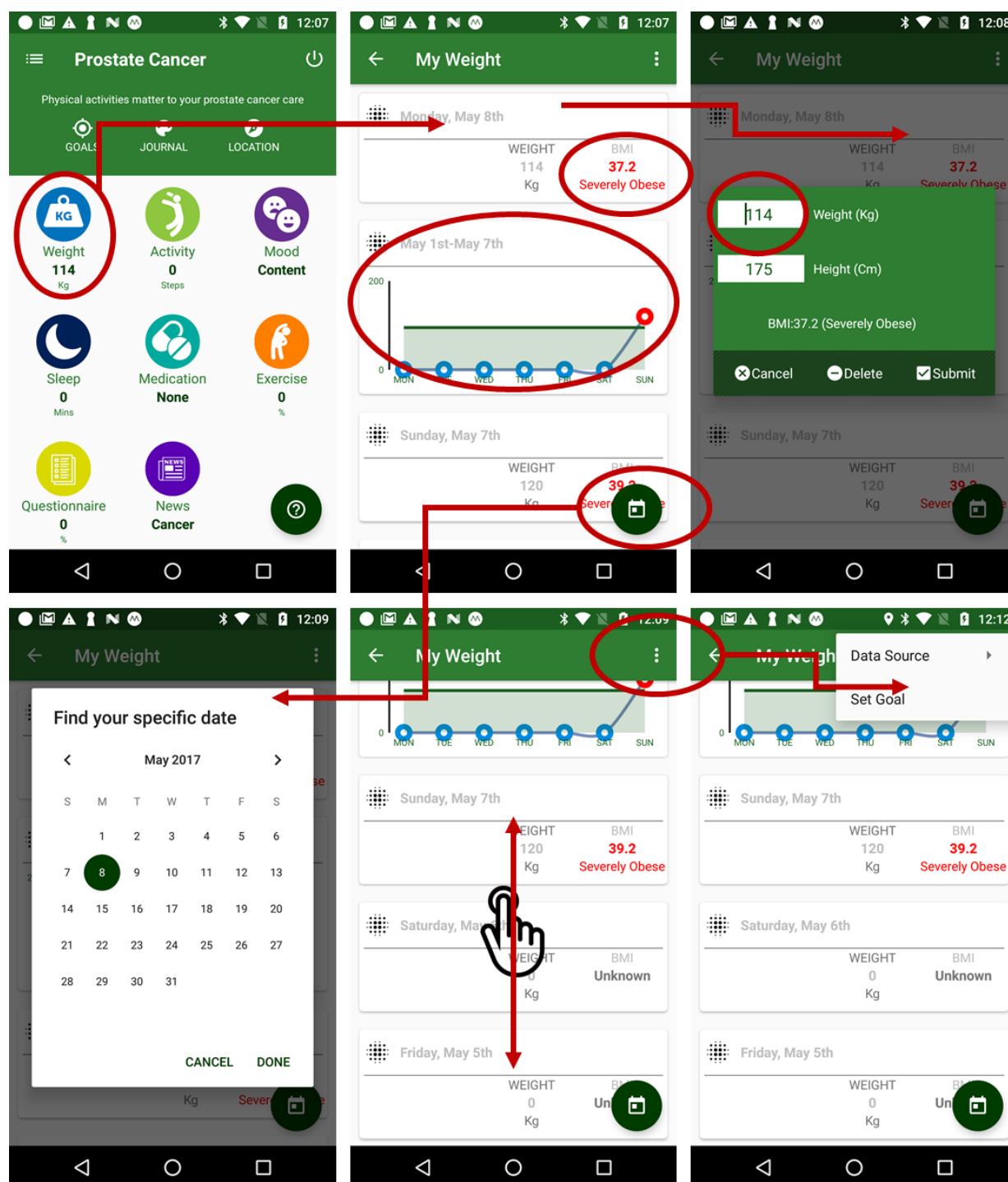


Figure 21. Accessing the Weight suite.

Activity suite: The activity suite allows the user view their current activity level for the day. The interface also provides quick access to the goal editing page. The user can also navigate backwards through historical records by swiping up and down or click the calendar to choose the specific

record. The interface also includes a summary on every Sunday and the day at end of the month. The interface also provides quick access to the goal editing page. The purpose of this suite is to provide a simple and fast method for a user to view data, which provides the user with feedback.

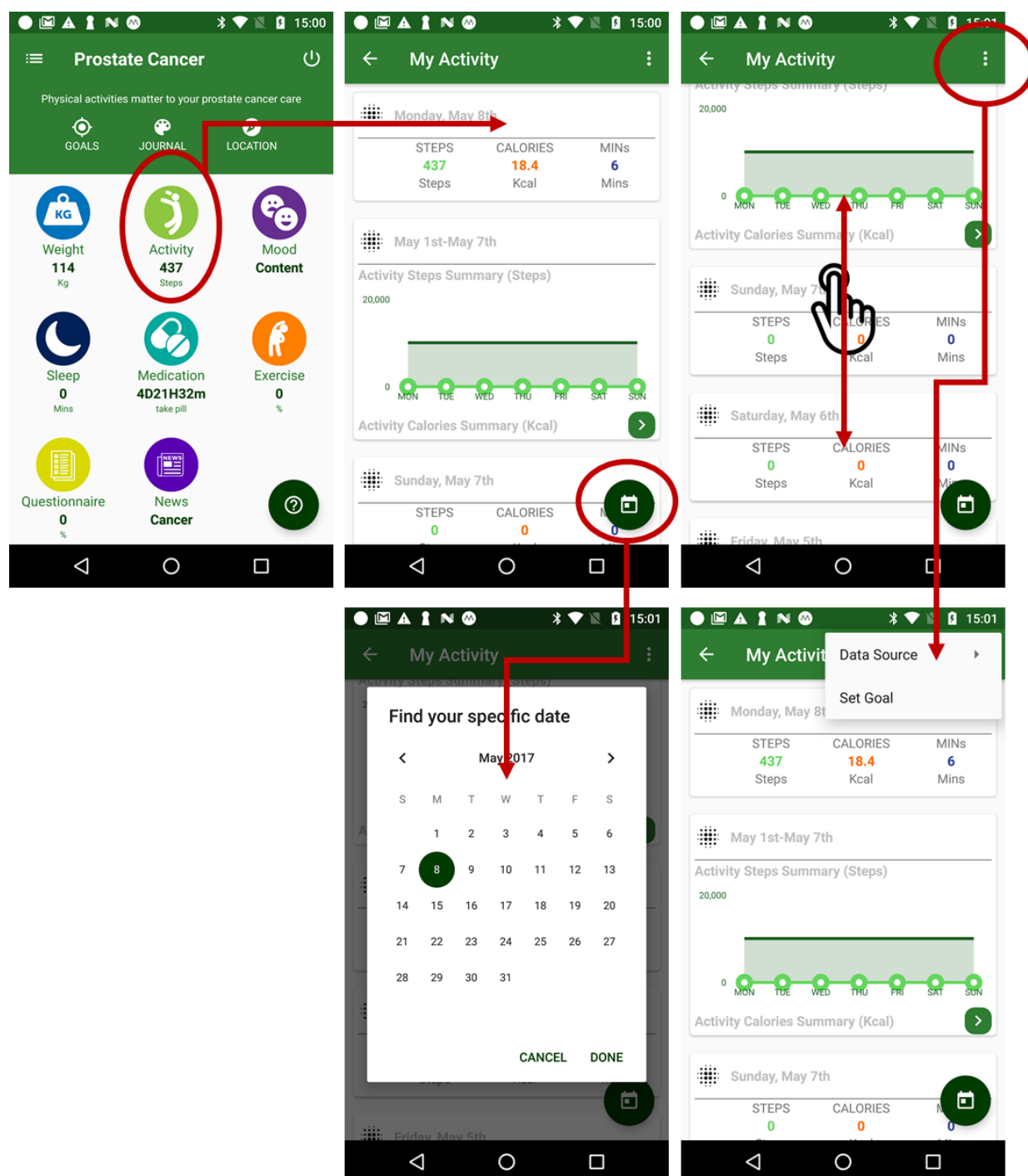


Figure 22. Accessing the Activity suite.

