# Opal—the Oncology Portal and Application

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**Abstract.** We describe Opal (Oncology portal and application), the smartphone app and patient portal that we have developed for radiation oncology patients at our comprehensive cancer centre. Opal is a novel communication tool to empower patients with their personal health information, including appointment schedules, clinical notes, radiotherapy treatment planning views, wait time management and just-in-time personalized educational material.

Opal is unique in four important respects: (1) it was developed from inside the healthcare system with a patient co-leading the development team; (2) it automatically personalises the provision of information to patients according to diagnosis and stage of treatment using the patient's data within our electronic medical record; (3) it was designed to encourage patients to submit patient-reported-outcome data by engaging them while they wait for appointments; and (4) it was built in a modular way to allow expansion beyond radiation oncology to include data from any electronic medical record in any medical discipline.

To develop Opal, our team addressed numerous challenges; cultural, logistical, and technical. We describe the complete development process, including patient engagement (focus group and survey), staff engagement, and the technical details underpinning Opal's secure communication architecture and frontend and backend software. A web-based demonstration version of Opal is available at depdocs.com/opal.

## 1. Introduction

A patient portal, in its most basic form, is an extension of a healthcare institution's electronic medical record (EMR) that is accessible to patients. It provides patients with a secure window into their personal health information (PHI) within the institution's EMR (Office of the US National Coordinator for Health Information Technology 2016, Canada Health Infoway 2016). Patient portals‡ have been demonstrated to improve healthcare quality, are associated with favourable patient outcomes, and are generally positively reviewed by patients and staff (Lin et al. 2005, Zhou et al. 2007, Osborn et al. 2013, Kruse, Bolton & Freriks 2015, Kruse, Argueta, Lopez & Nair 2015).

At our institution, a patient portal is not currently available either within our comprehensive cancer centre or within our affiliated general hospital. As described in this paper, we set out to develop a secure smartphone- and web-based portal for radiation oncology patients that is expandable to all patients within our cancer centre and potentially to all patients who receive care at our institution. Our goals in doing so were to (a) empower and educate our patients and (b) set up a mechanism to collect patient-reported outcome (PRO) data from our patients. We have called our solution Opal; the Oncology portal and application. A demo version of Opal is available online at depdocs.com/opal.

Opal is unique in four respects. Firstly, it was designed from inside the healthcare system with a patient as co-lead. Secondly, it uses data from the hospital's EMR to personalise the content and timing of information that is securely delivered to patients. Thirdly, and importantly in the present emerging era of clinical informatics (El Naqa 2014, Petersen 2015, Sloan et al. 2016), it was designed to encourage patients to submit PRO data by engaging them while they wait for appointments. Finally, Opal was designed to be EMR-agnostic and was built in a modular way so that its use may be expanded beyond radiation oncology to include all patients served by our institution.

Our patient portal development team, a research collaboration known as the Health Informatics Group (HIG), is led by a former patient (who is also a computer scientist), a radiation oncologist and a medical physicist. It also includes a radiation therapist, two software developers, and many graduate and undergraduate students in Computer Science and Medical Physics at McGill University who have contributed to various aspects of the software. Having patients and staff on the development team, who can provide their respective perspectives while simultaneously understanding the nuances of software development and the healthcare system, is an important and unique aspect of the HIG. It has allowed us to develop a patient-centered portal from inside the healthcare system.

‡ Patient portals are often confused with web or mobile-based personal health records (PHRs). Whereas a patient portal is an institution-controlled view of a patient's PHI under the custodianship of a healthcare provider, a PHR is a patient-controlled electronic health record under the control and custodianship of a patient.

## 2. Background—Demonstrating the Need

Initially, when the HIG formed, our broad goal was to use data to improve the experiences and outcomes of radiation oncology patients at our cancer centre. Our patient co-lead identified two areas for improvement from the patient's perspective: (1) the pain of waiting (in the waiting room for appointments and at home during radiotherapy treatment planning), and (2) the lack of PHI and relevant educational material provided to patients regarding their diseases and treatments. We set out to address the first problem by estimating waiting times using machine learning techniques (separate report in preparation). We soon realized that if we were to communicate personalised waiting time estimates to patients, we needed a secure and confidential method to connect with them. A smartphone app was the obvious choice. It provided personalised communication with the patient both in the waiting room and at home. As discussions around the functionality of a waiting time app developed, it became clear that such an app would essentially be a patient portal and, as such, it would address our second problem; the lack of PHI and relevant educational material provided to patients.

In developing a solution to share PHI and educational material with patients, it was important to demonstrate the need for such an effort and to solicit feedback from both patients and staff regarding the features and functionalities to be provided. We did so through a combination of a literature review, a patient focus group, and a survey of patients within our waiting rooms. Additionally, we assembled an oversight committee of staff and patient volunteers to provide continuous feedback and guidance to the leadership team.

### *2.1. Literature Review*

We were unable to find comprehensive reports in the literature regarding the process of developing a patient portal. At first glance, this is quite surprising given the large number of patient portals that are already in use in healthcare (Ford et al. 2016). However, a likely reason may be that the majority of portals to date have been vendor-developed, with little incentive to publish details that may be exploited by a competitor. Our experience is consistent with that recently reported by Otte-Trojel et al. (2016) who undertook a systematic literature review of patient portal development problems and solutions and concluded that, while they were able to identify five main problem categories, they were unable to find published evidence regarding the actual portal development process. The five problem areas identified by Otte-Trojel et al. are nevertheless quite helpful and include achieving: patient engagement, provider engagement, appropriate data governance, security and interoperability, and a sustainable business model.

Another recent report, by Baudendistel et al. (2015), provided evidence from ten German focus groups regarding the needs and requirements of prospective users of a patient-controlled mulitple-EMR-aggregating personal electronic health record. The Baudendistel et al. solution, which was targeted to colerectal cancer patients, is not

exactly a patient portal but their findings are nonetheless useful in our context. In particular, they found that patients want to be able to track their long-term medical history and that the information provided must be accessible and filtered to the patient's specific situation. Furthermore, they found that both patients and providers found value in clinically-relevant patient-generated data, such as information on pain, depressive feelings and the side effects of treatment.

Worldwide, there is growing evidence that patients want access to their health data and that, when provided with that access, they will use it. The *Open Notes* initiative (opennotes.org) in the United States is a salient example. As reported by Walker et al. (2015), by the end of 2014 over five million patients in the US had access to their physicians' notes through the efforts of the initiative. In Estonia, the Estonian Electronic Health record system, with mandated patient access to doctors' notes, was launched in 2008 and is considered a success (Tiik & Ross 2010). Europe-wide, the SUSTAINS consortium (sustainsproject.eu) are working on providing all patients in the EU with access to their EHR data as part of the eHealth Governance Initiative (Joustra-Enquist & Eklund 2004). Real-life pilot projects have been reported on the SUSTAINS website for eleven regions across Europe. In Canada, Mák et al. (2015) published a pilot study on providing lab test results to patients in British Columbia. They found no differences in the levels of anxiety among patients who received their lab results online compared to a control group. However, a lower level of comprehension was found among the patients who used the online facility, indicating the importance of providing patients with appropriate educational support.

For the specific context of radiation oncology, we are aware that several patient portal products are provided by the vendors of radiation oncology equipment and oncology information systems. However, only promotional literature and industry feedback reports (e.g. klasresearch.com) are available and we were unable to identify an existing product that suits our most basic needs—automated access to medical notes, automated personalisation of information, and multi-lingual support.

### *2.2. Patient Focus Group*

After an initial version of Opal was developed (January 2016), we invited a number of interested patients to participate in a focus group to provide feedback regarding its features and usability. Our radiation therapy team helped us to identify a cohort of engaged patients who had finished their treatments and whom they felt might make good focus group participants. Ten patients were identified and contacted and three ultimately participated. Those who declined indicated that they were unavailable on the date and time of the focus group.

Without showing patients the app or divulging its features, we started the focus group by asking the participating patients for their thoughts on what information they would like to see in an app/portal without regard to the technical, legal or logistical restrictions around providing such information. We then demonstrated the app and

observed the patients using it. Finally, we went through each of the features of the app and sought feedback. Most of the features suggested by the patients were already in place. These included hospital maps, radiotherapy treatment plan views with beam entry points, appointment schedules, waiting time estimates and notifications. Some suggestions, such as an inbuilt feature to pay for parking or a system to leave questions for call-back (rather than navigating the hospital's phone system) were not but will be included in future versions. Interestingly, we found that our focus group participants prefaced many of their responses with disclaimers such as "I doubt it is possible, but it would be nice if..." or "I wouldn't want to disturb my treating team by asking for this ... information, but it would be nice if I could see it myself in my own time...".

We found that the focus group experience was very beneficial. It affirmed to the team that we were on the right track with the features provided in the app and it allowed us to make a number of changes to improve its user-friendliness.

### *2.3. Patient Survey*

Our patient survey was developed as part of a larger survey regarding the experience of patients within our waiting rooms. We first asked participants for some demographic information (age and gender) and presented several introductory questions to ascertain if they had a smartphone and if they would use an app/portal to securely access their PHI. The main part of the survey then presented possible features of an app/portal and asked patients to rate their interest in having them using a five-point Likert scale, ranging from "not at all interested" to "very interested". Patients were invited to complete the main part of the survey only if they had reported that they have a smartphone.

