C3-Cloud

"A Federated Collaborative Care Cure Cloud Architecture for Addressing the Needs of Multi-morbidity and Managing Poly-pharmacy"

PRIORITY Objective H2020-PHC-25-2015 - Advanced ICT systems and services for integrated care

D5.3 Responsive Multi-Channel Patient Empowerment Platform

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EXECUTIVE SUMMARY

This document presents the demonstrator deliverable D5.3 “Responsive Multi-Channel Patient Empowerment Platform” implemented in Task 5.3. The goal of Task 5.3 was to integrate the outcome of the two previous WP5 tasks 5.1 and 5.2. With the Patient Empowerment Platform, the patient can view and use the care plan created together with the MDT (multi-disciplinary care team), collect data using the defined and implemented data collection tools and share this data with the MDT, and use the messaging and video communication tools to further interact with the MDT members. The Patient Empowerment Platform is developed following responsive design principles to work across a wide range of devices and platforms (PC, tablets, mobile) to provide a comfortable and uninterrupted user experience. All these are built on top of Medixine Suite patient engagement tools.

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1. INTRODUCTION

This document presents the demonstrator deliverable D5.3 "Responsive Multi-Channel Patient Empowerment Platform" implemented in Task 5.3. The goal of Task 5.3 was to integrate the outcome of the two previous WP5 tasks 5.1 and 5.2. Task 5.1 developed and delivered five key outputs as self-management materials for patients and their caregivers (described in deliverable D5.1). Task 5.2 developed interaction mechanisms for the patients and caregivers to collect and share structured and unstructured data; and for communication with the multi-disciplinary team (MDT) (described in deliverable D5.2).

The objective of the Patient Empowerment Platform (PEP) is to provide patients with access to their published care plan and associated relevant information, thereby increasing patient and informal caregiver participation in decision making. It aims to provide a computerized means to improve the interaction between patients and health professionals, as well as to collect relevant data to enable monitoring of care plan related activity status and progress. It directly interacts with the C3-Cloud Coordinated Care and Cure Delivery Platform (C3DP) to be informed about new and updated care plans, and to send back patient reported observations. It also directly communicates with the supported set of sensor devices to record patient measurements.

The core user functionalities and features to PEP users are:

- Make published care plans available to the users;
- Send reminders to patients to help them comply and stay on track with the interventions and activities included in the care plan;
- Allow patients to actively collect data related to the care plan activities;
- Allow health professionals and patients to communicate with each other using either messages or video appointments;
- Provide patients with access to relevant self-management material;
- Provide all PEP users with secure access to this information and functionality.

1.1. Demonstrator summary

The demonstrator is an online, Internet-facing system used primarily via a web application, which is accessed using a modern, standard web browser. The use of sensor devices requires physical device kits to be acquired and configured for use with the platform. No downloads or third party software is needed to use the demonstrator. Login credentials for users are created using the mechanisms described later in this document. Demo credentials can be created upon request.

The exact content and functionality available to any individual user at any specific time depends on the actual care plan created in the C3DP component. At the time of this report the integration work is in progress and will be completed by M26 of the project (June 2018). At the time of this report, there are some restrictions to the extent in which the functionality dependent on integration can be demonstrated. When the integration work is complete, all the functionality will be available as specified in WP3. PEP and the integration with other components was demonstrated at the review meeting in December 2017 in their state at the time of the review meeting. Further information about the integration of PEP with the other components will be described in D7.4.

1.2. Abbrevations and acronyms

Abbreviation / Acronym	Definition
C3DP	Coordinated Care and Cure Delivery Platform
MDT	Multi-disciplinary Team
PEP	Patient Empowerment Platform

1.3. Terminology

Multi-disciplinary care team. A team comprising members from various care sectors. The MDT collaboratively designs an integrated and personalised care plan for the patient. The MDT has access to patient data generated in all care settings.

Multi-disciplinary care team member. GPs, specialists, study nurses, pharmacists, physiotherapists, geriatricians, nutritionists, who comprise a multidisciplinary care team to provide care to a patient.

Patient. Patients with two or more of these chronic conditions: diabetes, heart failure, renal failure and depression, who can access the integrated care plan and their health data through C3-Cloud.

Informal caregiver. A person acting on behalf of the patient, who will have access to the patient's data and care plan. The informal care giver will have the same access permissions as the patient.

Questionnaire. A structured set of questions. The questions are ordered and grouped into coherent subsets, corresponding to the structure of the grouping of the underlying questions.

Care plan. Dynamic, personalized plan for a patient to tackle health issues, achieve health goals, and coordinate healthcare activities, collaboratively designed by MDT and executed by the systems in all involved care sectors.

Goal. A goal is a defined outcome or condition to be achieved in the process of patient care. Goals include patient-defined overarching goals (e.g., alleviation of health concerns, desired/intended positive outcomes from interventions, longevity, function, symptom management, comfort) and health concern-specific or intervention-specific goals to achieve desired outcomes.

Activity. An activity is a logical entity representing planned actions. C3-Cloud implements activities as activity definitions within the FHIR Care Plan resource instances.

Care plan activity. An activity defined in the care plan to maximize the prospects of the goals set within the care plan.

Questionnaire activity. The activity that requests patients to complete an assigned questionnaire at a specific time.

Observation activity. The activity that requests patients to enter the assigned observation during the activity period.

Measurement activity. The activity that requests patients to perform measurements during the activity period.

Questionnaire response. Questionnaire response provides a complete or partial set of answers to a questionnaire.

Observation. Measurements and simple assertions made about a patient, device or other subject. Observations are a central element in healthcare, used to support diagnosis, monitor progress, determine baselines and patterns and even capture demographic characteristics.

Message. A message exchanged between the MDT and a patient using the messaging functionality.

Medixine Suite. The software product on which PEP is built.

2. PATIENT-EMPOWERMENT PLATFORM

The PEP user application is a modern web application, which allows PEP users (patients and their informal caregivers) to access all the functionality to meet the objectives of the Patient Empowerment Platform. PEP is built on the Medixine Suite product.

2.1. Medixine Suite

Medixine Suite provides everything a healthcare provider needs for patient-centric connected care. Based on the open and scalable Medixine platform, the product provides key functionalities to patients and their informal caregivers. Medixine Suite functionality can be used for any disease or condition and can be used on mobile phones, tablets and desktop PCs. It supports all the most commonly used web browsers (e.g., Chrome, Firefox, Safari, Edge). The product can easily be connected to other systems and services using its extensive set of open APIs. The product supports configurable event notifications for connected applications and asynchronous communication pipelines. The product has powerful tools to configure and extend the functionality and content of the solution. These tools can, for instance, be used to configure dynamic questionnaires to collect data from the users. The user interfaces are built using responsive Single-Page Application (SPA) technology and content is loaded using advanced Ajax techniques, avoiding full page loads. The user interfaces are responsive, mobile-friendly HTML5 user interfaces.