Medication suite: The medication suite helps the user to see all the medications that are due on the current day, it also provides them with the functionality to confirm the medication event or create new one. It lists due medication events, allows event confirmation and event creation. Also, this interface is intended to display user data and allow historical review of data. Moreover, user can choose the alarm ringtone from the top-right menu.

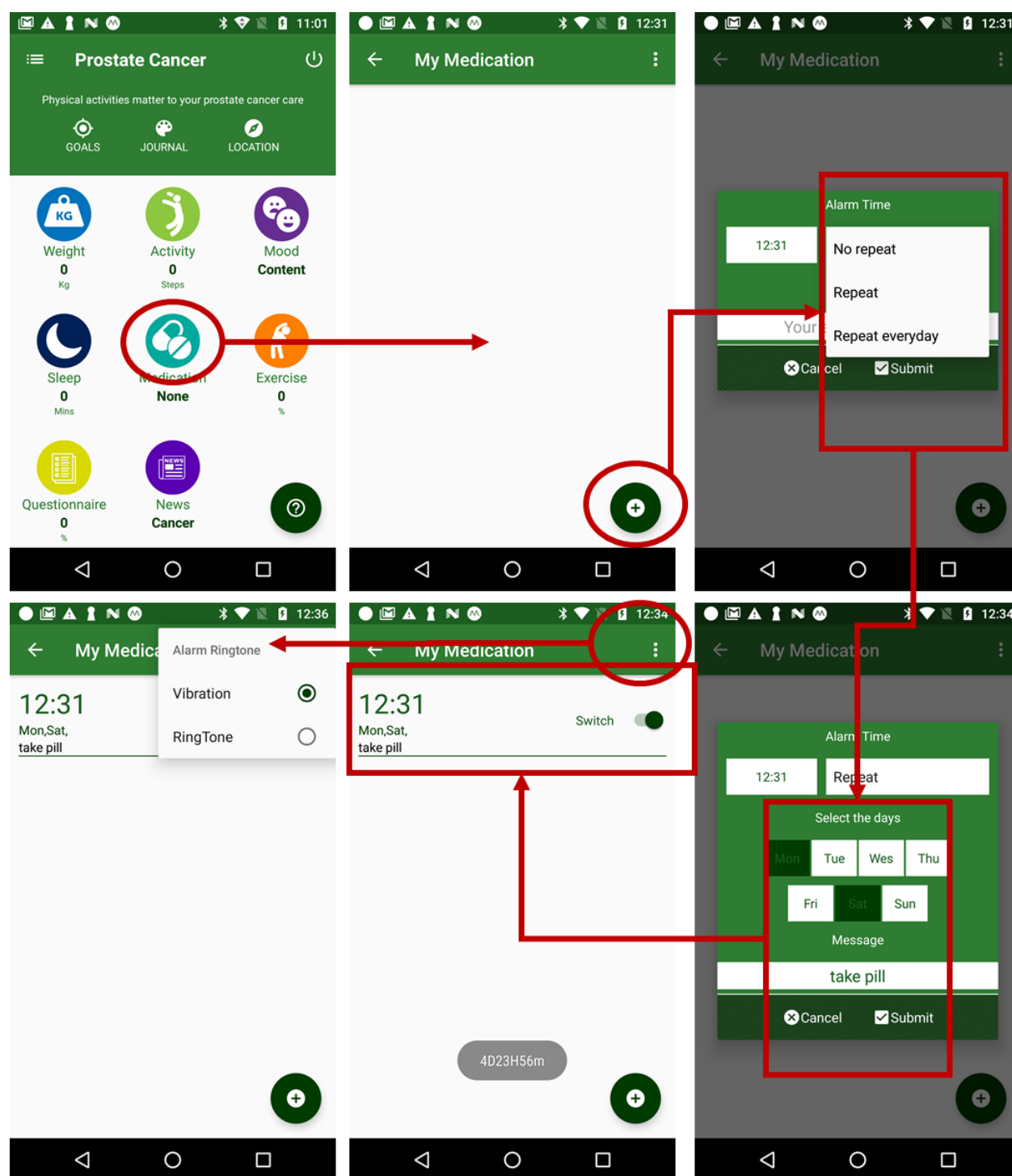


Figure 23. Accessing and using the Medication suite.

Sleep suite: The sleep suite helps the user enter and interpret their sleep duration and quality. Allowing manual input as well as automatic detection from wearable sensors (Fitbit). The sleep suite displays sleep data from sensors, as well as provides a data entry interface for manual sleep pattern entry. The interface also includes a summary on every Sunday and the day at end of the month.