A common concern voiced by staff is that patients would not want, or should not have, access to important PHI, such as lab test results or doctors' notes, without first reviewing them with their physicians. To determine patients' level of comfort with accessing their PHI, we presented survey participants with three possible levels of information and asked them to select which one they would choose if provided with the choice. The three levels included:

(i) I would like access to all of my medical record, including lab results, as soon as the information is available

(ii) I would like access to all of my medical record, including lab results, after I have reviewed them with my doctor

(iii) I would like access to just my appointment schedule and other need-to-know information

*2.3.1. Survey Findings:* A total of 174 patients responded to our survey. Of these, 59% (103) said they did have a smartphone. Figure 1 presents the distribution of patients by age group and the percentage of patents in each age group who reported having a smartphone. As was expected, smartphone usage is less prevalent for the older

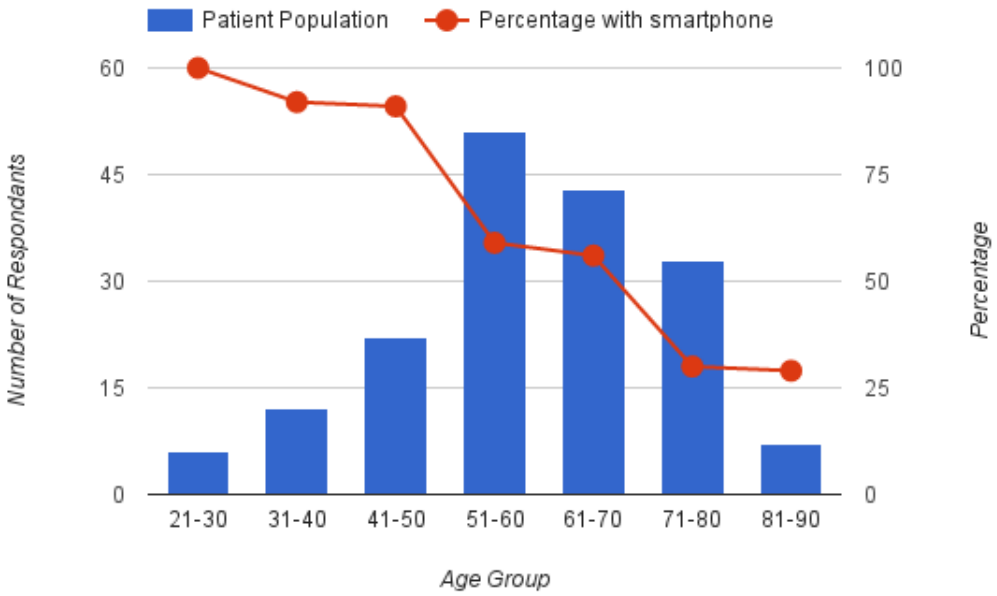



**Figure 1.** Distribution of the ages and smartphone usage of the 174 cancer patients who participated in our survey. 59% (103 out of 174) of the surveyed patients reported that they have a smartphone. The survey was conducted in our waiting room as part of a larger survey on patient satisfaction with waiting room management.

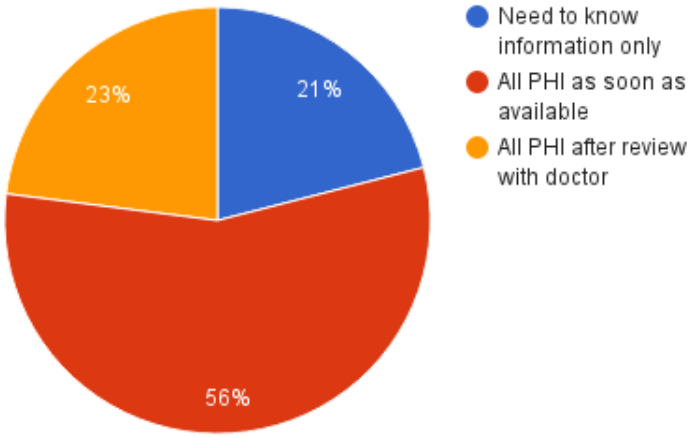



**Figure 2.** Patient preferences with regard to the PHI that they would like to access via an app/portal. We only included answers from patients who reported that they had a smartphone and who selected just one of the three options (n=100).

**Table 1.** Results from the main part of the patient survey regarding possible features of a patient app/portal. Participants were presented with possible features of an app/portal and asked to rate their interest in having them using a five-point Likert scale, ranging from "1 = not at all interested" to "5 = very interested". Column "Pos" shows the percentage of patients who rated their interest as 4 or 5, i.e. the total number of patients who said they were positively "interested" in having the feature. n indicates the number of participants who answered each question.

| Possible Feature | n | 1 | 2 | 3 | 4 | 5 | Pos |
|---|---|---|---|---|---|---|---|
| Your personal appointment schedule | 102 | 4 | 0 | 4 | 8 | 84 | 92 |
| Step-by-step status of your personal treatment planning while waiting at home before starting treatment | 95 | 11 | 1 | 7 | 9 | 72 | 81 |
| Personalised check-in and call-in for your appointments via your phone | 102 | 8 | 3 | 5 | 11 | 74 | 85 |
| Notifications sent to your phone to advise you that you are next in line to see your doctor or for treatment | 102 | 8 | 2 | 4 | 10 | 76 | 86 |
| Secure access to doctor's notes in your medical record | 101 | 10 | 3 | 4 | 11 | 72 | 83 |
| Secure access to your personal radiotherapy treatment plan showing beam configuration and possible areas of your skin that might be affected (radiotherapy patients only) | 90 | 16 | 3 | 11 | 11 | 59 | 70 |
| Secure access to your personal lab results | 101 | 9 | 4 | 6 | 9 | 72 | 81 |
| Contact information for your treating team | 101 | 6 | 3 | 6 | 16 | 69 | 85 |
| A secure messaging system with your treatment team | 101 | 6 | 4 | 6 | 13 | 71 | 84 |
| Educational material specific to your diagnosis | 101 | 7 | 2 | 7 | 21 | 63 | 84 |
| Educational material specific to your phase of treatment | 101 | 6 | 3 | 8 | 21 | 62 | 83 |
| Questionnaires to describe your symptoms or side effects before each appointment | 101 | 6 | 3 | 13 | 13 | 65 | 78 |
| Maps and hospital information | 101 | 9 | 7 | 16 | 10 | 58 | 68 |
| Parking information | 101 | 16 | 8 | 12 | 13 | 51 | 64 |
| Option to anonymously donate your medical data for research | 100 | 12 | 9 | 12 | 13 | 54 | 67 |



age groups. However, it is clear that a smartphone app would nevertheless have uptake across the age spectrum and so can be considered a potentially useful tool for all patients. In terms of patient preferences for access to their PHI using an app/portal, we found that the majority of respondents 56% would prefer to have access to all of their data immediately as they are available. The remainder of respondents were roughly evenly split between accessing all their data after review with their physician or accessing just need-to-know information, such as appointments and educational material. Figure 2 shows the breakdown of patient preferences. Table 1 presents the results of the main part of the survey and shows that the vast majority of patient respondents indicated that they were very interested in all of the possible features of an app/portal that we presented.

We note that our survey was conducted after the main features of Opal had been developed and it was not intended to be a statistically rigorous examination of patient preferences. Rather, the goal of the survey was to affirm patient preferences prior to

initial release.

### *2.4. Staff Input*

Over the course of development of Opal, the HIG team leaders have presented the project and the planned features and functionality of the software to various staff groups, from ground-level care-givers to senior management, within our institution. The purpose of these presentations was threefold: (1) to ensure awareness and buy-in for Opal by staff at all levels, (2) to address staff concerns regarding the data provided to patients, and (3) to seek support to continue development of Opal beyond its initial release.

## 3. Challenges and Design Goals

### *3.1. Technical Challenges*

The technical challenges encountered when designing a patient app/portal are numerous but not insurmountable. We identified the following eight overriding technical challenges that guided development of Opal from the beginning:

(i) Personalised and automated communication: In order to deliver personalised, relevant, and just-in-time information to the patient, a rules-based backend infrastructure that transfers PHI and non-PHI data to the patient when certain "trigger" conditions are met is required. For example, when the patient checks in for an appointment, it should be possible to automatically send them a PRO questionnaire to be completed while waiting. The questionnaire should be specific to their diagnosis and stage of treatment.

(ii) Security: At all levels it is imperative that our app/portal solution is secure. Our radiation oncology EMR (*Aria* by Varian Medical Systems, Palo Alto, CA) should never be publicly exposed and internal hospital servers should not be accessible from outside the hospital's firewall; most data should flow outwards and any data that must come in (such as questionnaire responses) should be appropriately filtered and, to guard against injection attacks, never directly used to execute queries. Individual patients must be securely authenticated in order to access their data, and in the case that an individual's account were to become compromised, other patient data and the hospital's IT infrastructure should not be put at risk.

(iii) Confidentiality: It is important that all data that are transferred between the hospital and the patient are encrypted at all times and may only be decrypted by the patient. Furthermore, data stored on the patient's phone or web browser should be sand-boxed (i.e. insulated in an area of memory that is not accessible to other applications) and encrypted so that other applications on the device, or a device thief, cannot access them under any circumstances.

(iv) Waiting room management system compatibility: As Opal started off as a project to communicate personalised waiting time estimates to patients, full integration

with our waiting room management system software was considered essential from the beginning. The patient should be able to check-in for appointments via Opal and be called-in to the examination/treatment room by means of a notification to their smartphone.

(v) Multi-platform: Our solution must work equally well as a traditional web portal in a web browser and as an app on both Android and iOS smartphones.

(vi) Multi-lingual: As our hospital is in Québec, it is important that French and English are supported equally at all levels. Furthermore, the patient must be able to change language preference at will.

(vii) Modularity: The frontend and backend software architecture should be built in a modular way such that new functionality and features (modules) may be added later without affecting those that are already in use.

(viii) Scalability and generalizability: The frontend and backend software should be EMR agnostic and able to accommodate expansion to other departments/hospitals with expected increases in users and in the amount and types of data.

### *3.2. Desired Features and Functionality*

Based on the feedback received from patients and staff, we set out to develop five information categories to be arranged under tabs/menus within Opal. These included:

(i) Home Screen/Overview: Notifications and up-to-date pertinent information personalised to the individual patient, such as next appointment, status of treatment/treatment planning and waiting room management.

(ii) My Chart: PHI specific to the individual patient, including appointment schedule, doctors' notes, radiotherapy treatment plan views, lab test results, and secure messaging with the treating team.

(iii) General Information: Information regarding the hospital and cancer centre that is not personal to an individual patient.

(iv) Educational Material: Relevant, just-in-time educational material that is specific to the individual patient's diagnosis and phase of treatment.

(v) Account Settings: Tools to allow the patient to change preferences such as synchronization with a personal calendar, notifications to the phone and preferred level of PHI, as per figure 2.