The Medixine Suite technology stack follows traditional logic for web-based services and consists of Operating System (Microsoft Windows Server), Data storage (Microsoft SQL Server), Web Server (IIS) and Programming platform (.NET). The database layer contains some supporting functionalities but the actual business logic is built into the application layer. Configurations for Windows, SQL Server and IIS follow standard conventions which means that Medixine Suite can be hosted in practically every environment capable of hosting Microsoft technologies (Azure, AWS, Google Cloud, private clouds, traditional hosted servers etc.). The application logic is based on modern resource-based thinking and the application logic is exposed through a REST API that is structured around those resources. The core logic includes role-based access configuration for different operations, full audit trails of operations performed in the system, application ecosystem model, dynamic and extensible data modeling tools, event subscription model for integrations and extensible support for multiple languages and cultures.

2.2. PEP Application

The PEP users interact with the Patient Empowerment Platform using the PEP Application component. All users of PEP must register and authenticate themselves before they can use the PEP Application. After successful authentication, the user is redirected to the main view of the selected patient. On this main view, the user sees an overview of the most relevant information and has access to all functionality and the more detailed views of the various functional areas of the application.

The application layout consists of three main parts: the header, the body and footer (Figure 1). The body area displays either the main view or one of the pages of the detailed functional areas.

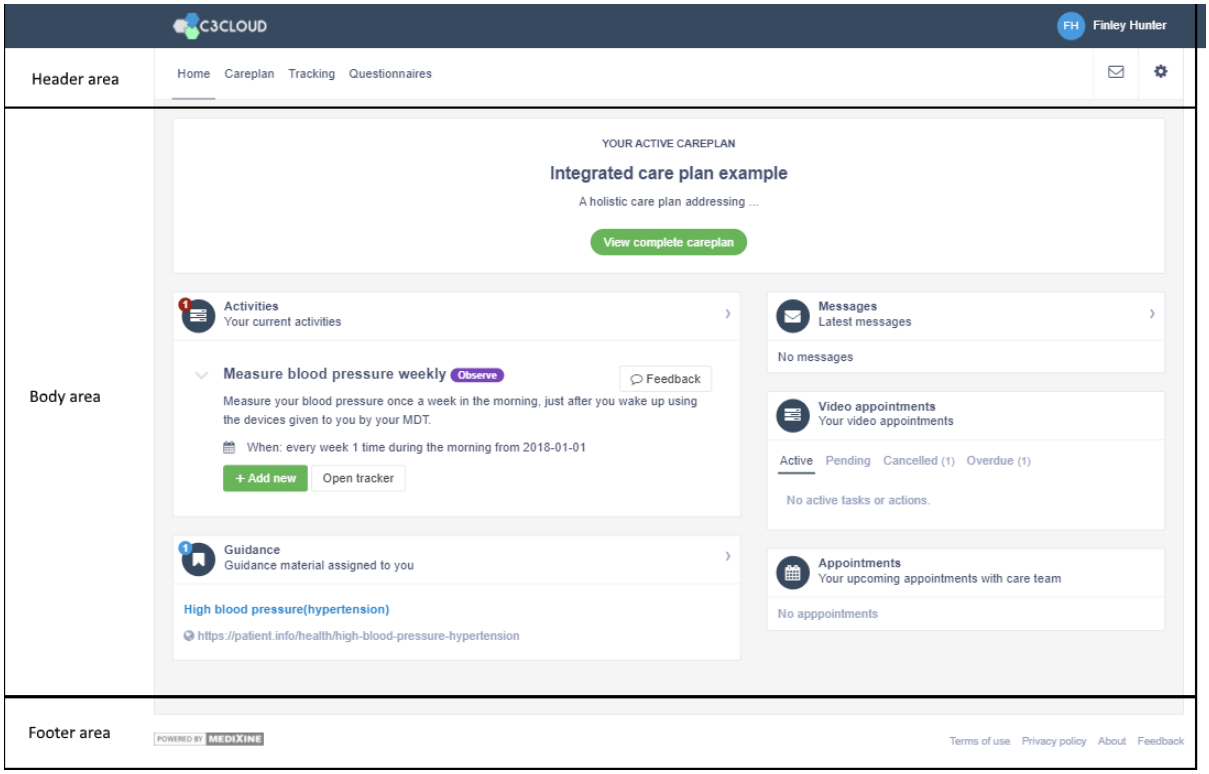

Figure 1. Patient Empowerment Platform default layout

The PEP Application can be used on different devices including desktop computers, tablets and smart phones. The application adapts its views to the different screen sizes of the devices (Figure 2). This is enabled by the responsive user interface design used by the application.