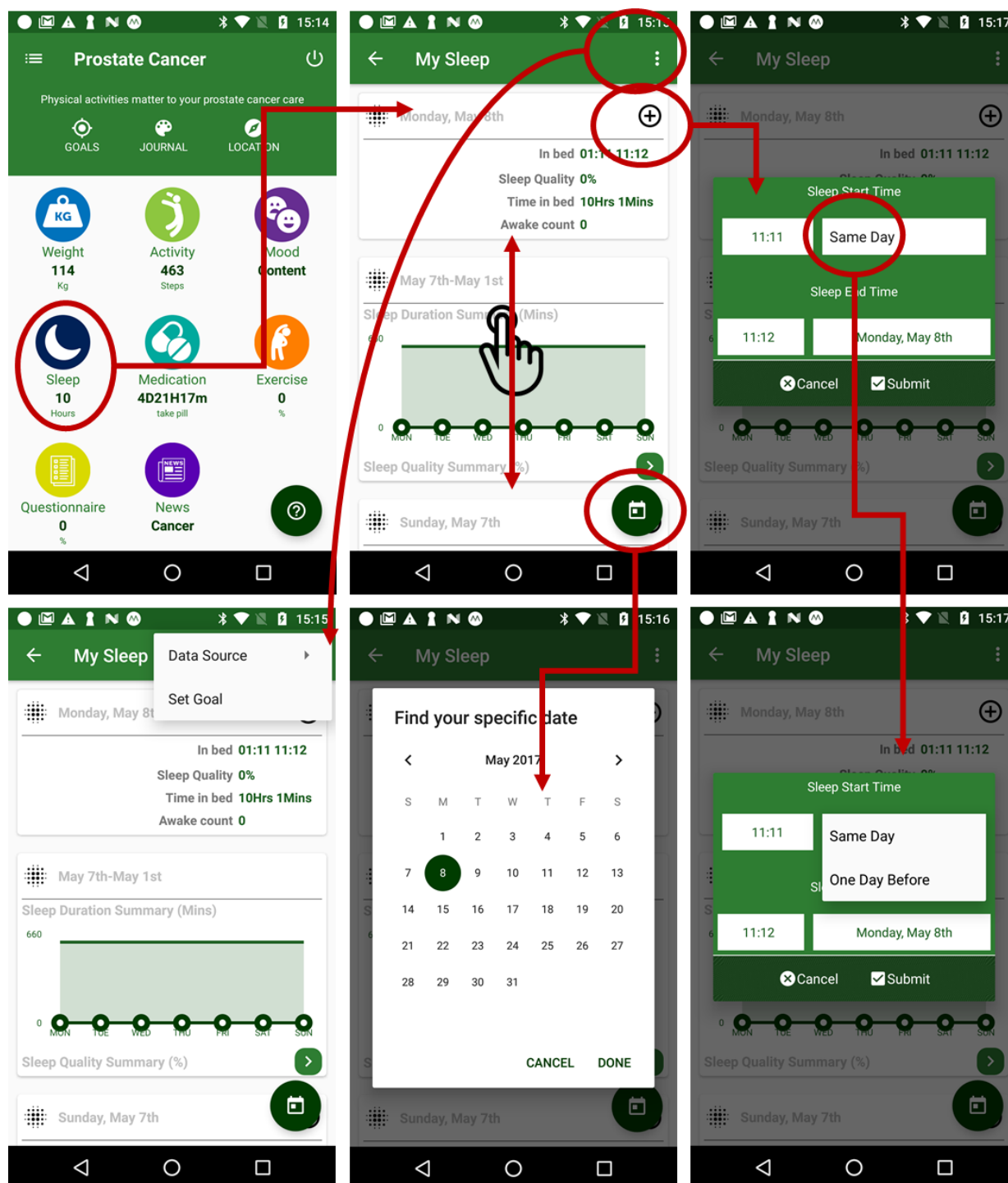


Figure 24. Accessing and using the Sleep suite.

Emotion suite: The emotion suite allows the user to enter their emotional state at any time of the day and the interface provides feedback in the form of an emotion dial. The water container is displays a range from very happy (green) to very unhappy (red). The suite also introduces the user to a relaxation technique in the form of a breathing exercise. This suit provides an interface for manual data entry of the user's emotional state, and user feedback in the form of a coloured water container. The suite interface allows the launching of a breathing exercise interface. The suite will also display summaries of user data and allow the historical review of data.

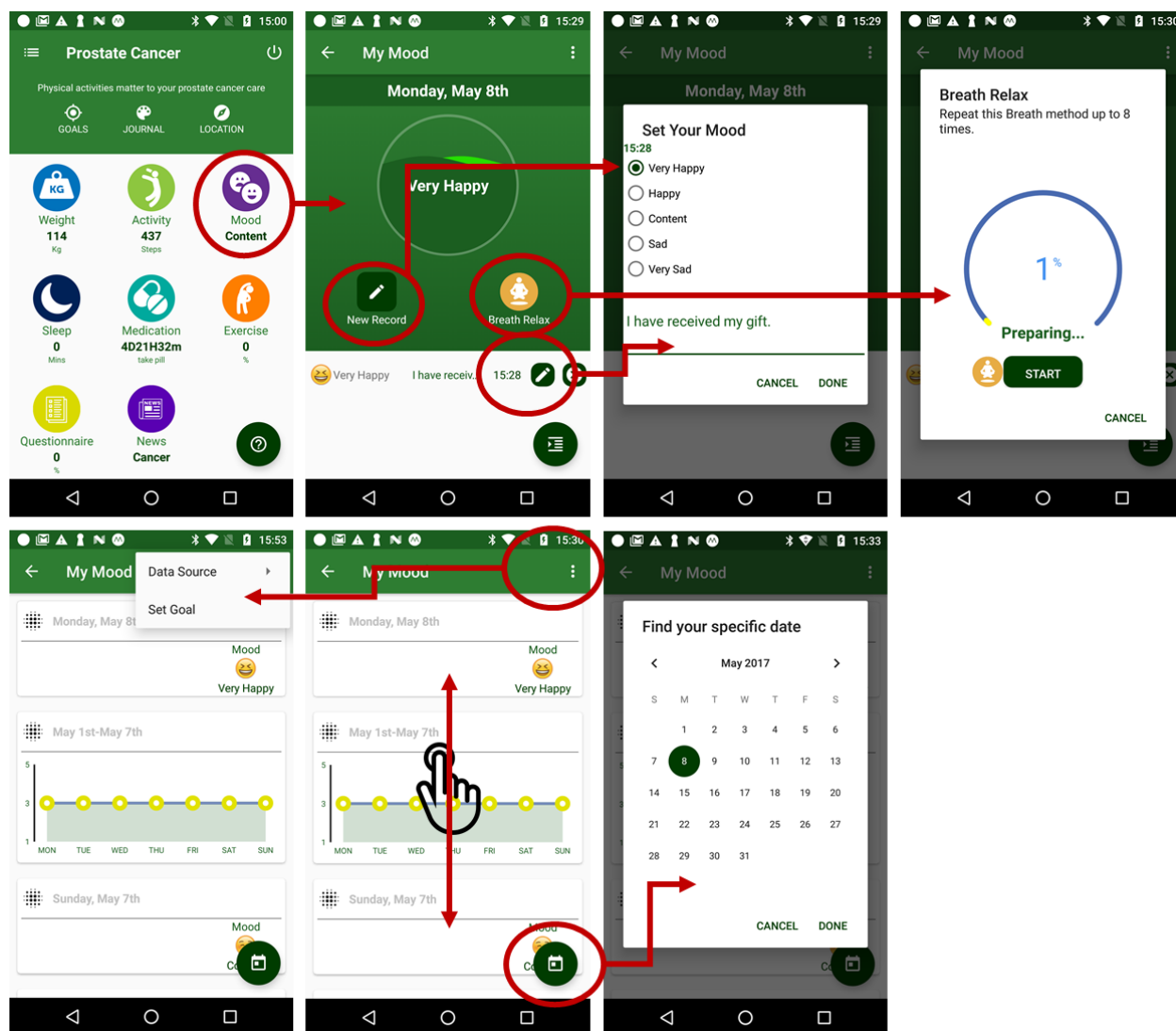


Figure 25. Accessing and using the Emotion suite.

Exercise: Exercise to help rehabilitation of pelvic after surgery. These include Pelvis exercise (10 times per day), Legs exercise (10 times per day), and Breath exercise (5 times per day). Video demo and exercise guidance are provided. The app also allows the users to record and check progress every day.