Table 2 lists the features and functionality identified for inclusion under each information category. In the Results section below, we provide screenshots of each tab within the app. Based on feedback from staff, it was clear at the outset that not all of the features that provide patients with access to their PHI, as identified in the focus group and survey, would be acceptable to clinicians by the time of first release of Opal. Some features such as secure messaging and lab results were considered too controversial for initial release. Other features, such as appointment change requests, may require staff

workflow changes and are under evaluation by management. Nevertheless, it was agreed that, at a technical level at least, as many features as possible should be included in the initial development so that, when their use is approved in the future, they may easily be switched on. Features included and excluded from the initial release are indicated accordingly in table 2.

### *3.3. Logistical and Cultural Challenges*

The challenges to developing an app/portal for patients are not just technical. In order to ensure the success of the finished product, a number of logistical and cultural challenges needed to be addressed within the design of the app/portal itself and in the way in which the concerns of patients and staff were addressed. The following logistical and cultural challenges were identified:

(i) Financial backing: Financial support for the development of Opal (mainly salary support for programmers and students) was provided by non-commercial resources internal to our institution. Please see the Acknowledgments section for full details.

(ii) Language support: Full and equal support for French and English is imperative for the patient population served by our hospital within the Québec healthcare system. Once the technical challenge of providing the app/portal in both languages was addressed, we left translation until the end. This allowed us to make changes as necessary without the need to constantly re-translate.

(iii) Staff workload: It was clear from the beginning of the project that any service that is provided by the app/portal should not increase the workload on clinical staff. The personalisation and provision of data should be automated, except for initial setup of the publishing rules in the Publish Manager (see below). Patient registration for Opal will be facilitated by providing step-by-step sign-up instructions for patients and staff and a minimal easy-to-use interface for the registration clerks. The provision of treatment planning views showing radiotherapy beam entry points to patients (explained below) requires a minimally-disruptive protocol for the dosimetry team. At the time of writing, the protocol is still in development.

(iv) Patient engagement: To achieve our goals of (a) empowering and educating our patients and (b) collecting PRO data, it is imperative that patients actually use Opal. We have been conscious from the outset that a patient app/portal needs to appear simple and useful (Lazard et al. 2016) and that patients must be provided with an incentive to use it (Mafi et al. 2016).
Design simplicity was achieved by grouping information as shown in table 2, by allowing user-controlled font sizes, and by fine-tuning the layout based on focus group feedback. Incentive is addressed using two strategies: (1) through integration with our waiting room management system and (2) by facilitating delivery of personalised PRO questionnaires while waiting for appointments. We envisage that patients will use Opal to check-in for their appointments on arrival at the

**Table 2.** Categories of information and features/functionality identified by patients and staff to be provided to patients via Opal. The majority of information provided to patients via Opal is personalised to their disease and phase of treatment.

| Category (Menu/tab) | Features/Functionality | Personalised | Initial Release |
|---|---|---|---|
| Home Screen/Overview | Next appointment | ✓ | ✓ |
| | Notifications (e.g. new document, new message, etc) | ✓ | ✓ |
| | Posts (messages from treating team and general hospital announcements) | ✓ | ✓ |
| | Status of treatment/treatment planning | ✓ | ✓ |
| | Waiting room management (check-in, call-in, waiting time estimate) | ✓ | ✓ |
| My Chart | Diagnosis information | ✓ | × |
| | Notification archive | ✓ | ✓ |
| | Appointment schedule with appointment location maps | ✓ | ✓ |
| | Appointment change requests | ✓ | × |
| | Treatment/Treatment planning information | ✓ | ✓ |
| | Access to (selected) doctors' notes and nursing notes | ✓ | ✓ |
| | Lab test results | ✓ | × |
| | Messages from treating team | ✓ | ✓ |
| | Secure two-way messaging with clinicians | ✓ | × |
| | Patient-reported outcome questionnaires | ✓ | ✓ |
| General Information | Phone directory and contact information (personalised on login) | ✓ | ✓ |
| | General hospital announcements | × | ✓ |
| | Patient charter | × | ✓ |
| | Parking information | × | ✓ |
| | General hospital maps | × | ✓ |
| | Way-finding | × | × |
| | Leave feedback regarding app/portal | × | ✓ |
| | Facility to report bugs in the app/portal | × | ✓ |
| Educational Material (relevant and just-in-time) | Videos | ✓ | ✓ |
| | Booklets | ✓ | ✓ |
| | Pamphlets/fliers | ✓ | ✓ |
| Account Settings | Language preference | ✓ | ✓ |
| | Font size | ✓ | ✓ |
| | Synchronization with phone's calendar | ✓ | ✓ |
| | Facility to update contact information | ✓ | ✓ |

hospital. In doing so they will be provided with a continuously-updated waiting time estimate and assurance that they will be called for their appointment via their smartphone. While waiting for consultations, they will also be encouraged to complete a personalised PRO questionnaire, incorporating validated questions, that will save on consultation times and allow patients to monitor their own outcomes over time.

## 4. Software Design and Implementation

Building a patient portal, while addressing the technical, logistical and cultural challenges that it entailed, required significant time, resources and management. The support of hospital management at all levels was crucial and allowed the project to proceed. We met with our hospital's IT Security and Governance team early on and outlined our initial work and our plans. In follow-up, they provided a comprehensive assessment of our solution and a list of recommendations to be addressed before going live. Recommendations included not only addressing the obvious issues of security and confidentiality but also dealt with concerns regarding consent, service-level support, long term sustainability, annual risk assessments, documentation and general enterprise-readiness.

In an effort to provide the community with some information on how to go about developing an app/portal, as called for by Otte-Trojel et al. (2016), we describe here the technical solutions that we developed to address both the challenges we set ourselves and the technical concerns of our IT Security and Governance team.

### *4.1. Overview of Communication Architecture*

To securely serve data to Opal, while simultaneously insulating access to our EMR databases, we developed a custom database, known as *OpalDB*, that is internal to our hospital's firewall. To manage OpalDB, we use the MySQL database management system hosted on a Linux server with automatic mirroring to an independent fail-over server and nightly backups to a backup server. Figure 3 presents a schematic of Opal's communication architecture. Select data are transferred from the EMRs to OpalDB using a "cron job" *Auto Update* scheduler, hosted on our Linux server, that copies across approved appointments, tasks, documents and lab test results. Access to the documents is provided by means of mounting the appropriate MS-Windows shared hard drives on the Linux server using the Common Internet File System (CIFS) protocol. Approval and timing are determined by a list of "publishing rules" that are set using a *Publish Manager* interface. As described below, the Publish Manager is a webpage that allows the clinical team to configure the publishing rules and to decide which data are publishable to patients, when, and how they appear in the app/portal.

Secure serving of data through the hospital's firewall to Opal is facilitated by *Firebase*, a backend-as-a-service cloud database operated by Google Inc. (firebase.com).

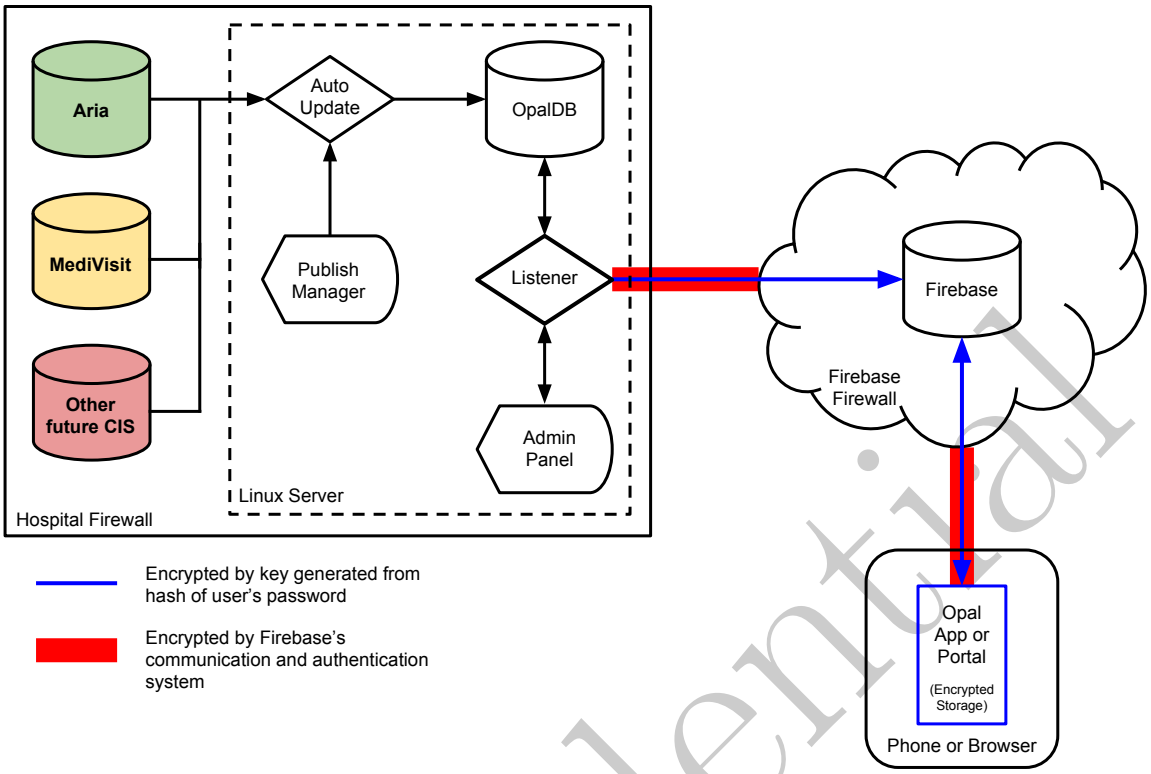



**Figure 3.** Schematic of Opal's communication architecture. The dashed line delineates Opal's backend software. Each component is described in the text.