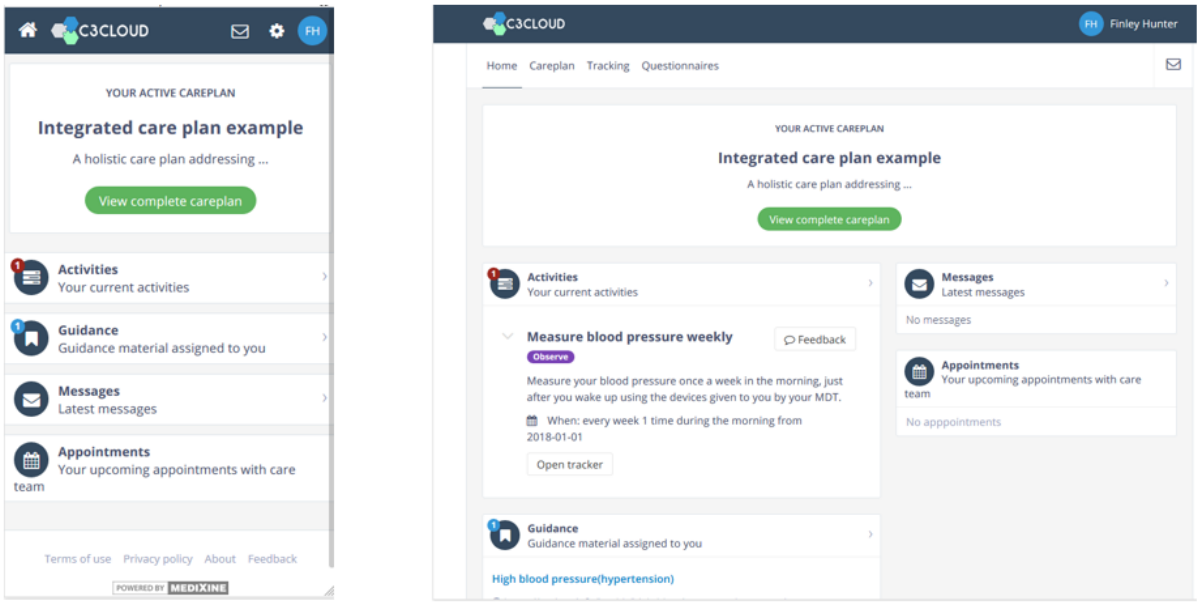

Figure 2. PEP responsive design works well on different screen sizes

2.3. Functional areas

The Patient Empowerment Platform includes functional areas, which provide the functionality needed to meet the objectives of the PEP. This includes the following main areas:

1. The **Careplan** area to view and interact with the active care plan and its content. The care plan views include the set goals, assigned guidance and activities to perform.
2. The main data collection areas **Questionnaires** and **Tracking** to add data and view collected data. The Questionnaires for the patient questionnaires and the Tracking area for measurements and other observations the patient is requested to collect.
3. The **Messaging** area to communicate with the MDT members (view messages sent by MDT and sends messages to MDT).
4. The **Video appointment** area for the video appointments between a patient and a health professional.

These functional areas presented in more detail later in this document.

2.4. Footer area

The default footer area contains the following links/pages:

1. *About page*. This page contains a short overview and description of the C3-Cloud service and in particular PEP. On this page, there is a links to more detailed information available on the project site.
2. *Access to the privacy policy*. The privacy policy informs the user how C3-Cloud collects, uses, discloses, and manages the personal data of the patients and how this information is protected. This is the same information the patient was given when the patient was enrolled in the service.
3. *Terms of use*. This page contains the rules by which the patients and informal caregivers must abide when using the C3-Cloud service.
4. *Feedback*. This form allows the patient to contact the local service provider and either give general feedback on the service or ask general, non-clinical questions. This contact channel is not intended for clinical communication with the care team.

3. PEP USER MANAGEMENT

Patients are given access to the patient information and functionality via PEP. To provide secure access the patients are registered as PEP users before first use and they must authenticate themselves every time before they can access the application. The informal caregivers of patients can also be granted access to PEP with the patient's permission. This enables them to help and act on behalf of the patient they are linked with.

The actual process and implementation to fulfil this depends on what local authentication services are available. The following methods to provide access for patients and informal caregivers to PEP are supported:

Method 1: An external authentication service is used and the patients/informal caregivers are registered in C3-Cloud with the same identifier as the external authentication service returns to PEP for authenticated users.

Method 2: A patient/informal caregiver is registered in C3-Cloud, but the patient identifier and the authenticated PEP user identifier are not the same.

Method 3: The patient invites, using PEP functionality, an informal caregiver to access PEP.

Patient self-registration without prior authorization by the local healthcare organization is not supported in C3-Cloud.

3.1. Patient registration

3.1.1. Method 1

1. The patient is registered as a C3-Cloud patient by the local healthcare organization. A Patient resource is added in the FHIR repository. The unique patient identifier of the Patient resource is the same person identifier as the external authentication service provides for authenticated users (e.g. a national person identifier or similar). This enables the automatic matching of the logged in user and the patient record/information.
2. The patient information in FHIR is made available to PEP via integration.
3. When the user logs in, PEP matches automatically using the person identifier the user with the patient record.
4. The user is now authorized to access their own patient information and to use the PEP functionality.
5. PEP displays the main patient workspace page to the logged in user.

3.1.2. Method 2

1. The patient is registered as a C3-Cloud patient by the local healthcare organization. A Patient resource is added in the FHIR repository. The unique patient identifier of the Patient resource is NOT the same person identifier that an authenticated patient user has. The Patient resource information contains a valid email address and a valid mobile phone number.
2. The Patient information in FHIR is made available to PEP via integration.
3. PEP sends an invitation to register to the patient by email and sends a unique access code to the patient by SMS. The email invitation contains a link to access and register in PEP.
4. The invited patient clicks on the link in the invitation email and a web page is opened in the patient's web browser. The user enters the unique registration access code and can now register a PEP user account. If the user already has a user account in the system, the user can log in using that account (i.e. doesn't have to create a new account).
5. The user enters the requested minimal registration information for the user account. When the user has completed registration, the user is authorized to access their own patient information.
6. PEP displays the main patient workspace page to the logged in user.

3.2. Informal caregiver access

3.2.1. Method 1

1. The informal caregiver is registered in C3-Cloud by the local healthcare organization. A RelatedPerson resource is added in FHIR. The informal caregiver is registered as a member of the patient's care team. The unique identifier of the RelatedPerson resource is the same person identifier as the external authentication service provides for authenticated users (e.g. a national person identifier or similar).
2. The RelatedPerson information is made available to PEP via integration.
3. When the user logs in, PEP matches automatically the user identifier with the RelatedPerson.

4. The informal caregiver is now authorized to access the information, and act on behalf, of the patients the informal caregiver has been registered for.
5. PEP displays the main patient workspace page to the linked patient.

3.2.2. Method 2

1. The informal caregiver is registered in C3-Cloud by the local healthcare organization. A RelatedPerson resource is added in FHIR. The informal caregiver is registered as member of the patient's care team. The unique identifier of the RelatedPerson resource is NOT the same person identifier as the external authentication service provides for authenticated users. The RelatedPerson resource information contains a valid email address and a valid mobile phone number.
2. The RelatedPerson information is made available to PEP via integration.
3. PEP sends an invitation to register to the informal caregiver by email and sends a unique access code to the patient by SMS. The email invitation contains a link to access and register in PEP.
4. The invited person clicks on the link in the invitation email and a web page is opened in the user's web browser. The user enters the unique registration access code and can now register a PEP user account. If the user already has a user account in the system, the user can log in using that account (i.e. doesn't have to create a new account).
5. The user enters the requested minimal registration information for the user account.
6. The informal caregiver is now authorized to access the information, and act on behalf, of the patients the informal caregiver has been registered for.
7. PEP displays the main patient workspace page to the linked patient.