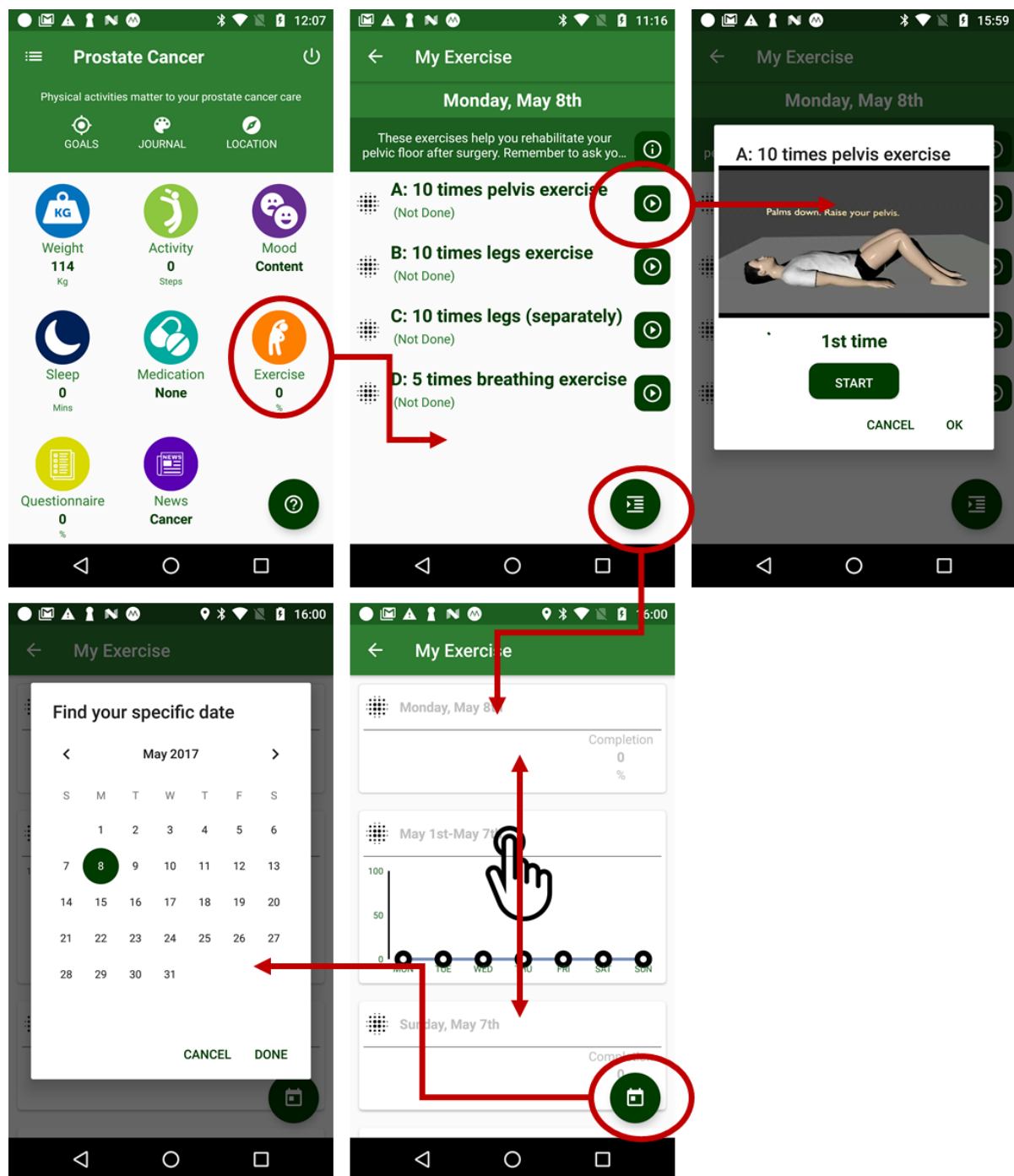


Figure 26. Accessing the Exercise suite.

Questionnaires: This includes the Surgical Data Collection questionnaire and cancer data collection after surgery.

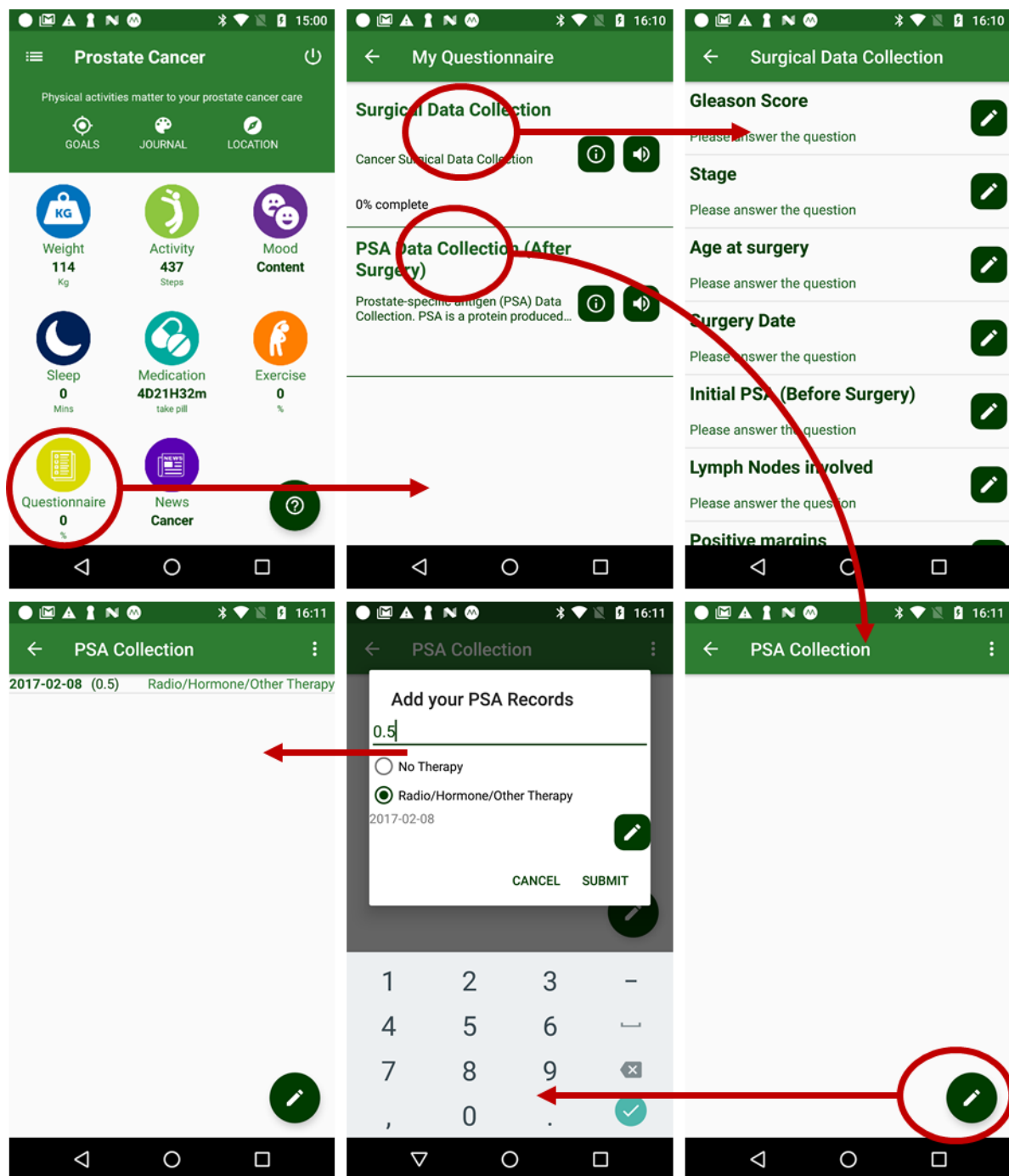


Figure 27. Accessing the Questionnaire suite.

News: This app provides guidance/news for patients with prostate cancer. By using the filter function, the patients can search and choose items on the list and view the details.