Firebase is designed such that all applications that are connected to it are served data in real time. As such, if any data on Firebase are changed, all connected applications immediately see the change, and vice-versa. This allows us to ensure that patients always have access to their most up-to-date medical data. Using Firebase as a communication tool provided our team with three distinct benefits: (1) it obviated the need to purchase and configure external servers and to maintain a DMZ§, (2) Firebase provides authentication tools and SSL encryption by default, which addressed many of our security and confidentiality concerns, and (3) as already mentioned, Firebase serves data in real time, an important feature that would otherwise require significant resources for our team to develop from scratch.

### *4.2. Security and Confidentiality*

Security and confidentiality are achieved at several levels. User authentication and data access within Firebase are rules based (firebase.com/docs/security). Opal users first need to register in person within our hospital, where they set their usernames and passwords for authentication using Firebase. Additionally they answer a number of

§ A *DMZ*, or demilitarized zone, is an external facing sub-network that is commonly used to expose data from an organisation's private internal network to the Internet without exposing the internal network.

security questions; to be used in the event that they need to reset their passwords. Their Opal accounts are then connected, within OpalDB, to their PHI data in the hospital's EMR(s). A hash representation of their passwords, generated using the SHA256 one-way hashing algorithm (NIST 2015), is used as the key to encrypt all data that are sent to/from the hospital and to/from Opal. Encryption is achieved using the AES algorithm (NIST 2001). All communication with Firebase is encrypted by default. However, encrypting the patient's data ourselves, before sending them through Firebase, ensures that all data within Firebase (even if they are only stored there for a maximum of five minutes; see below) are encrypted and cannot be read by Firebase employees. Also, in the event of a compromise (e.g. password retrieval through a phishing attack), only the patient's own data are compromised, and the compromise cannot extend further than Firebase. Furthermore, neither Firebase nor Opal know, or need to know, anything about the hospital's servers.

Physical security of PHI data on a patient's smartphone or web browser cannot be guaranteed and the inherent risk must be minimized. While the data within Opal are stored encrypted and sand-boxed from other applications, the patient has a responsibility to maintain the physical security of their phone and the secrecy of their password. Periodic pop-up alerts within Opal remind the patient to secure their phone with a security code. To mitigate against possible compromise, all users are automatically locked out of Opal after five minutes of inactivity. The real time connection with Firebase is maintained but the user must re-enter their password in order to access the functionality of Opal. At the backend level, as described below, all patient activity (logins, downloads, updates, etc) is logged with timestamps and device identifiers.

### *4.3. Backend*

The backend (data access layer) of Opal resides on our Linux server inside the hospital's firewall, as shown by the dashed line in figure 3. In addition to the custom OpalDB database, the backend comprises the Publish Manager, an Admin Panel, an Auto Update scheduler and a Listener. The purpose of the backend is to retrieve data from the hospital's EMR(s), store them in OpalDB, listen for authenticated data requests from the frontend (Opal app/portal) and serve the requested data to the frontend via Firebase. Each of the components that comprise the backend are described below.

*4.3.1. Publish Manager* All of the data that reside in OpalDB are accessible to the patients that own them. As such, it is important to strictly control their insertion into OpalDB. The Publish Manager provides this control. Three basic data types are encountered: personal data, personalised data, and tagged data. Please see table 3 for descriptions. A schematic of the Publish Manager is provided in figure 4. Essentially, it is a web interface internal to the hospital that allows authorized users to (a) control the personal data that will be shared with patients (b) create content (educational material,

**Table 3.** Data types that are served to patients via Opal and their attributes. All non-personal data are available in French and English.

| Data Type | Description |
|---|---|
| Personal data | PHI that belong to individual patients and are retrieved from the hospital's EMR(s). |
| Personalised data | Data, such as educational material and hospital announcements, that are published only to those patients for whom they are pertinent. For example, only breast cancer patients should receive breast cancer educational material and only patients receiving radiotherapy on treatment machine N should receive an announcement that it will be closed for maintenance on a certain date. |
| Tagged data | Data that are used to supplement personal or personalised data. For example, maps may be tagged to appointments to show their locations or an educational document may be tagged to the notes of Doctor X to explain his/her way of writing. |

posts, questionnaires, etc) and apply personalisation rules, and (c) create tagged data that will be used to supplement the personal and personalised data.

A PHI aliasing interface is used to translate clinical codes into more meaningful patient-friendly terms, in English and French. For example, many different codes are used internally to describe consultation appointments but it is only necessary for the patient to know that they have an "appointment with your radiation oncologist". Likewise, aliases may be created for documents, radiotherapy treatment planning tasks and lab test results.

Personalisation is achieved using rules-based triggers that publish relevant, just-in-time information to the patient. For example, pre-treatment breast cancer information can be sent to breast cancer patients prior to treatment, skin care information may be sent to the same patients during treatment, and an invitation to attend a survivorship education session may be sent post-treatment. Likewise, as already described, PRO questionnaires may be published to patients in the waiting room tailored to their diagnosis and phase of treatment. A PRO questionnaire may be tagged with a notification from the patient's oncologist to appear on the patient's smartphone, such as "*A symptom questionnaire has been sent to you. Dr. X kindly requests that you complete it now while waiting for your appointment. Thank you.*".

*4.3.2. Admin Panel* The Admin Panel is a roles-based web interface with three functions:

(i) It is used by clerks to register patients. Registration essentially involves authentication on Firebase and linking an account on OpalDB with a medical record in the hospital's EMR(s). The patient is required to register in person at the hospital, to input their password and to provide answers to a number of security questions, to be used in the event that their password needs to be reset.

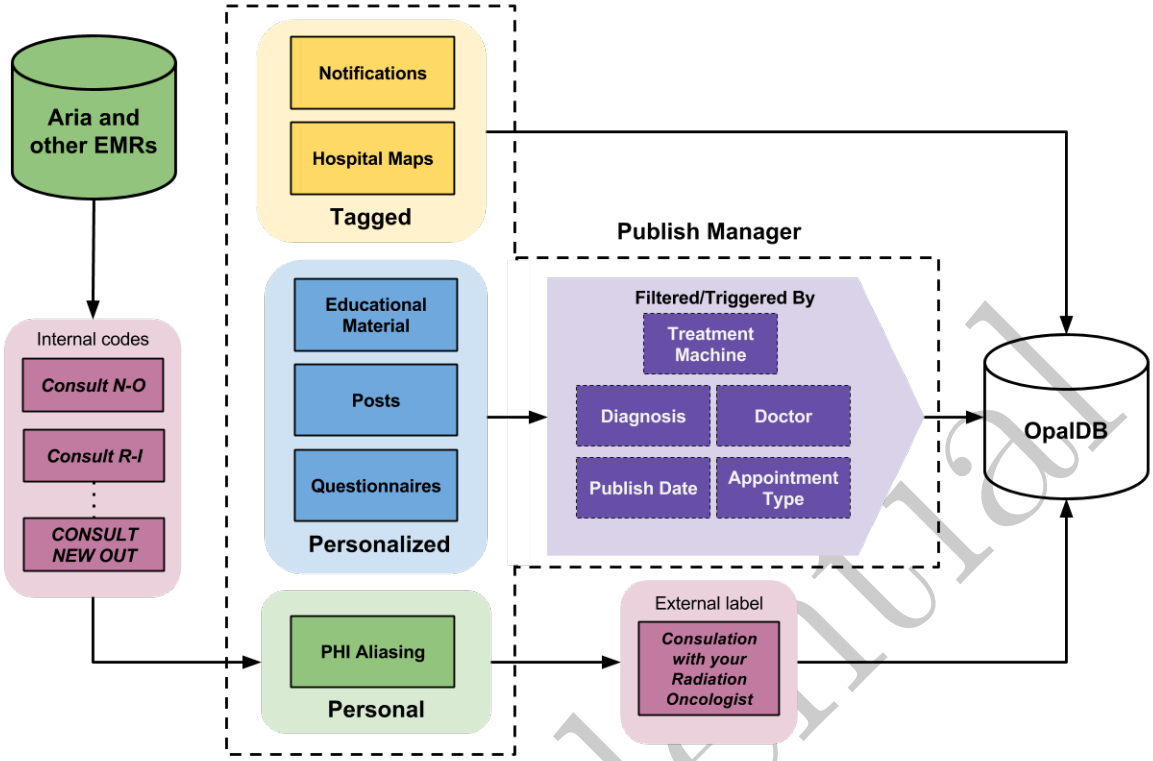



**Figure 4.** The Publish Manager, delineated by the dashed line, is the part of Opal's backend infrastructure that controls which data are shared with patients and how and when they appear within the app/portal. Three types of data are encountered; personal data from the hospital's EMR(s), personalised data that are send to patients when pertinent, and tagged data (such as maps and notifications) that are used to supplement personal and personalised data. The Publish Manager provides an aliasing function to translate internal clinical PHI codes to meaningful external labels and a filtering/triggering function to personalise data publishing to patients.

(ii) It may be used by physicians for secure two-way messaging with patients and to see the app as it appears to their patients. This functionality is designed to mitigate concerns that physicians might not know what information their patients are receiving.

(iii) It may be used by superusers and the hospital security team to access Opal's activity logs. All patient logins, data access requests and data changes are logged in OpalDB using MySQL's *Triggers* function.

*4.3.3. Auto Update Scheduler* The Auto Update scheduler is a shell command that is generated by the Publish Manager software and run on a regular basis (every 2 minutes) by the *cron* service on Linux. It copies new data from the hospital's EMR(s) to OpalDB according to the selection and filtering rules set up by the Publish Manager.

*4.3.4. Listener* The Listener is a *node.js* script that monitors and communicates with Firebase. When the frontend app or portal requests data, it places a token on Firebase that is immediately seen by the Listener. The Listener then fetches the appropriate data from OpalDB, encrypts them using the one-way hash of the patient's password and copies them to Firebase, where they are immediately propagated to the Opal app/portal on the patient's device (smartphone/web browser). As soon as delivery to the device is complete, Opal deletes the data from Firebase. In the event of a disruption in the connection to the patient's device, the Listener deletes the data from Firebase after five minutes. This ensures that stale patient data, albeit encrypted, are never sitting on Firebase. In general, the Listener pushes data outward. However, certain data types, in particular PRO questionnaire responses, two-way patient-clinician messaging, and appointment check-ins are accepted inward.