3.2.3. Method 3

1. The patient logs in into PEP and opens Access settings in Patient settings.
2. The patient clicks on "Invite" and fills in the invitation form.
3. When the patient has completed the invitation form, PEP sends the invitation to the informal caregiver. This includes the email with a link to register and the unique access code sent by SMS.
4. The invited informal caregiver clicks on the link in the invitation email, enters the unique access code and completes registration. If the user already has a user account in the system, the user can log in using that account (i.e. doesn't have to create a new account).
5. The informal caregiver is now authorized to access the information, and act on behalf, of the patients the informal caregiver has been registered for.
6. PEP displays the main patient workspace page to the linked patient.

4. CARE PLAN

In the Careplan area, the user can access and view the active care plan. When the MDT publishes a new or an updated care plan to the patient, PEP sends a notification message to the patient. The notification informs the patient that the new or updated care plan is available in PEP. The patient logs in and views the set goals, the assigned guidance with relevant information and the activities to perform.

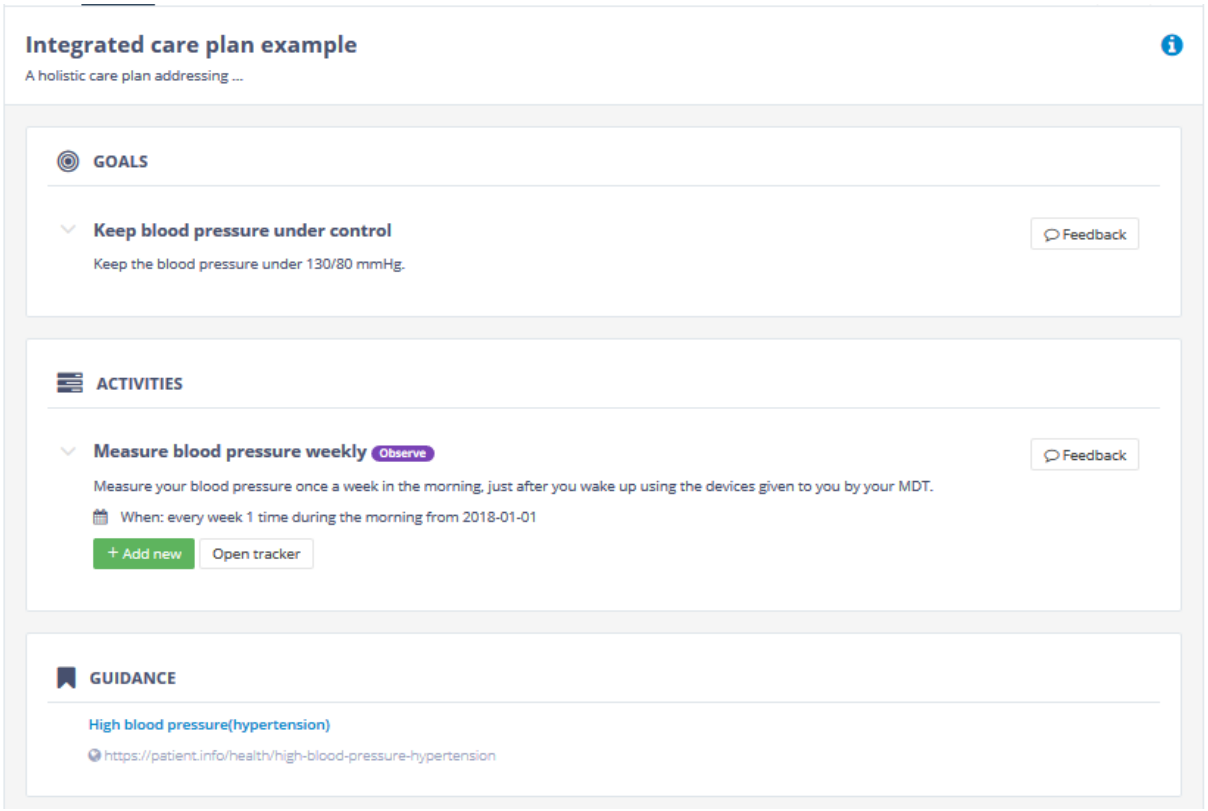

Figure 3. Care plan example with goal, activity and guidance

4.1. Goals

The patient can view the list of agreed/set goals and their details. The list displays the most essential information of the goals (Figure 4). The patient can also open and view the additional details of each goal (Figure 5).