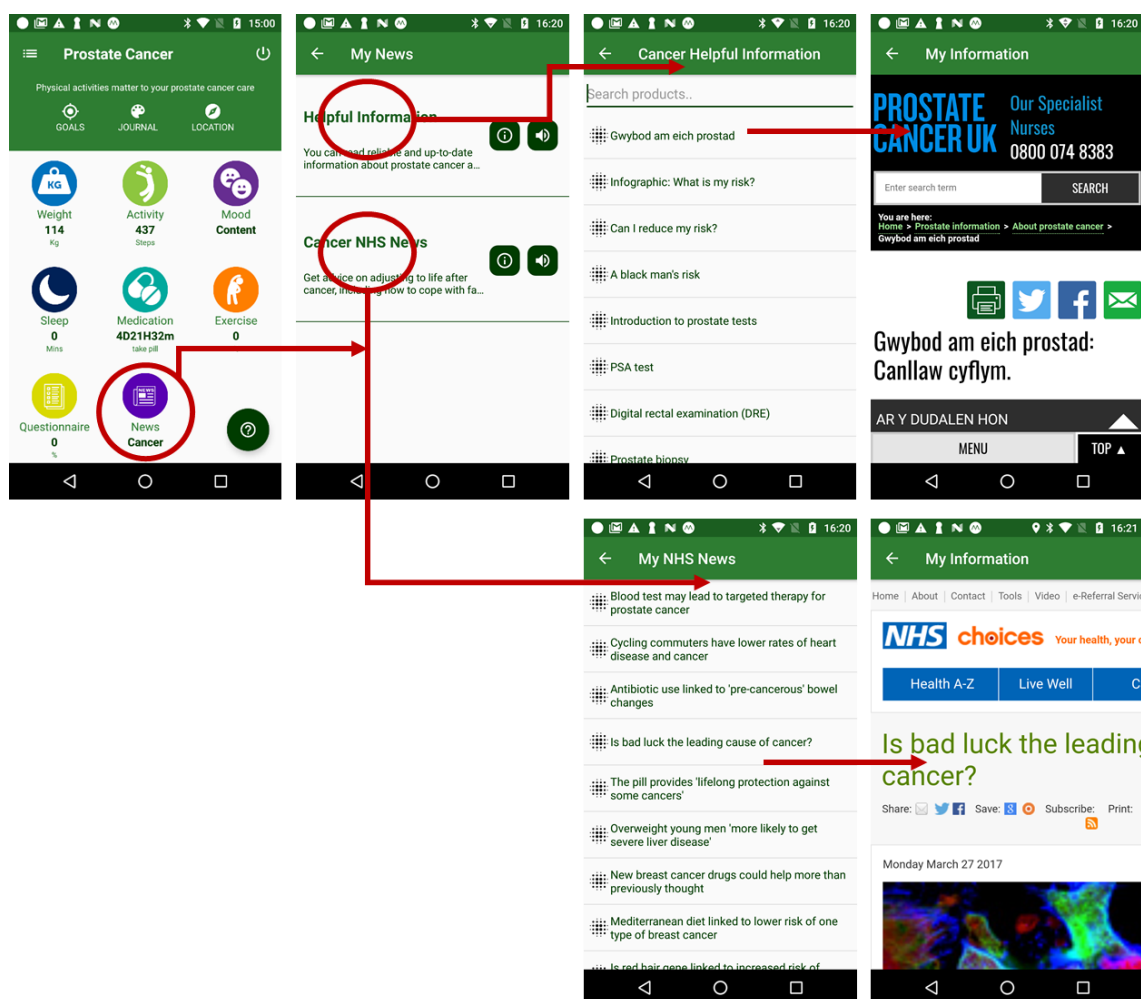


Figure 28. Accessing the news suite.

Calendar The calendar displays one month of information at a time in a standard calendar format. The individual cells of the calendar can indicate the presence of scheduled events and data status (Data on the server/local). The yellow point means the data is only saved on local database. The blue point means the data is only saved on the server database. The red point means there are events on that date. The calendar page gives the user an overview of their data in the specific day as shown in Figure 29.

Daily Summary: The Day Summary view is where a user can review their activity in fine detail as shown in Figure 30.

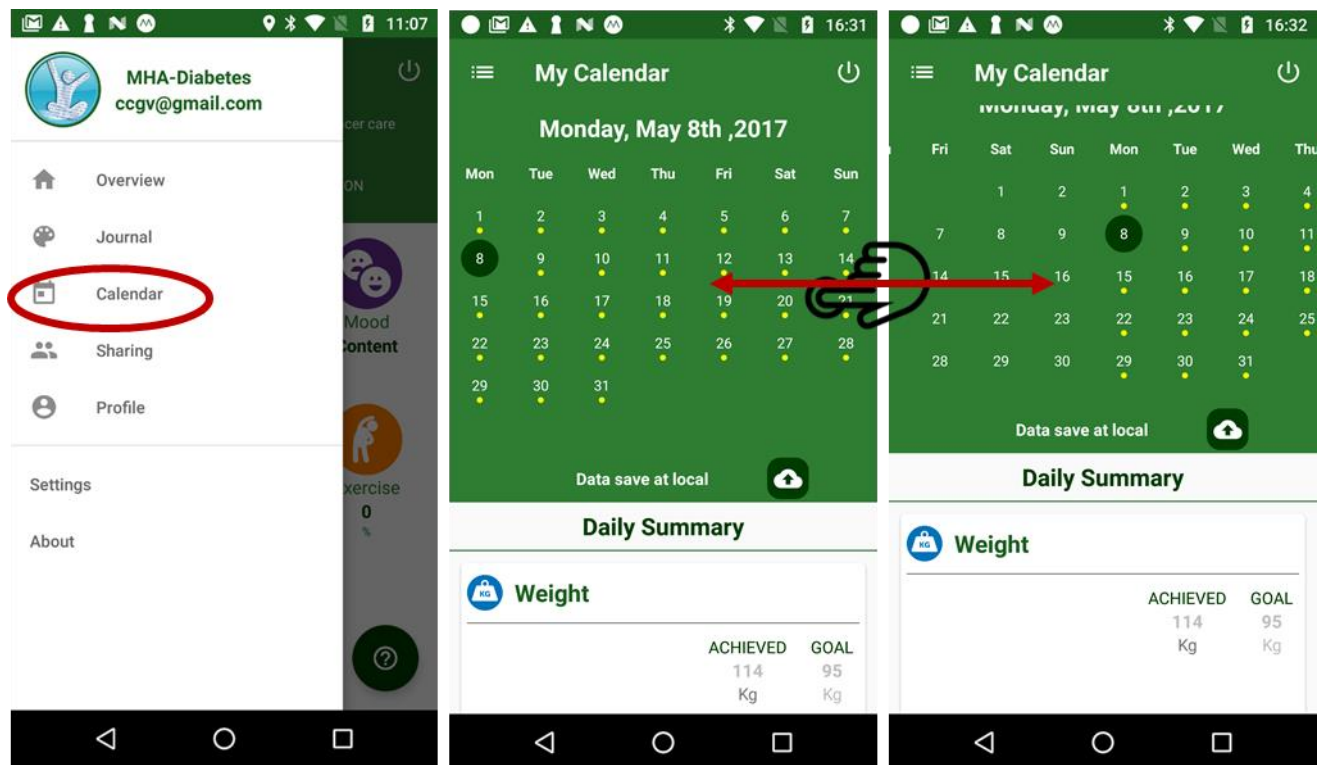


Figure 29. Accessing and using the Calendar page.