### *4.4. Frontend*

Two versions of the Opal frontend have been developed; an app for smartphone devices and a portal for web browsers. The architecture is the same for each but the content format differs between them. Both versions are written in *AngularJS*, a Javascript framework provided by Google Inc. The content for the app is formatted using *OnsenUI*, a CSS and Javascript framework, with native phone functionality for Android and iOS provided by the *Apache Cordova* framework. The content for the web portal is formatted using *Bootstrap* by Twitter Inc. and *Angular Material* by Google Inc. The responsiveness of Bootstrap and Angular Material also allow rendering of the web portal on a tablet device.

Opal's frontend software uses the modularity offered by the model-view-controller (MVC) architecture of AngularJS. Figure 5 presents a graphical abstraction of the frontend. A "model" stores data that are retrieved from Firebase in the form of services and class variables. A "view" is responsible for displaying all portions of the data to the user (i.e. the visual style of the content). A "controller" provides the link between the model's data and their associated view. It provides users with a means to send commands from the view to the model in order to update the model's state (e.g. answering a question in a questionnaire). Likewise, the controller responds to model changes (e.g. new data received from Firebase) and sends commands to the view to update its representation of the model. An *Update* service is used to communicate encrypted JSON data with Firebase across an encrypted SSL channel and to direct all incoming and outgoing data to/from the appropriate models. As described earlier, due to the security requirements surrounding patient data, data are stored encrypted within the device storage, are decrypted by the controller using the patient-provided password, and the whole application is sand-boxed so that the data cannot be accessed by any other application.

MVC is a powerful design concept that facilitates modularity, one of the key technical design goals of Opal. It provides for separation of concerns by isolating data

logic from the user interface layer, facilitating an easy way to extend the functionalities of Opal. If new functionality is to be added, a new model (or service) can be developed to prepare the data needed by the view; a new view can be used to display the data; and a new controller can provide the mapping between the model and view. The process of adding new functionality thus does not interfere with existing functionality.

### *4.5. Patient-reported Outcome Questionnaires*

To collect PRO data, we have developed a backend interface to create and publish PRO questionnaires and a frontend module within Opal to display them. The backend interface forms part of Opal's Publish Manager, as shown in figure 4. A use case diagram describing Opal's questionnaire infrastructure is provided in figure 6. Within the questionnaire interface, clinicians may create questionnaires and prepare publishing rules to automatically send them to their patients. Targeted patients are then prompted on their smartphones to complete their clinician's questionnaires upon check-in for selected appointments. During consultation, clinicians need not spend time re-asking questions that the patient has already answered. Rather, they may view their patients' responses and augment them as appropriate with clinician-reported data. In this way, both the patient and the clinician experience tangible benefits from using Opal's PRO system.

For our initial release of Opal we will provide patients with a basic PRO interface within the app that will publish the Edmonton Symptom Assessment System questionnaire (Bruera et al. 1991) to be completed once-per-week on the day that the patient has an intra-treatment visit with their physician. A very basic Questionnaire Interface at the backend will provide physicians will access to the data that have been collected from their patients. For subsequent releases of Opal we envisage more comprehensive support for PRO collection and for PRO-based research.

### *4.6. Testing, Debugging and Release*

In developing Opal we have made use of the *Github* web-based distributed revision control and source code management service (github.com). We developed the smartphone app and web-portal in tandem but ultimately just the smartphone app will be released patients in our initial offering. To test and debug the app we followed the standard alpha and beta software development cycle. At the time of writing, we are in the closed-beta phase with non-patient volunteers and our patient team member providing feedback to the development team using Github's *Issues* interface. We provided our non-patient volunteers with test accounts and test data (appointments, documents, etc) in the Aria EMR to simulate as much as possible real patient scenarios. Our patient team member has access to her actual PHI via the app. In order to release the app to invited volunteers without publishing it in the Apple and Android app stores we used the *Crashlytics* software. Once closed-beta testing is finished and we have satisfied all the concerns of our IT Security and Governance team, we will complete

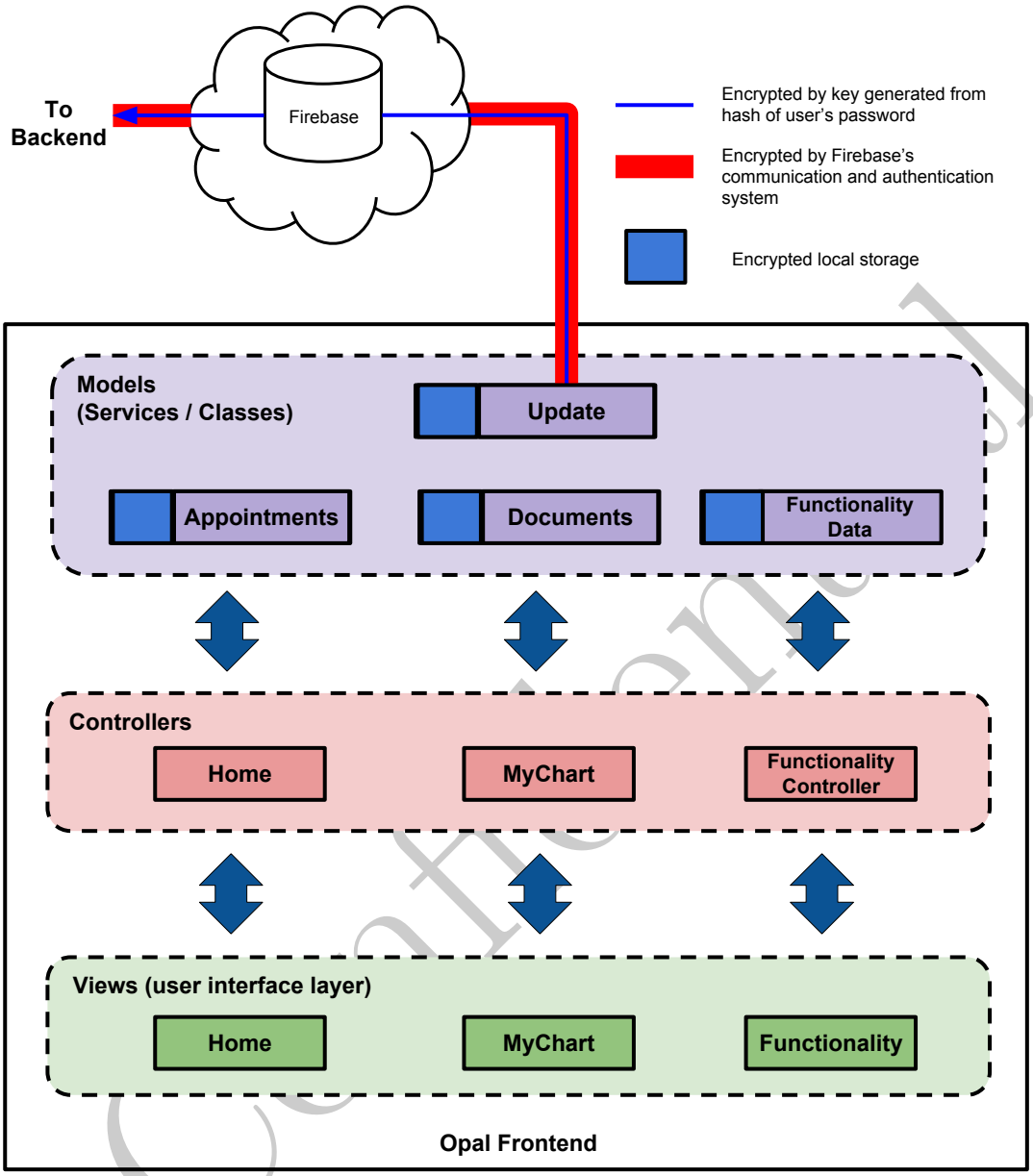



**Figure 5.** Abstraction of Opal's frontend software. The smartphone app and web portal use the same data and basic AngularJS framework but differ in the way that content is displayed. The frontend is designed to use the modularity offered by the model-view-controller (MVC) architecture of *AngularJS*. The user interacts with the *Views* layer to manipulate data in the *Models* layer by means of *Controllers*. Each functionality provided by Opal has its own model, view and controller, allowing new functionalities to be added without disrupting existing functionalities. Communication with the backend is channeled through a single *Update* service that maintains a real-time connection with Firebase. Two functionalities are shown; the display of Appointments and Documents in the Home and MyChart views, respectively. Additional functionality may be added, as indicated by the rightmost model, controller and view.

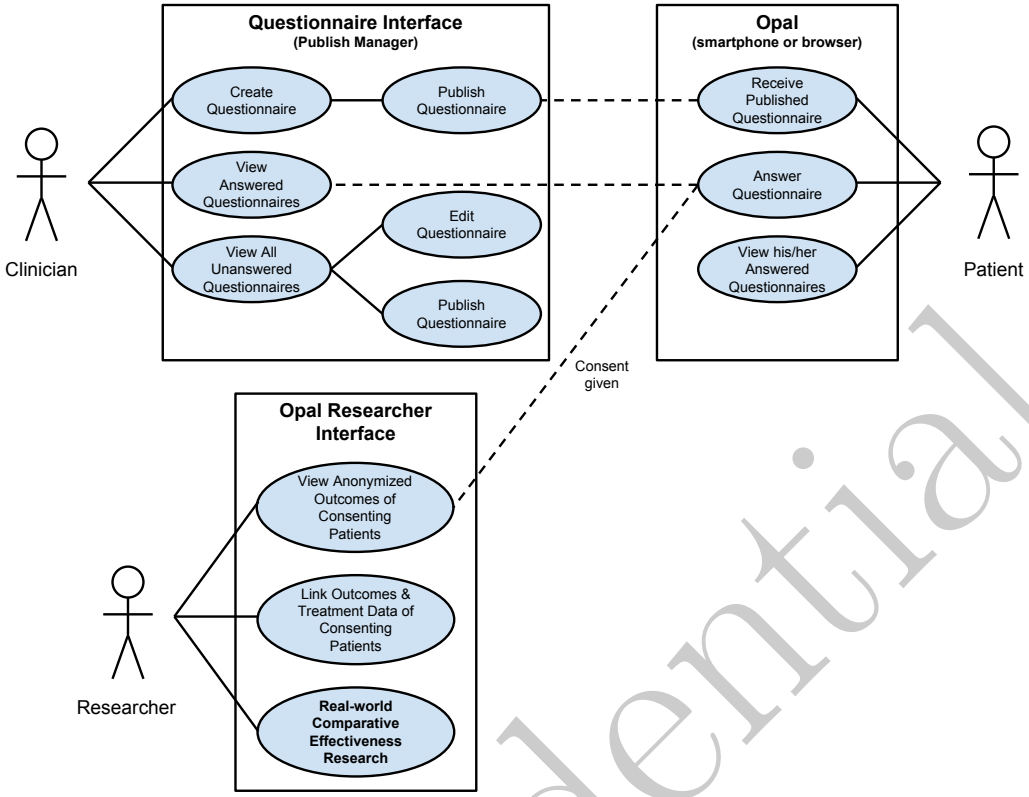



**Figure 6.** Use case diagram showing how Opal's questionnaires infrastructure for collecting PROs may be used by clinicians, patients and researchers.