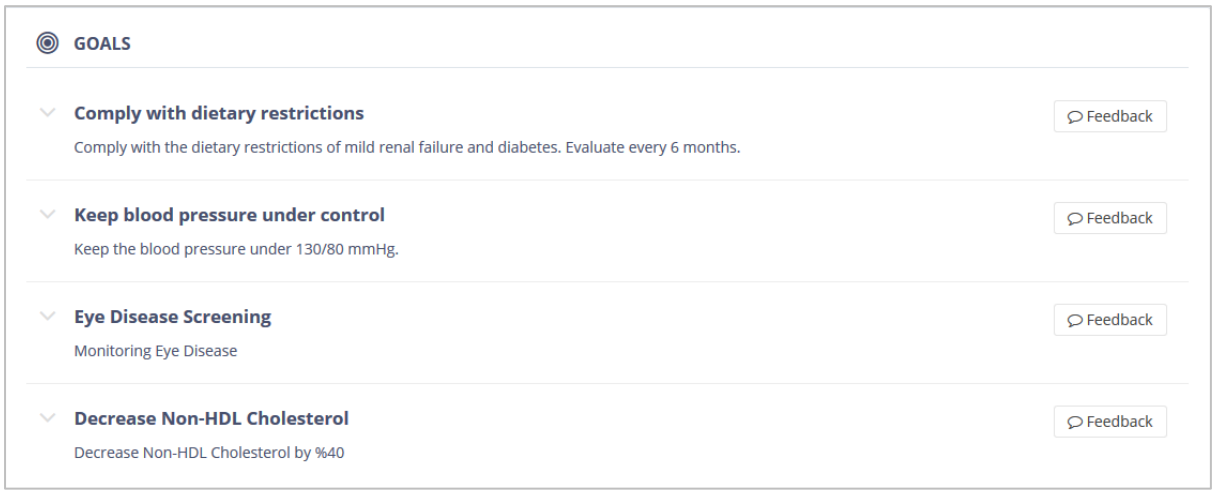

Figure 4. Example of care plan goals displayed to patient

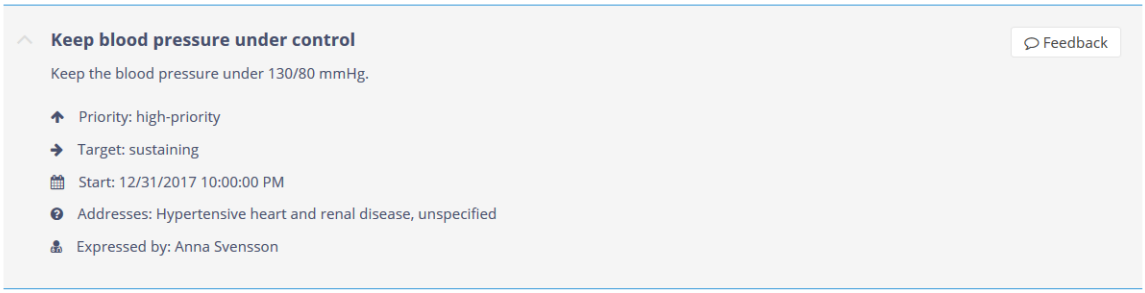

Figure 5. Goal details

4.2. Activities

PEP displays the active activities, for which the patient is the active performer. This includes activities of type general (activities the patient performs as part of daily or weekly routine, e.g., diet, exercise etc.), medication activities (the medications prescribed to the patient), requests to fill in patient questionnaires and requests to collect measurement or other observation data. The core information of each activity includes the descriptive title and description texts and the intended timing of activity (when and how often the patient should do the activity). The activity can be set to be performed once or set as a recurrent activity performed for instance once every day in the morning. The patient can also view additional details of each activity.

General activities

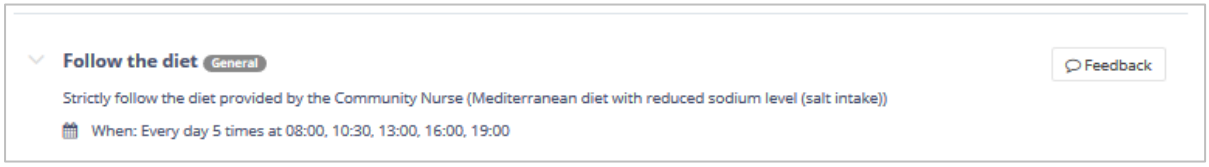

Figure 6. Example of general activities

Medication activities

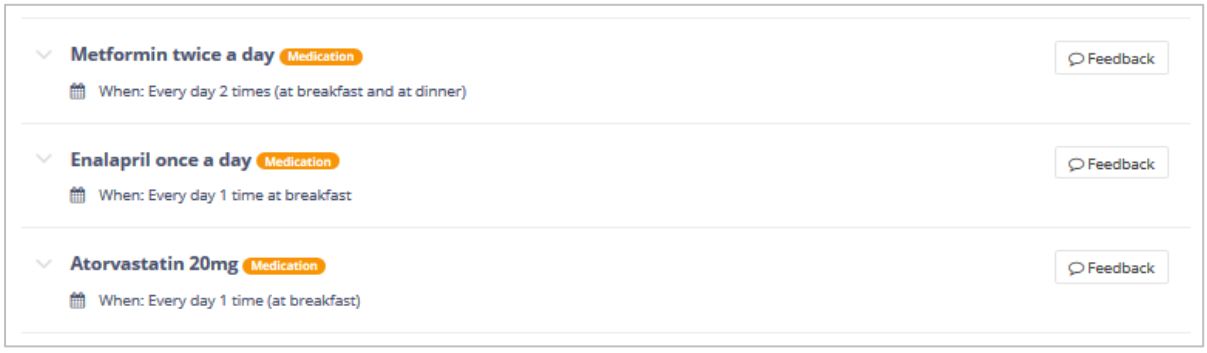

Figure 7. Example of medication activities

Questionnaire activities

Figure 8. Example of questionnaire activities

Observation activities

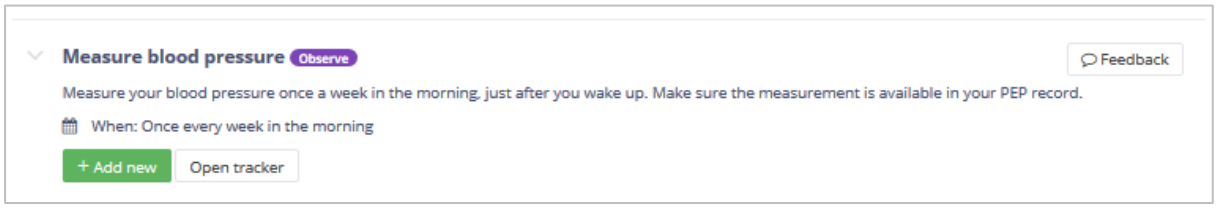

Figure 9. Example of measurement activity

4.3. Appointments

The patient can view published appointments for activities performed at the health provider's locations. For each appointment, PEP displays the descriptive title and description (these tell what appointment this is), the booked date and start time (when the appointment is) and location (where the patient is to go for the appointment).

Figure 10. Example patient appointment

4.4. Guidance/ Training Materials

The MDT chooses in C3DP which training materials are most suitable for the patient and assigns them to the care plan. When the patient views the care plan, PEP shows the list of assigned educational training materials with links to access these materials. The patient can open any of the assigned training materials by clicking on the asset link.

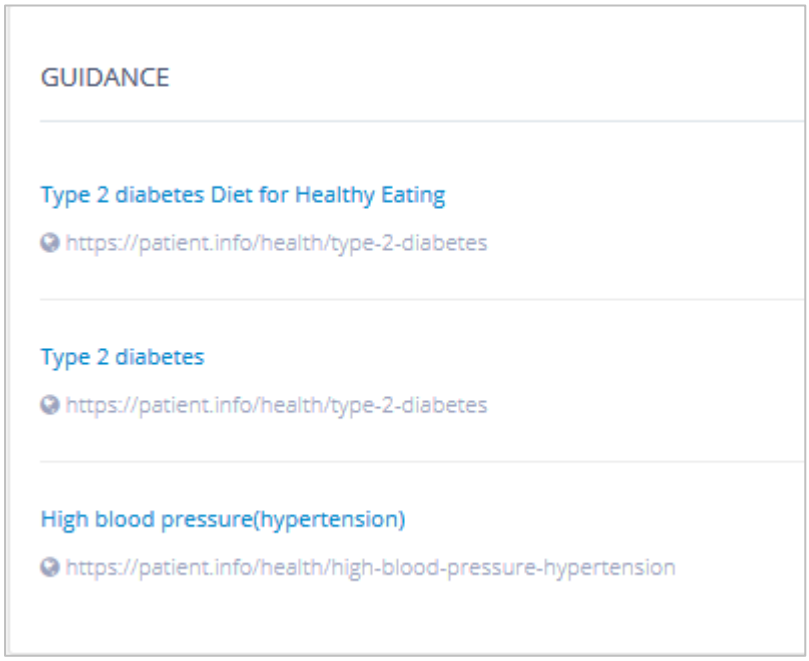

Figure 11. Example of list with links to assigned guidance

Figure 12. Example of external guidance opened by patient

4.5. Care plan feedback

The patient can additionally provide feedback to care team about the care plan, its goals and/or activities. The patient can give the feedback for the care plan in general or for any specific goal/activity.