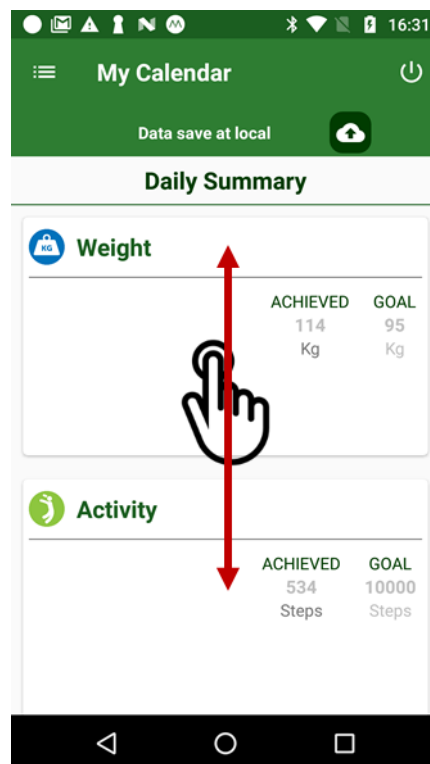


Figure 30. Accessing the Day View page.

Sharing Page: The social page provides users with the opportunity to search for friends within the platform and send them a friend request. This kind of social interaction is intended to help motivate and encourage users to participate with the platform. The social page allows users to connect with other platform users to form social groups and allow group activities, such as the game.

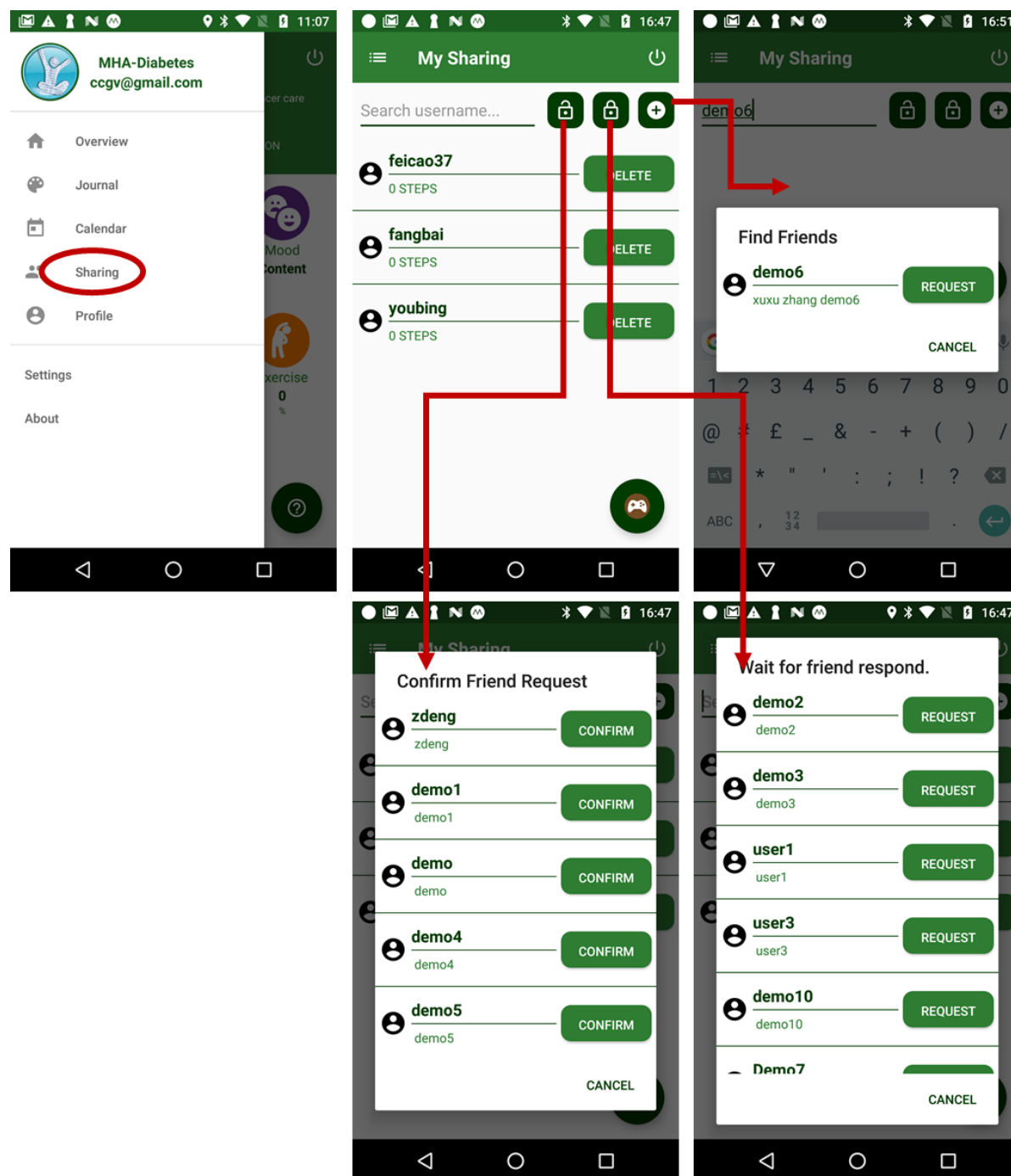


Figure 31. Accessing and using the Sharing page.

Game: The mountain climbing game converts steps into distance progression up a mountain. The game integrates aspects of the social functionality of the application by pitching a user against their social group. The game is intended to invoke some competition between users, further incentivising them to be active and engage with the platform. This provide the user with feedback on the competitive mountain climbing game.