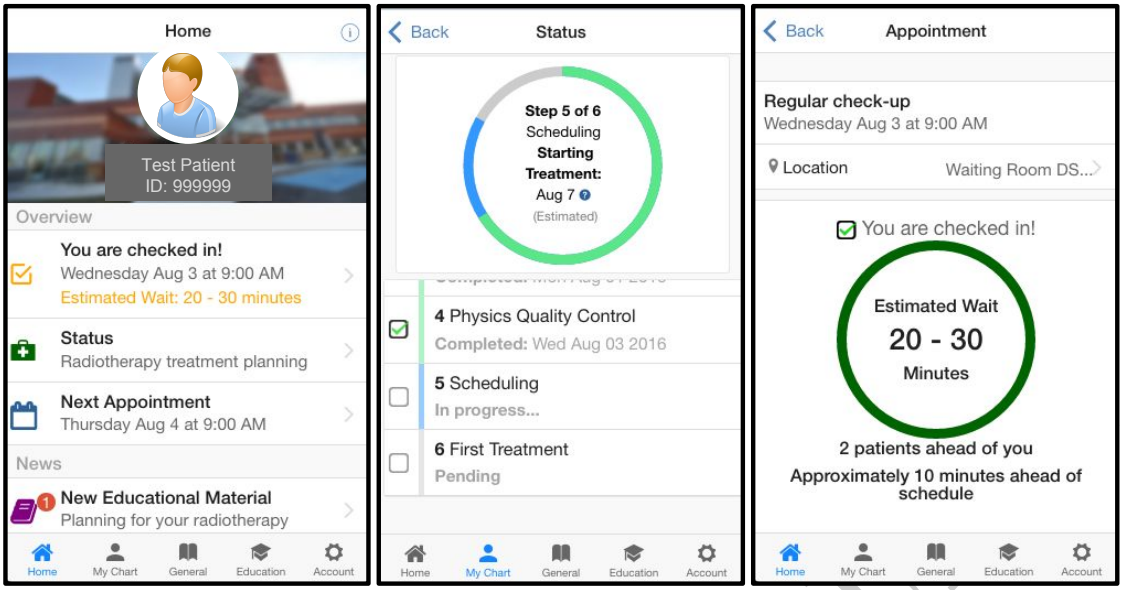
translation into French and move to open-beta testing with a pilot group of actual patients. Finally, when we are satisfied that the app is ready for general release (end of 2016 target), we will proceed with general release of the app and then complete development of the web-portal.

## 5. Results

In this section we describe the smartphone app that will be released in open-beta to select patients and we provide a preview of the web-portal. An online demo of the smartphone app is publicly available at depdocs.com/opal.

### *5.1. Backend Interfaces*

The Publish Manager and Admin Panel, which are only visible and used by staff, are complete. The same Publish Manager and Admin Panel serve both the smartphone app and the web-portal. Screenshots of the Publish Manager, Admin Panel and web portal are provided in the online supplementary material.




(a) (b) (c)

**Figure 7.** Screenshots of Opal's Home screen and associated sub-views. (a) The Home screen, where pertinent information and alerts are displayed. (b) The status sub-view shows where the patient is in the treatment planning pipeline or treatment schedule with predicted completion dates. (c) The waiting room management interface, where the patient may check-in for appointments and receive waiting time estimates.

### *5.2. The Home Screen*

The app's Home screen, figure 7, provides the patient with easy access to up-to-date pertinent information. Such information includes the date of next appointment, an overview of the patient's medical status (e.g. position in the treatment planning pipeline or number of radiotherapy fractions completed and remaining), notifications tagged to personal or personalised data (e.g. "*You have a new document*"), messages from the treating team, and general hospital announcements. Once read, notifications and announcements on the Home screen are archived in the "Notifications Archive" section of the "My Chart" view, described below.

The Home screen was identified as the most appropriate place for waiting room management communications. On the day of the patient's next appointment a "*Check-in for your appointment*" button is provided. It is only enabled when the patient is geo-located within 200 m of the hospital, as determined by the phone's GPS. Once checked-in, the patient is provided with a wait time estimate as well as information pertaining to the busyness of the clinic and the number of patients ahead of them (figure 7 (c)). Notifications to the smartphone (via the Apple and Android push notification services) allow the patient to leave the waiting room and wait to be called from the cafeteria or the hospital's garden, comfortable in the knowledge that they will be called for their appointment when the time comes.

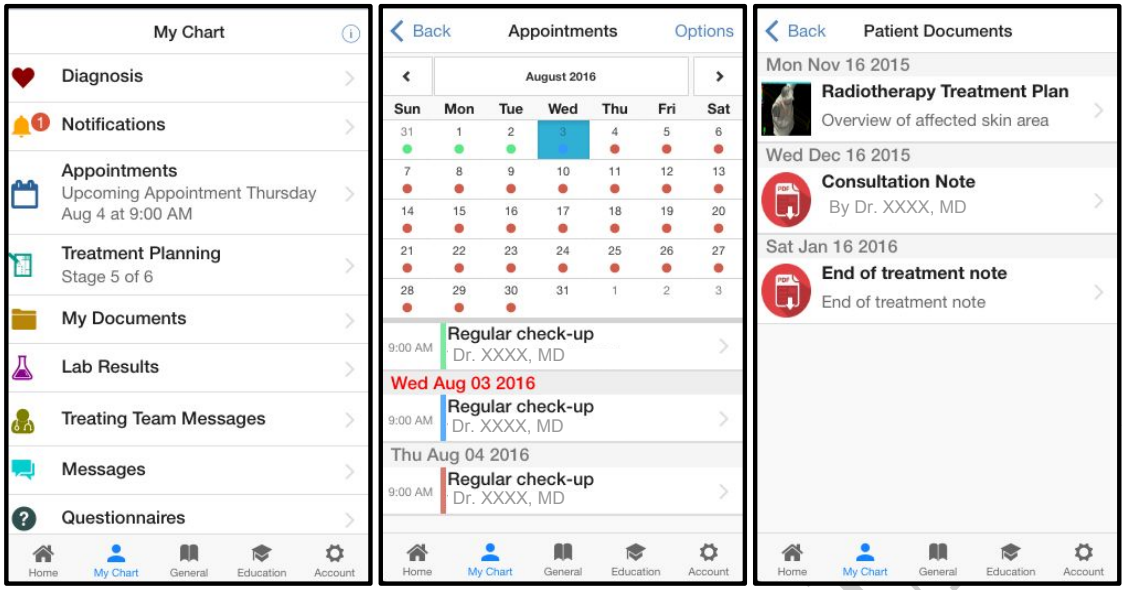



**Figure 8.** Screenshots of Opal's My Chart screen and associated sub-views. (a) In My Chart the patient has access to part of their medical record within the hospital's EMR(s). (b) The Appointments sub-view, showing all past and upcoming appointments. Appointments change colour on completion to provide radiotherapy patients with a sense of progression. (c) The My Documents sub-view provides the patient with access to select documents in their medical record, including a view of their radiotherapy treatment plan.

### *5.3. My Chart*

The "My Chart" view holds all the patient's PHI. Screenshots of the My Chart view and various associated sub-views are provided in figure 8. It is important to note that all PHI data provided via the app/portal are already available within the hospital's EMR. As such, there is no requirement for staff or patients to input data.

Within the "My Documents" sub-view (figure 8 (c)) the patient has access to their clinical notes. We plan to publish the following five documents to our radiotherapy patients on initial release: (1) Consultation notes, (2) End-of-treatment notes, (3) Brachytherapy notes, (4) Follow-up notes, and (5) Radiotherapy treatment plan 3D beam views.

As Opal may potentially be used to share all documents within our hospital EMR(s) with our patients, we envisage a long-term roll out of additional document types for radiation oncology, medical oncology and for other specialties at our general hospital. The details of which documents and when they will be made available will depend on further discussions with the clinical teams and patient representatives. An interface with each EMR will then need to be developed to complete the process.

### 5.4. General Information

General information is information that is relevant to all patients at our centre regardless of their diagnosis and phase of treatment. Such information is typically already available on the hospital's website and as such may be scrapped from it for automatic inclusion in Opal. Furthermore, as this information is not personalised to the patient, it is also provided by default in the Welcome screen of the app before the patient authenticates and logs in.

Some general information, while available to all patients, can be filtered in a personalised manner for the patient upon login. For example, while access to the hospital's phone directory is provided prior to login, a subsection of relevant contacts is highlighted for the patient once logged in. Highlighted contacts include the patient's oncologists, members of their treating team and phone numbers for the radiotherapy treatment rooms where they receive daily treatments.