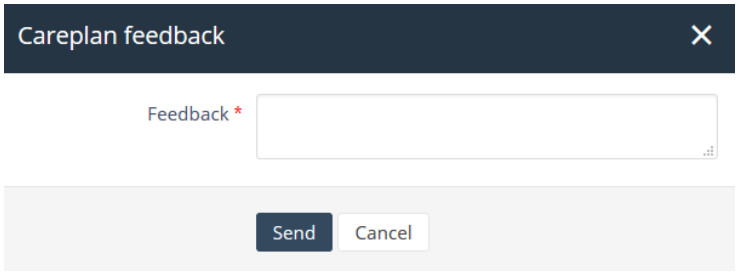

Figure 13. Care plan level general feedback

4.6. Goal feedback

The patient can share feedback and progress of a specific goal.

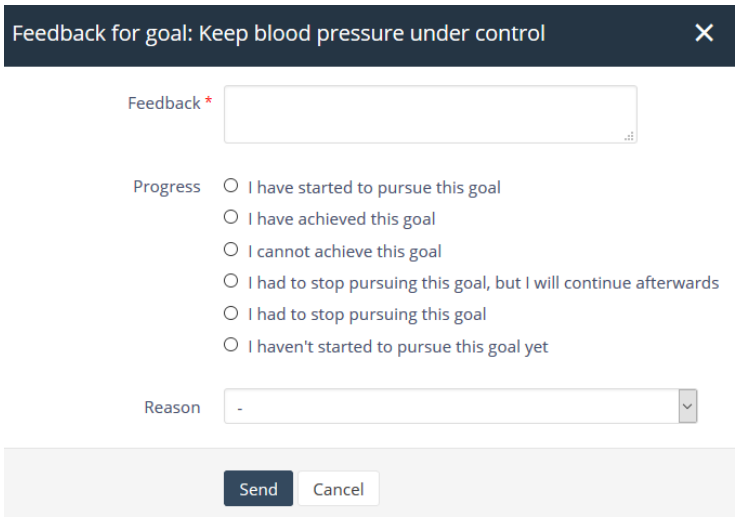

Figure 14. Form to enter goal feedback

4.7. Activity feedback

The patient can share feedback and progress of a specific activity.

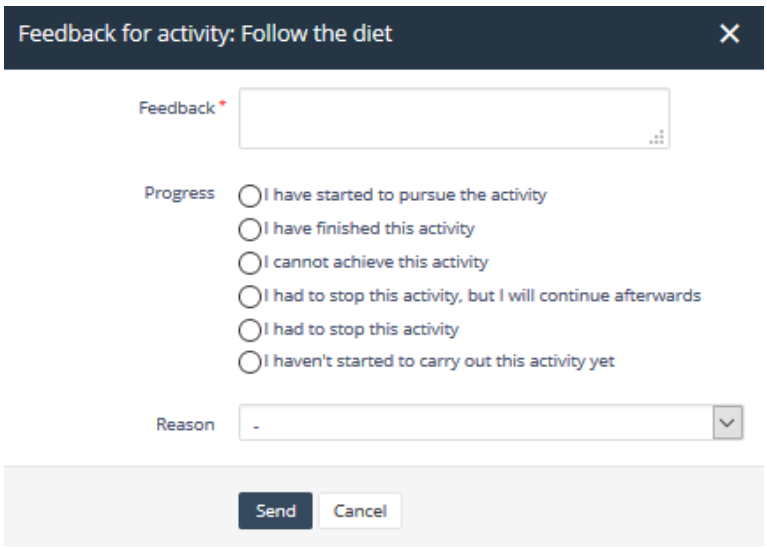

Figure 15. Form to enter activity feedback

5. DATA COLLECTION

One of the objectives of PEP is to provide computerized means to collect relevant data and information to enable monitoring of care plan related activity status and progress. The main ways to collect structured data are patient questionnaires, measurement data from connected sensor devices and other observation data entered manually by the patient (e.g. meal photos). Data collection is presented in detail in deliverable D5.2. Examples of these three types of data collection are presented briefly below.

5.1. Patient questionnaires

The patient is assigned an activity to complete a patient questionnaire. The patient clicks on the link in the activity details and PEP opens the questionnaire to be filled in. The patient answers all the questions

and the completed form is stored. The data is shared via integration with C3DP, which can for instance notify relevant care team members and presents the answers to the care team and its members