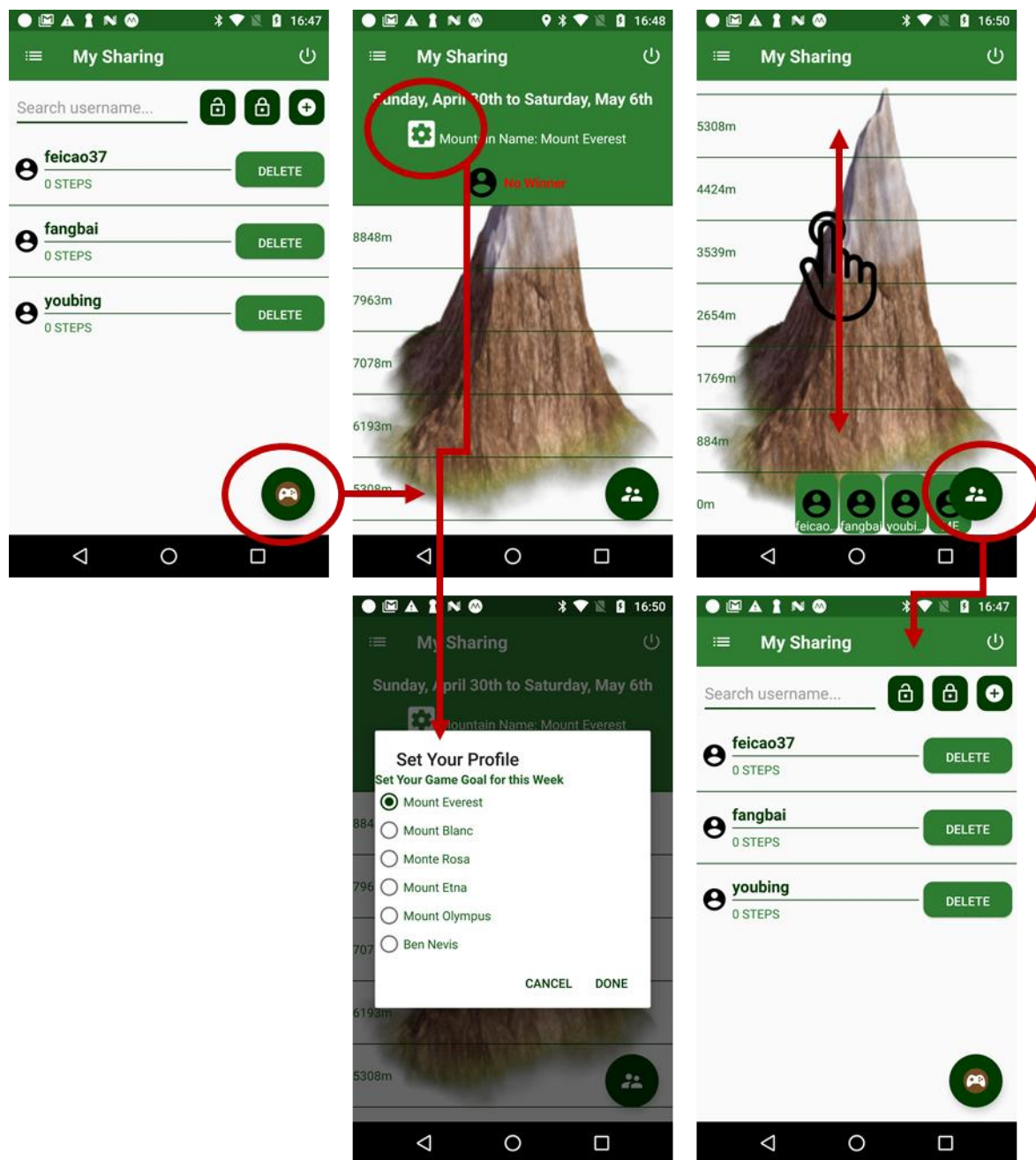


Figure 24. Accessing the Game suite.

Profile: The user profile allows the user to enter personal information in different categories. The profile covers common biochemistries information such as weight and height, as well as common information such as name and age. The profile view allows the users to add and upload to the iMC platform important personal information and a detailed medical history.

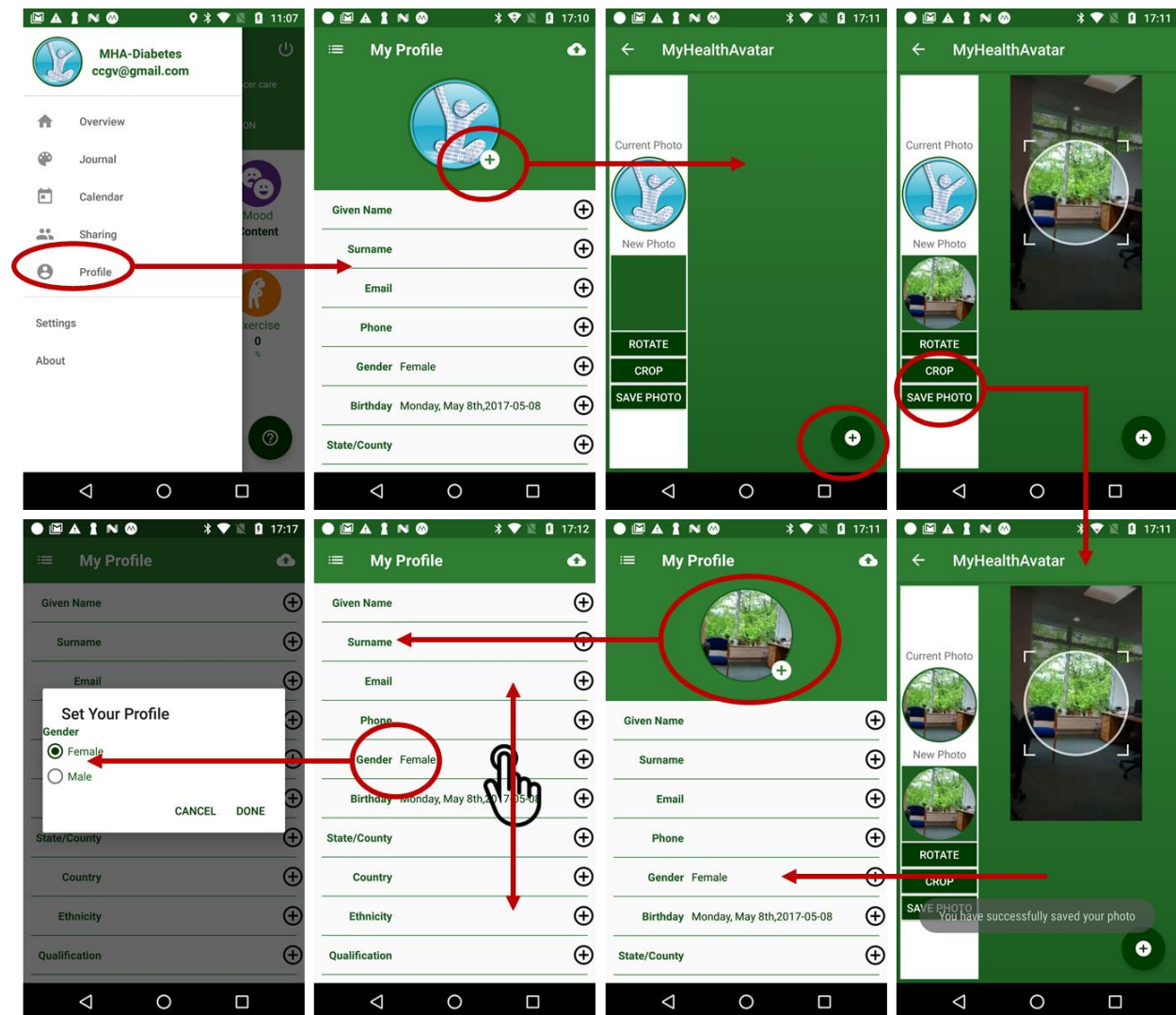


Figure 32. Accessing the Profile page.

Settings: The settings page allows the user to customise their MHA experience and to tailor the application's features and functions to better serve their objectives and life style requirements. The settings page exists to allow the application user to turn on and off the application's features, it also serves to allow the user to schedule when some features become active and select what data is used by those features.