### 5.5. Educational Material

Copious amounts of educational material are available to patients online and are provided on paper by staff at the start of treatment. However, such information may or may not be relevant to the patient's diagnosis and phase of treatment. The provision of general and sometimes irrelevant educational material that requires the patient to dig for what they need has been shown to contribute to cognitive overload (Paas & Sweller 2014). Relevant educational material that is provided to patients in a "just-in-time" manner at "teachable moments" (Knowles et al. 1980) may help reduce cognitive overload and improve patient compliance with treatment instructions.

With an app/portal that is tethered to the hospital's EMR it is possible to automatically filter educational material such that it is relevant to the patient's specific diagnosis and to provide it at the time it is needed. Within Opal, using the rules-based Publish Manager, pre-treatment information may be provided before treatment, side-effect management information during treatment and post-treatment information after treatment. Figure 9 shows how our hospital's patient education material appears within the Education view of Opal. Our patient education colleagues identified feedback from patients regarding the use and usefulness of educational material as important. Accordingly, we included a five-star rating system, as shown in figure 9 (b), to allow patients to rate the usefulness of each piece of educational material that is provided.

## 6. Discussion

Providing patients with access to their PHI and obtaining PROs from them are two topics of current interest in healthcare. In radiation oncology, however, no major successes have been reported to date and the automated provision of PHI and the collection of PROs remain a challenge. With a patient, who is also a computer scientist, a radiation oncologist and a medical physicist leading our team, the Health Informatics

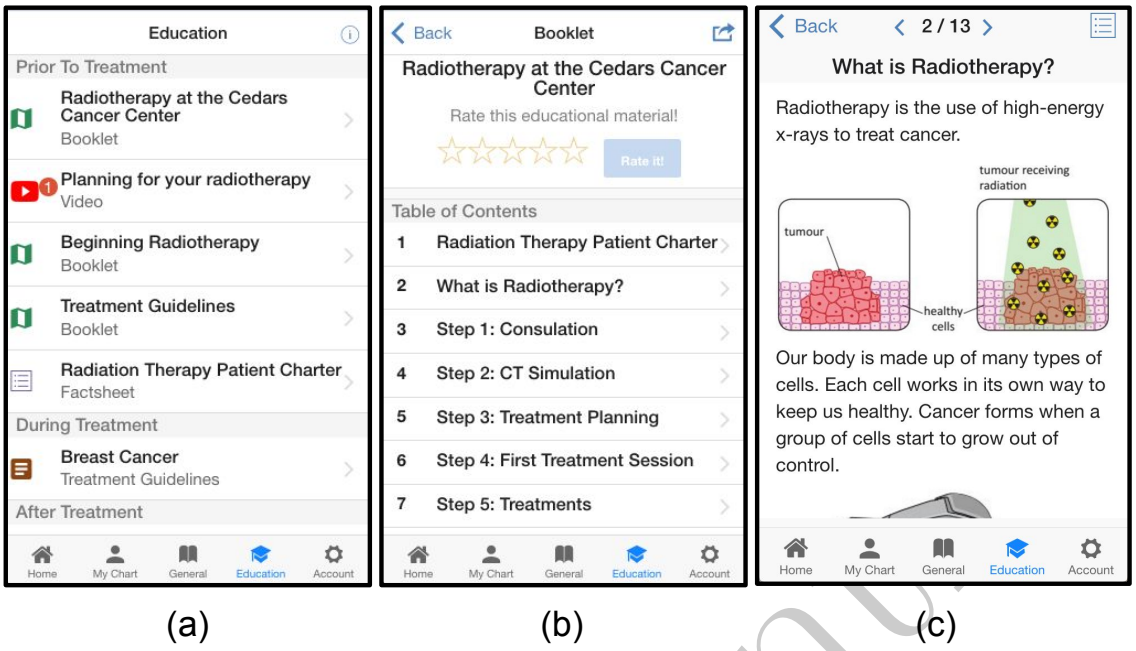



**Figure 9.** Screenshots of Opal's Education screen and associated sub-views. (a) The Education screen is split into information that is relevant before, during and after treatment (b) Each educational document has a table of contents and a five-star prompt for the patient to rate its usefulness. (c) Existing educational documents have been converted into a responsive html format.

Group, we set out to meet the challenge. The result is Opal, a smartphone app and web portal for radiation oncology patients that is currently in closed-beta release and scheduled for full release in the autumn of 2016. We believe that Opal is unique, not only in the way that it has been developed, in a patient-centered manner from inside the healthcare system, but also in the way that it automates personalised electronic communication with patients.

Opal was designed and built to minimize added workload on clinical staff through automated personalisation of the information provided to patients. Personalisation was achieved through development of a rules-based backend interface that provides relevant, just-in-time information to patients based on their diagnosis and phase of treatment. A novel PHI aliasing system, conceived and developed by our group, allows us to automatically translate internal clinical codes into multi-lingual (French and English) labels that are accessible to patients. In terms of security and confidentiality, which are of utmost importance when sharing PHI information with patients, Opal achieves both through the use of Firebase, a real-time cloud database, and by encrypting all data before they are sent along Firebase's secure communication channels.

For the collection of PRO data we have built a full suite of software tools that allow clinicians to create and publish questionnaires and analyze patient responses. Integration with our waiting room management software will help us ensure that the patient is prompted to complete questionnaires as appropriate once checked-in and

waiting for appointments. Responses will then be available for physicians to review during consultation.

From its formation, the goal of the HIG has been to improve the experiences and outcomes of cancer patients. With Opal we believe we can start do so. We are conscious of the increasingly-prevalent phenomenon dubbed the "burden of treatment" (May et al. 2009), whereby the patient's care workload adds to their existing burden of symptoms and side effects. Opal we believe, will empower patients with their PHI, with information regarding their treatment status, and with relevant just-in-time educational material. This empowerment, we hope, will in turn help patients schedule their daily lives during radiotherapy, help them better understand their diagnoses and treatments and, in the process, lessen the burden of treatment. The usefulness of Opal and its success in improving patient experiences and reducing their treatment burdens can only be determined through hands-on use. No doubt, once released to patients many of the features and functionality that we have developed for Opal will require refinement and changes to ensure success.

## 7. Conclusion and Future Work

From inside the healthcare system, with a patient co-leading our team, we have designed and developed a patient portal for radiation oncology patients. Our product, Opal, integrates with our electronic waiting room management system, will deliver PHI and relevant personalised information to patients in a just-in-time manner, and will collect PROs from them. Furthermore, Opal was designed to be modular and EMR-agnostic so that its use may be expanded to all oncology patients within our comprehensive cancer centre and potentially to all patients within our general hospital.

Our next steps are to test and evaluate the smartphone app in the hands of our radiation oncology patients and to complete the web-portal. As we move forward we will prioritize the extension of Opal to include lab test results, appointment change requests, way-finding and secure messaging, while simultaneously working with our colleagues in other disciplines for wider adoption. We are also in discussion with colleagues at other centres regarding the expansion of Opal to include other radiation oncology EMRs.

## 8. Conflict of Interest

None

## 9. Acknowledgments

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## 11. Supplementary Material

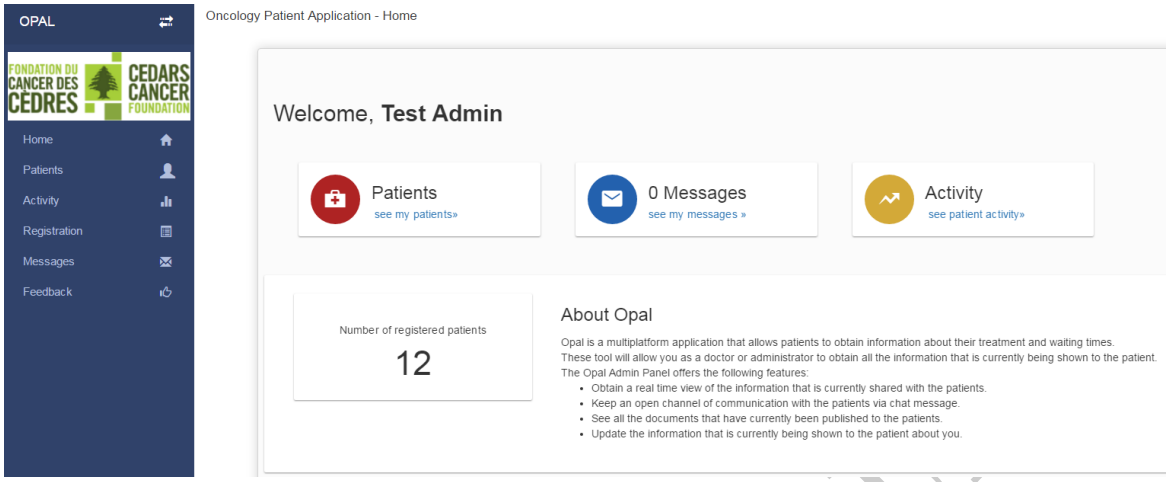


**Figure 10.** Screenshot of Opal's backend Admin Panel that is accessible to authorized staff inside our hospital's firewall.