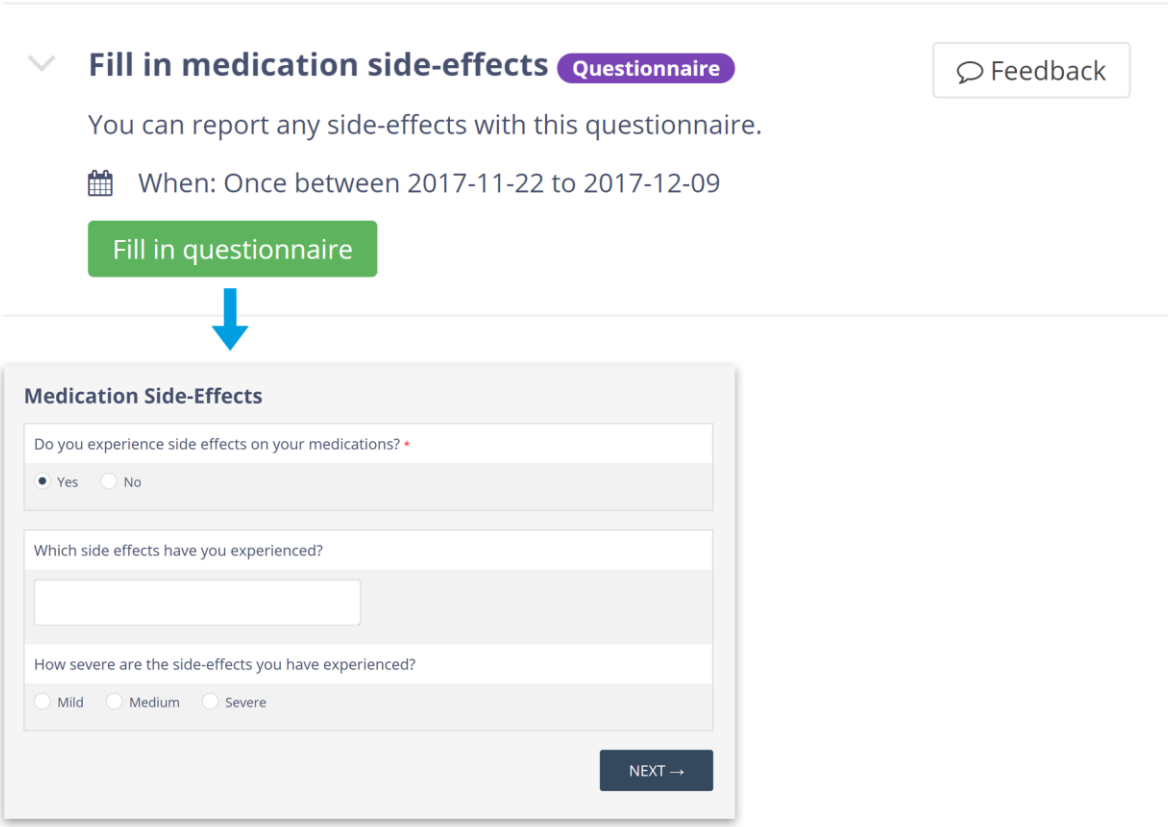

Figure 16. Example of patient questionnaires used

5.2. Patient sensor devices

The patient is assigned an activity to do measurements using a sensor device. The patient uses the sensor device as instructed and the values are uploaded and stored automatically in PEP and shared with the other components of C3-Cloud. The stored data is available to the care team and its members.

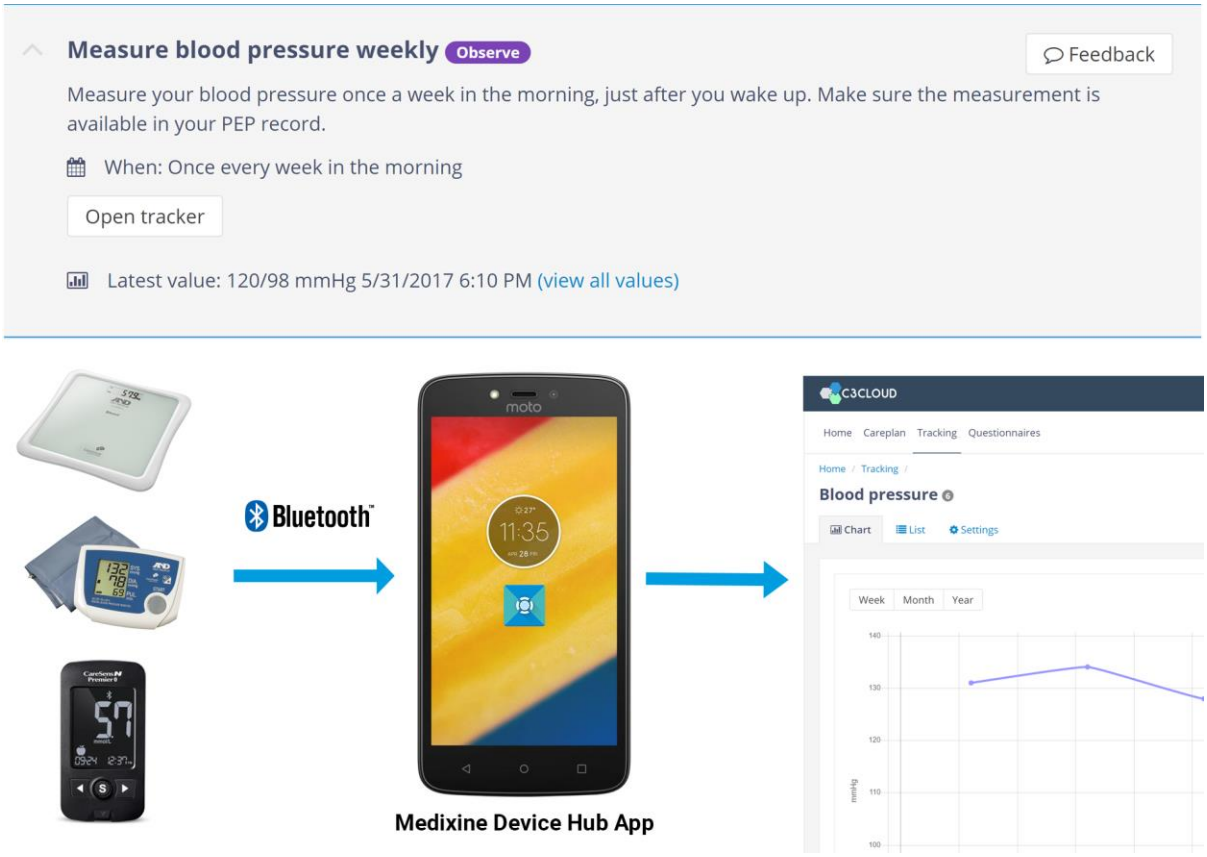

Figure 17. Example of data collected with sensor device

5.3. Other observations

The patient is assigned an activity to enter an observation manually. The patient clicks the link in the activity details to enter the requested data. The value is stored in PEP and shared with the other components of C3-Cloud. The data entered by the patient is available to the care team and its members.

Meal photos are an example of this type of observation data the patient can store and share with the care team.

Figure 18. Example of other data collected

6. COMMUNICATION

PEP provides computerized means to improve the interaction between patients and health professionals. Sharing the care plan and collecting structured data are essential for this objective, but in addition to these, the patient and professional need to communicate with each other to discuss the care of the patient. With modern technology this communication can be done remotely without the patient or the professional having to travel to the other. Medixine Suite supports this ad-hoc communication both via messaging (text) and with video appointment (real-time video, audio, chat).

6.1. Messaging

With messaging, the patient can receive secure messages from care team members and send messages to the care team. When the patient receives a new message, the patient is notified. The patient logs in, opens messaging and reads the received message. The patient can reply to the message, if the patient has any follow-up questions or comments to the message.