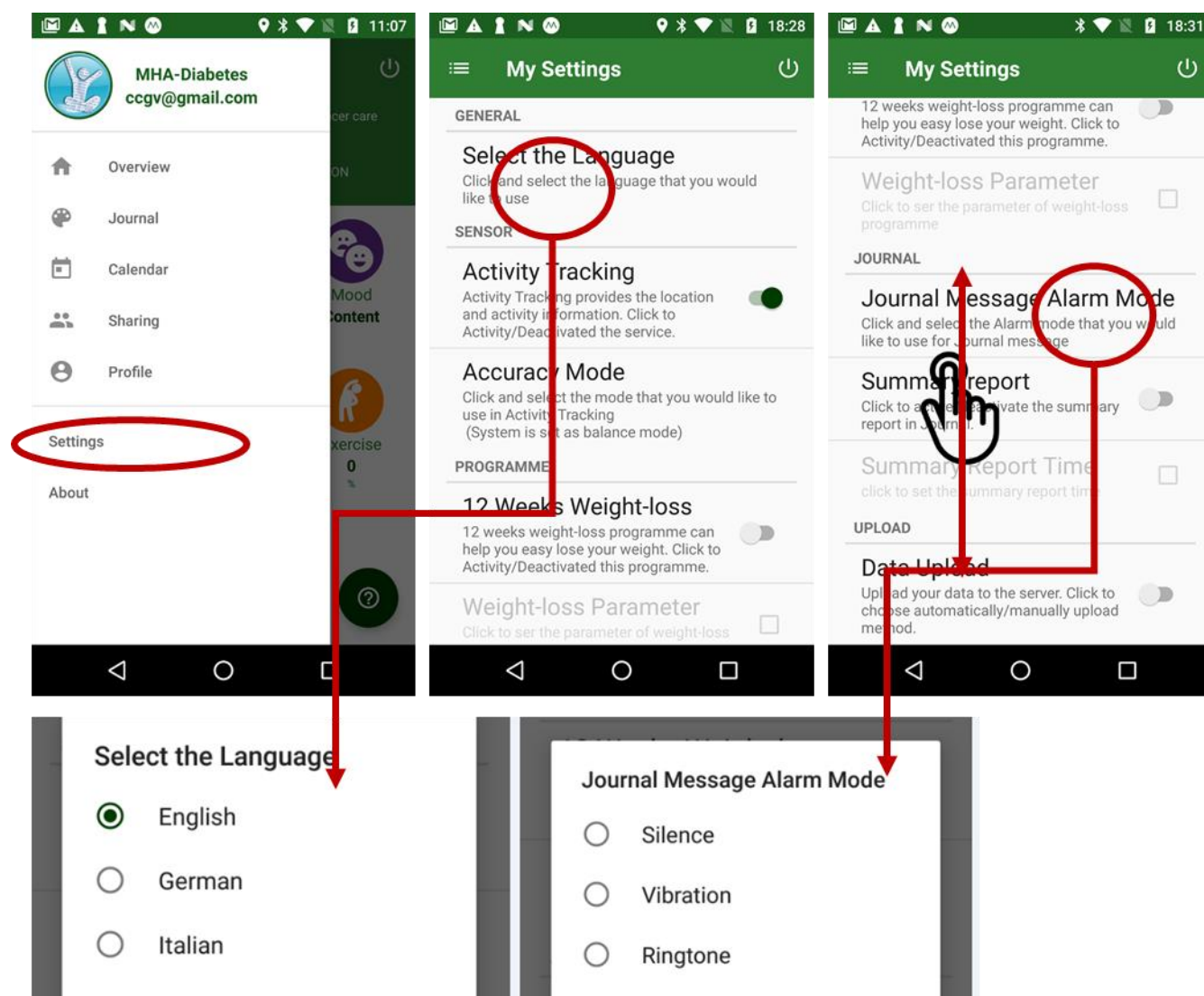


Figure 33. Accessing and exploring the Settings page.

About: The about page display a list of informative topics. Each topic links to a bespoke instruction or informative video hosted on YouTube.

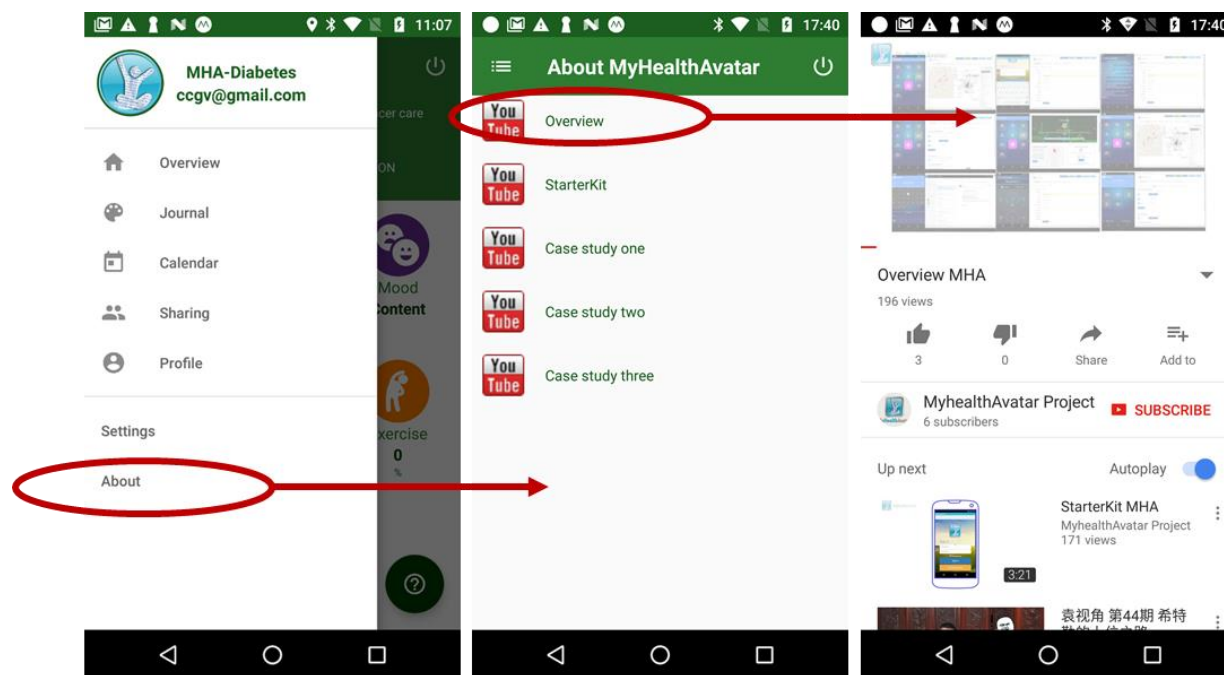


Figure 34. Access and use the Help page.

5. Conclusions

The iPHR system has been expanded to a fully-fledged solution for cancer patients throughout their therapy process based on the recommendations of the first evaluation and the requirements of the iManageCancer project. Although the system has been initially designed to target cancer patients, most of the available apps are general purpose apps and can be used independent of the primary disease – currently only the psycho-emotional monitoring and profiling apps are cancer specific. To the best of our knowledge the developed PHR is currently the only system-free, web-based, open source and optimized for mobile and other devices, allowing health monitoring and sharing through multiple apps and e-Diaries and providing intelligent added value services. To this direction, a number of publications has already been accepted in key conferences in the area of eHealth.

The MyHealthAvatar app, on the other hand, offers a range of tools for the self-management of cancer in terms of lifestyle and physical activities. These tools can be accessed through a mobile application. These tools are mainly designed to target patients with prostate cancers and help them to:

- Know their health status and performance by viewing their self-collected data
- Improve their knowledge about health and diseases by tailored information provision
- Raise their risk awareness and perceptions about diseases by personalised risk assessment
- Engage in health and fitness activities by recommending relevant programmes and courses
- Help look after weight, fitness, calories, emotion and sleep.

6. References

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