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CHALLENGE 3: EPITIC (Digital patient-doctor communication channel for epilepsy management)

Pitch

Solution that leverages existing corporate IT systems to facilitate the empowerment of patients with epilepsy, and their convenient communication with doctors.

Motivation and description

Epilepsy is a prevalent disease within neurological pathologies and affects 0.7 - 1% of the general population. At least half of the patients with epilepsy are young and active. These patients need regular follow-ups with hospital Neurology services or Epilepsy Units. Waiting list for successive appointments in the doctor office is variable, with an average of 6-9 months. The number of unexpected visits is 1.7 per day, and minimum wait for a scheduled review is 30 days, in case of a decompensation for any reason.

Consultations related to epilepsy account for 2% of total visits to the Emergency Department, and there is an average of 1.4 daily visits to the on-call neurologists within the Servicio Murciano de Salud (SMS). Most of these consultations are due to the decompensation of known epileptic patients or precipitated seizures. On the other hand, neurologists have little time in consultation to train and inform patients and their families. Therefore, the current way of monitoring epilepsy does not fit the needs of patients nor doctors.

There are two main groups of patients:

- Patients well controlled and without side effects (50% of patients) Who attend face to face appointments for follow up. These patients tend to be young and active workers, who attend the doctor's office for no reason. The frequency of your periodic visits is 6 to 12 months.
- Patients with refractory epilepsy or poor control (35%). Need closer monitoring with visits every 2-3 months, or even monthly if they are decompensated. They cause multiple emergency visits when they do not have access to their reference neurologist. In many cases, it is feasible to improve their clinical situation by making small adjustments of medication. The telephone consultation service is insufficient to cover the demand of care for these patients.

An indicator the quality of life perceived by the patient is the [QUOLIE-10 scale](#), an internationally validated method to measure imbalance in care. The score is standardized by a formula at a final scale of 0 to 100, with its highest value indicating the highest quality of life perceived. In a [Spanish validation study](#) with stable patients the average score is around 75 points, with a variability less than 2 points if repeated after 6 months.

Main objective

The main objective is to improve the quality of life perceived by epileptic patients by facilitating a more convenient communication with his doctor and empowering him to better manage his disease.

As a secondary objective, the Challenger also wants to learn how to easily integrate 3rd party patient facing mobile solutions through its corporate IT systems.

Pilot functional scope

Compulsory requirements

1. Information exchange channel between patients and doctors (neurologists).
 - a. Patients would choose from several templates to create the message, depending on the message type.
 - b. Doctors should be able to send the same message to different patient groupings.
 - c. The records of exchanges should be accessible any time.
2. Calendar management. So, patients and doctors can easily add and review historical data about epileptic episodes.

3. Alert doctors that a relevant event or incidence needs their attention. Ideally configurable by their channel(s) of preference (email, alert in smart phone, electronic health record, etc)
4. Facilitate access to informative resources for self-empowerment, like documents and videos. Including on a survey to assess [QUOLIE-10](#) indicator, and a mechanism to request and collect the patient outcomes over time.
5. Usable and intuitive, especially for patients.

Desirable requirements

1. Medication management. Possibility that doctors incorporate and modify prescriptions.
 - a. Ideally integrated with SMS corporate medication system.
 - b. Supporting added value tools, like reminders and/or patient adherence encouragement via gamification.
2. Connection with 3rd party devices like smart bands to track sleep patterns and/or exercise.
3. Information summaries and analytics on the available data to empower patients and facilitate better disease management by the patients themselves, in collaboration with their doctors.
4. Optimized for multi-device access (desktop, mobile device, etc) for doctors and patients.

Pilot set up (requirements and compliance)

After a selection process conducted by the challenger, **30 patients** will enrol in the pilot together with **3 neurologists**.

Ethical and Data Protection

The approach of the pilot must be previously validated by an Ethics Committee of the Servicio Murciano de Salud. The Committee will pay special attention to the collection of informed consents of patients by solver and the protection of personal data, observing the requirements established by the new European data protection [Regulation \(EU 2016/679\)](#) and the Spanish law. Among others an Impact Analysis document, with identified risks and proposed measures, will be required to the Solver.

If deemed necessary, the Solver will be asked to anonymize the data according to mechanisms established by the Challenger. At any case, the Solver cannot exploit or make use of the data for different purposes than the ones agreed with the Challenger and, after pilot end, all copies of the data must be transferred back to the Challenger or deleted.

Technological

When the pilot starts there will be available an App for local patients developed by the SMS that incorporates, among others, user authentication. The new App developed by the Solver must be called from the SMS App, so user identification takes place leveraging corporate mechanisms via the OAuth standard. The Solver App will notify the SMS systems about certain events and situations. Ideally via HL7 messaging, but web services could be an option. This information may include registration status, activity, progress and periodic (summarized) clinical information.

The systems and servers needed for running the piloted App will be hosted by the Solver. If the complexity of the connections were too high or the personal data could be at risk, these systems should be hosted in SMS servers. This will be established in a technical session at the beginning of the project. Anyway, the Solver will provide mechanisms to guarantee that SMS can exploit the data.

The solver App will be available for Android and iOS.

Data

No initial data will be provided for pre-load. All participants will have to register for free and fill their own data.

Expected impact and KPIs

1. [QUOLIE-10](#) indicator. Increase of an average of 2.5 points per month of usage, with a maximum of 10 points during the total intervention period.
2. Reduction in number of epileptic crisis in patients. Equivalent part of 20% in a whole year, based on intervention duration.
3. Reduction in the number of physical visits of patients. A) To the doctor office: at least in a 15% for the medium of the group of patients involved and B) To the emergency room: at least in a 20%

The SMS will study the possibility of developing an analysis of the economic impact by the methodology of Social Return of Investment (SROI) to take the decision to scaling-up this solution.

Business opportunity

At the level of the SMS this project would be replicable in 9 Neurology services, with around 50 neurologists apart training specialists (resident doctors). At national level there are 30-50 epilepsy related units in public hospitals, with at least 700 neurologists working in them. Potential users are estimated in 8,700 patients in the Region of Murcia and 278,400 in Spain.

This communication channel can be extended in a standard way with the same technology to many other pathologies, inside and outside SMS, with a great possibility of growth.