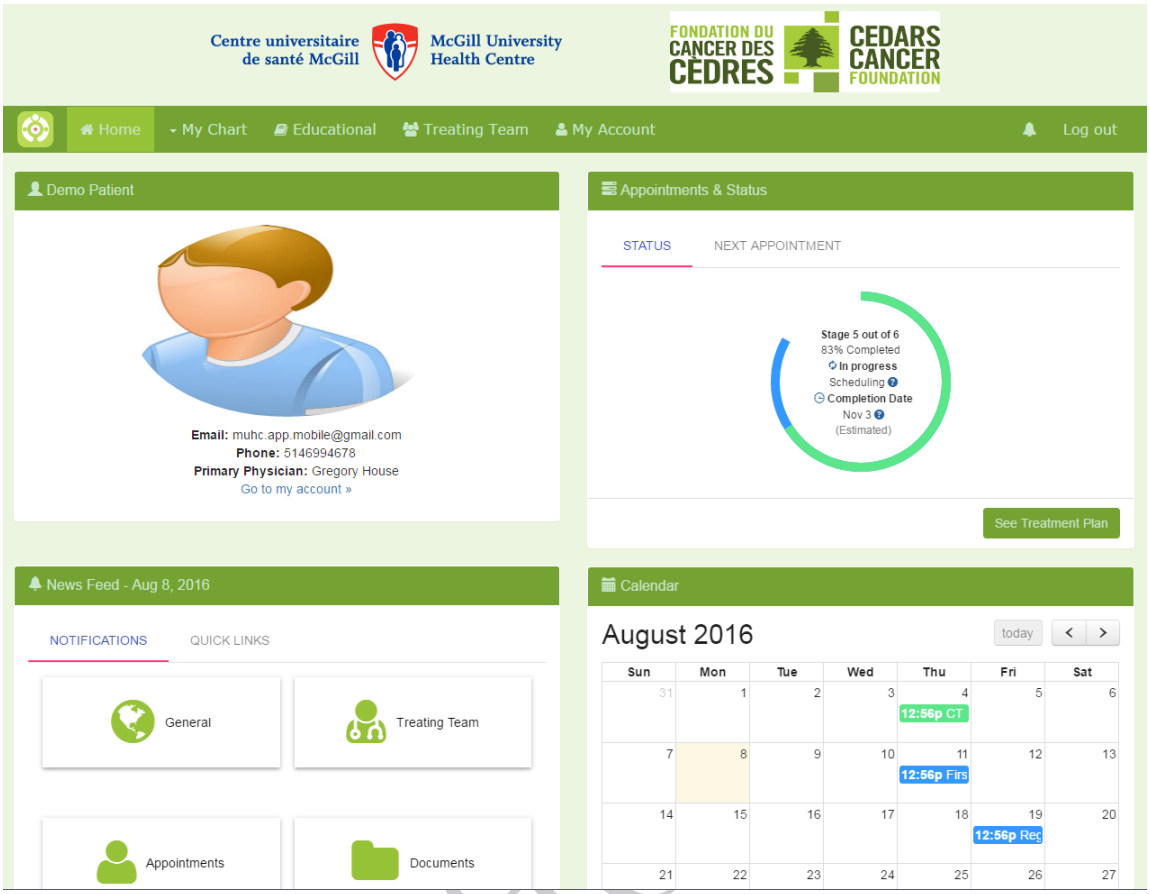


**Figure 11.** Screenshot of Opal's web-portal homepage. The web-portal version of Opal is still in development. It will be released after completion of the open-beta release of the smartphone app.


**Figure 12.** Screenshot of Opal's web-portal appointment page. The web-portal version of Opal is still in development. It will be released after completion of the open-beta release of the smartphone app.

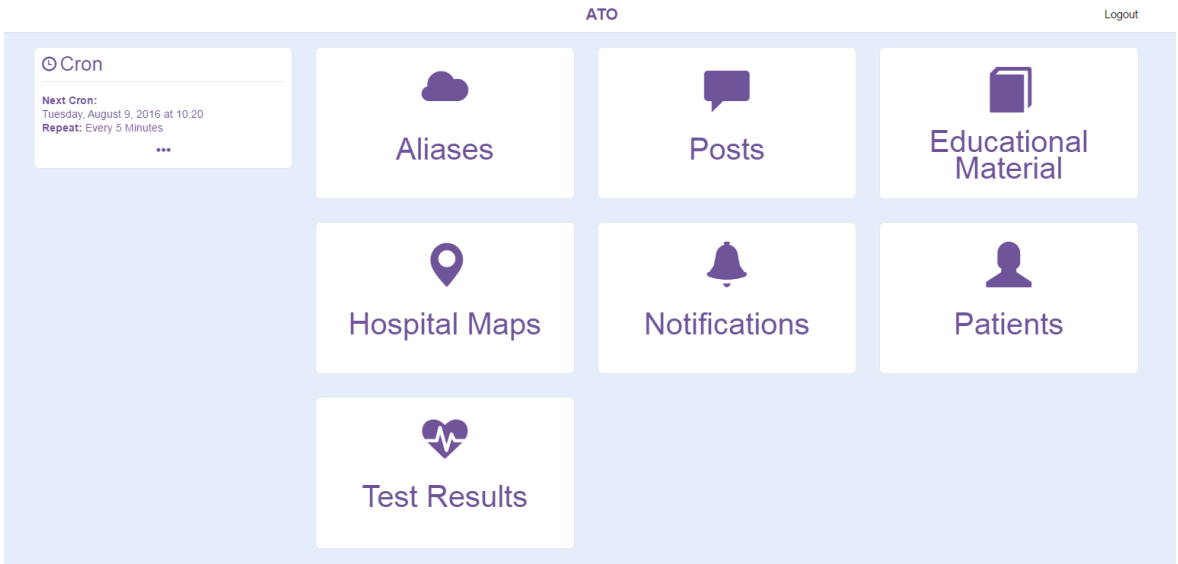


**Figure 13.** Screenshot of Opal's backend Publish Manager. Authorized staff members may set up triggers to govern which PHI are published to patients and when and prepare rules to personalize information by diagnosis and stage of treatment, among other options.

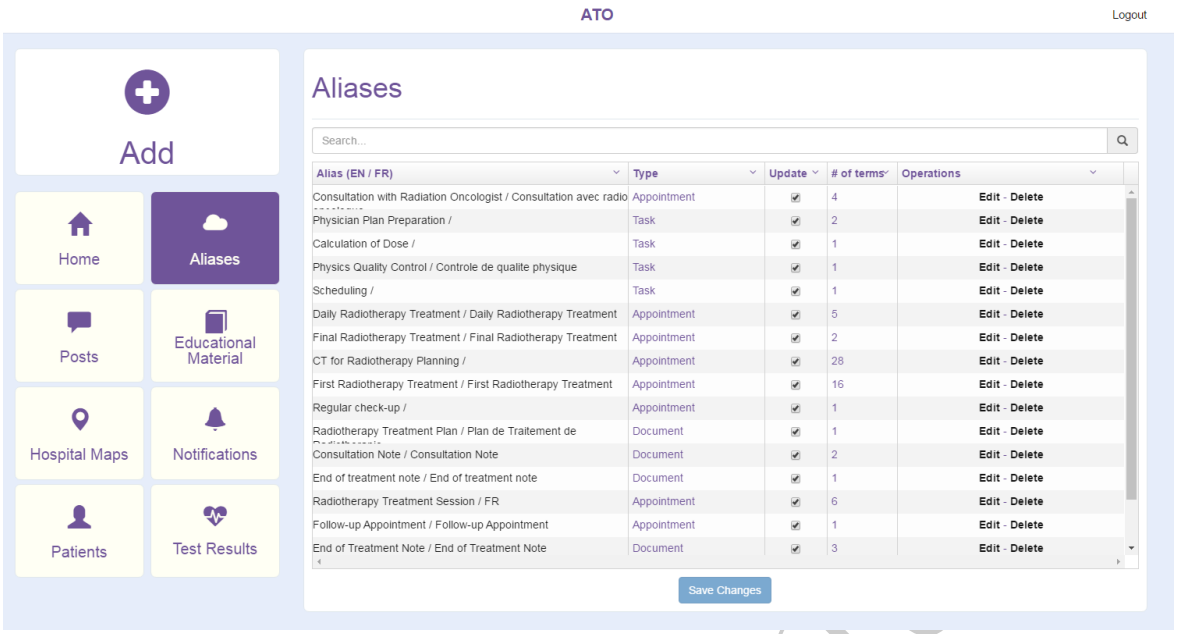


**Figure 14.** Screenshot from Opal's Publish Manager interface. Aliasing is used to translate internal clinical codes to external labels (in French and English) that are more meaningful to patients.

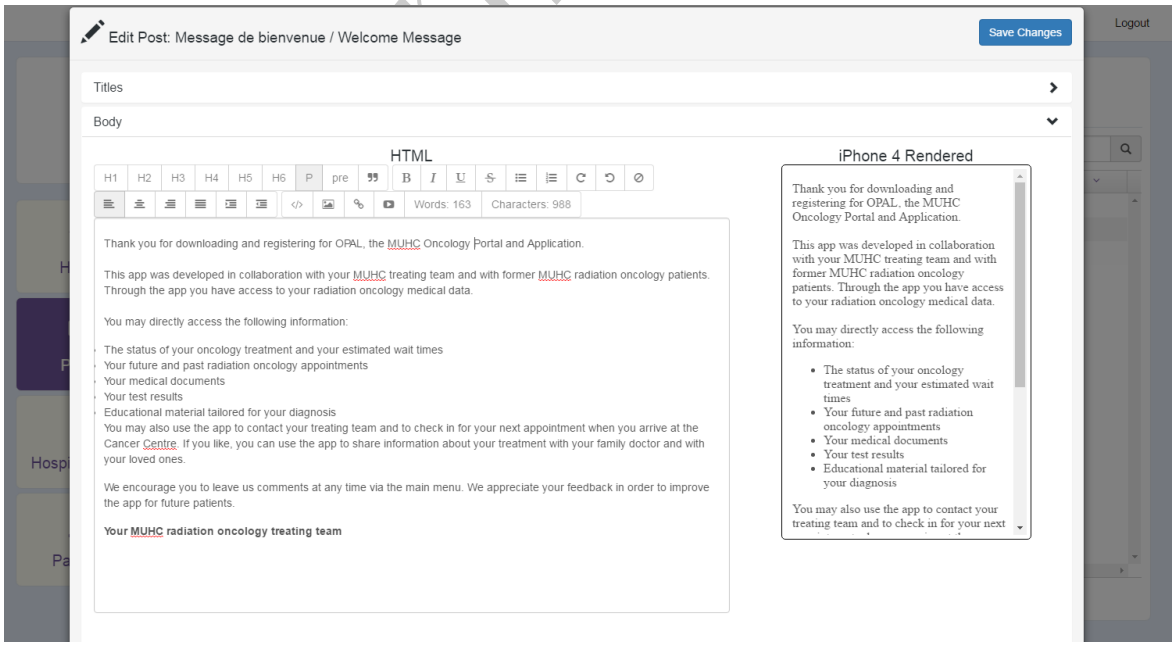


**Figure 15.** Screenshot from Opal's Publish Manager interface. Authorized staff users may create posts to be published to patients inside the Opal smartphone app and web-portal.