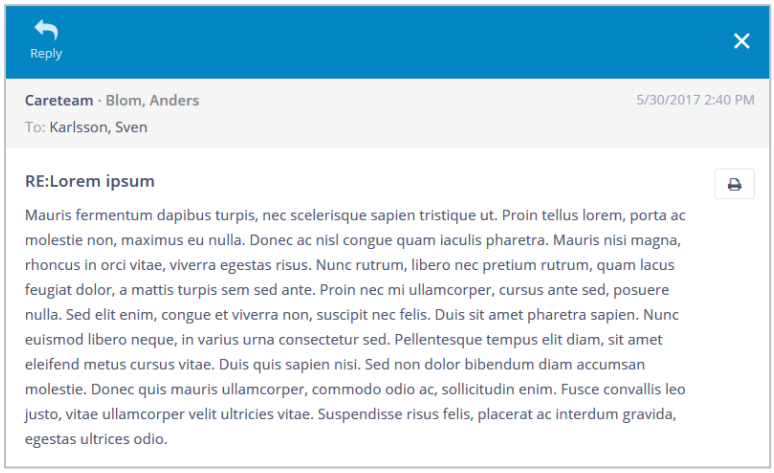

Figure 19. Patient reads message sent by MDT member

The patient can also start new conversations with the care team if the patient has any questions or information the patient needs to share with the care team and its members.

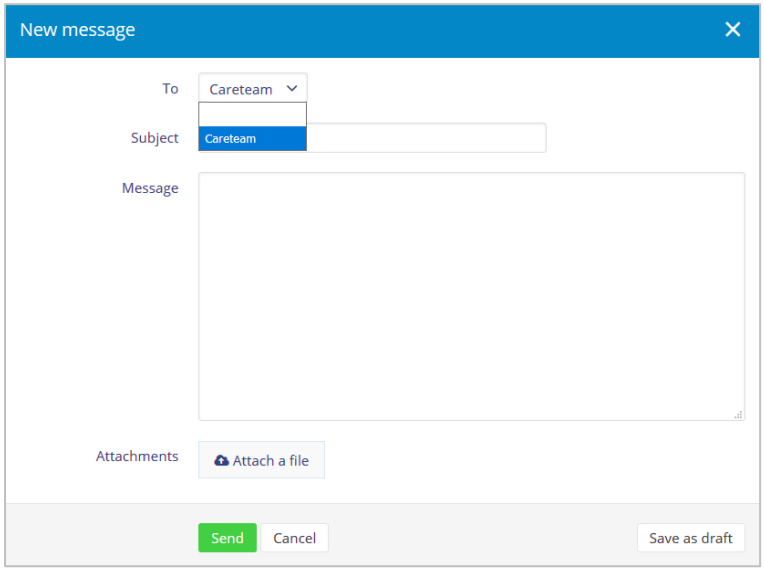

Figure 20. Patient is sending a message to the care team

6.2. Video appointments

With Video appointments a care team member can have an online appointment with the patient. The video appointment is booked in advance and displayed in PEP in the list of the patient's appointments. When it is the time for appointment, both log in and open the video appointment.

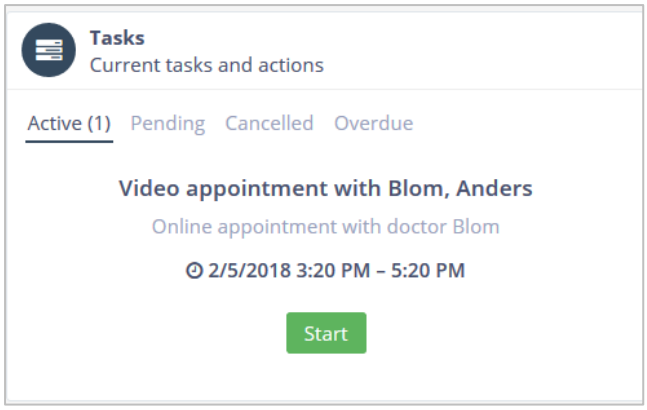

Figure 21. Patient sees online appointment about to start

They can now discuss the care of the patient. When they are finished, they end/close the video appointment.

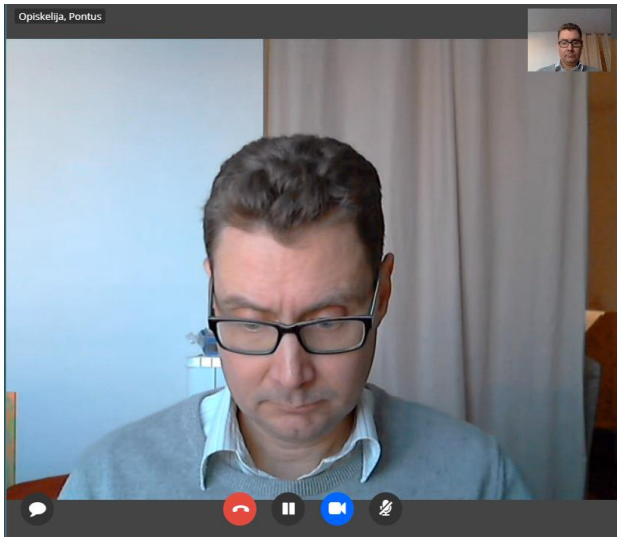

Figure 22. Patient in video appointment with professional

7. INTEGRATION WITH OTHER C3-CLOUD COMPONENTS

The integration and data sharing with other C3-Cloud components is done via the centralized FHIR repository. When a component changes data in the FHIR repository, the component sends an event to other components to signal to it to fetch and process the new data. The majority of the integration and data sharing of PEP is with the C3DP component. The integration work is in progress as part of task T7.4 and completed by M26.

Data collection related resources were reported in D5.2. Additionally, the following FHIR resources are used in the integration with other C3-Cloud components:

Resource	**Description**
Patient	The core information of the patient enrolled in C3-Cloud
CareTeam	The MDT of a patient.
Practitioner	A health professional, who is a member of patient MDT.

RelatedPerson	An informal caregiver of a patient.
CarePlan	The integrated care plan of a patient.
Goal	The care plan goals set in the care plan.
CarePlan.activity	Questionnaire, observation or a general activity assigned to the patient by the MDT.
DeviceRequest	Measurement activity assigned to patient by the MDT.
MedicationRequest	Medications prescribed to the patient.
Appointment	Patient appointments related to the care plan.
CommunicationRequest	Guidance and training materials assigned to the patient
Communication	Messages between patient and MDT.