Rare Disease Patient Portal

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Abstract

Data Driven Decision Making is an approach to govern business by taking decisions based Data Analytics backed by verifiable data. In this course we have learned how data has evolved, why data is important and how it helps in making clear decisions. To come up with effective analysis and interpretation we should have quality data which would help informed business decisions. Initially, we have to find specificity and context in the ambiguous problem statement. To achieve this we follow decision process, critical thinking process, problem solving process, analytics techniques and finally came up with a solution to create this portal. Rare diseases patients face similar problem when they are diagnosed with a disease and don't know what steps to take initially or at certain point of their disease duration. This portal will help patient`s family take informed decisions on the basis of the data we collected by converting it from unstructured to structured and performing analytics on it.

1   Introduction

Having a rare disease or a family member who has a rare disease can be a huge challenge for all family members. The uncertainty that people face in this situation is very disheartening. Various problems faced by the people around rare diseases include delay in diagnosis, misdiagnosis, high cost of treatment and orphan drugs, finding available medicines, and consulting the right therapist for the treatment. Even on the internet, there is not a lot of information and resources about every existing disease. For that reason, the common problem that people face is unpreparedness for the financial toll that the disease can have on the family.

Since most of the health insurance companies do not cover rare disease treatments and orphan drug costs there are very high costs associated with having a rare disease. Patients cannot rely on health insurance for such diseases. For most rare diseases, there is little to no websites that can help patients and families learn about the disease cost and initial steps to take. For the few more common rare diseases there is some insight online, however, most of the information on costs comes from scholarly articles that are usually have been created somewhere else or a long time ago.

In this project, we aim to implement a portal that fulfills the goals mentioned below.
Goal.
- To inform rare disease patients and their families about the disease.
- To give accurate prediction of medical and non-medical financial costs of having a rare disease that is specific to the type of disease, stage, location and age of the patient.
- To predict the costs for 3 years in future.
- To show that there are other financial costs associated with having a rare disease like the cost lost opportunity.
- To display the breakdown of costs and predictions.

- To convey the sensitive information in a way that is friendly, non-frightening, accurate and easy to understand.

2   Rare Disease and Associated Costs

The definition of a rare disease or rare disorder varies from country to country. In Europe, if a disorder or disease affects fewer than 1 in 2000 people, it is considered as rare. Whereas in USA, if a disorder or disease affects fewer than 1 in 200000 people, it is considered as rare.

Over 6000 rare diseases are characterized by a broad diversity of disorders and symptoms that vary not only from disease to disease but also from patient to patient suffering from the same disease.

The fact that there are often no existing effective cures adds to the high level of pain and suffering endured by patients and their families.

There are a lot of factors that should be accounted when looking at the cost of having a rare disease. They include the following types of costs:

Direct medical costs:
Refers to all costs due to resource use that are completely attributable to a healthcare intervention or illness and all follow-up costs for other medication and health care interventions in ambulatory, inpatient, and nursing care. All specialist care, including emergency care, as well as rehabilitation and physiotherapy is considered.

Direct non-medical costs:
Include direct costs associated with non-medical things such as additional paid professional caregivers, non-health transportation and social services.

Indirect costs:
These include costs that are not directly associated with the disease such as lost opportunity for the patient and the caregiver.

3   Design

The Rare Disease Patient Portal is a web application that can be easily accessed by the caregivers of rare disease patients. The portal includes details for 4 of the rare diseases: Hemophilia, Cystic Fibrosis, SMA and CVS. When the users select any of the mentioned diseases, some details about the disease such as, the cause of the disease and statistics about the people affected by that disease are shown to them. The users then follow the instructions and fill out the required information and eventually get the information about the treatment requirements and estimated treatment costs.

The initial user input is separated in a two-page story because the patients and their family will be under a lot of stress already and the portal will provide additional information on every page and explicit reasoning for why their data is being collected and how it affects the results. Similarly, the result page is separated into three pages. That ensures that the users will not see potentially traumatic information without their consent and willingness to see that information. For example, if the family only wants to see one-year cost prediction, they will be overwhelmed and stressed to see that the costs will only grow in three years.

On the backend the portal has six data tables: disease, location, therapist, medicine, therapy requirement and medicine requirement. The details about the database can be found in the next section.

The user will not see all of the underlying analytics and computations because that information can be repetitive and unnecessary especially when users are just trying to find out about such sensitive topic, nevertheless, the portal will still provide additional insight into what goes into the final results on every one of the result pages. The one year and three-year prediction result pages will have a bar graph with insight under it, however, the cost of lost opportunity result page will only contain text explanation of how much extra care the patient will need and how much will be lost because of it.

The overall design is focused less on telling the user how much money the disease will cost them, but rather highlighting the causes for such costs and adding additional support and information about the disease. The app lets the user know what therapies and medicines will be required, as well as, what is the amount of therapy sessions and medicine they will need for the rare disease.

The user first selects the disease about which they want to enquire. A form with basic description of the disease is displayed, the user then selects the proper option based on whether the disease is newly discovered or not. A form is displayed with more information based on the stage of the disease along with required questions such as age of the patient, the location of the user and the salary of the caretaker with proper description about why a particular information is being asked. This leads to the results page which has the basic information about the medicines and the therapies required for the disease along with 3 tabs to see annual costs, next 3-year cost projections and cost of lost opportunity. The flowchart given below, explains the design flow of the application.
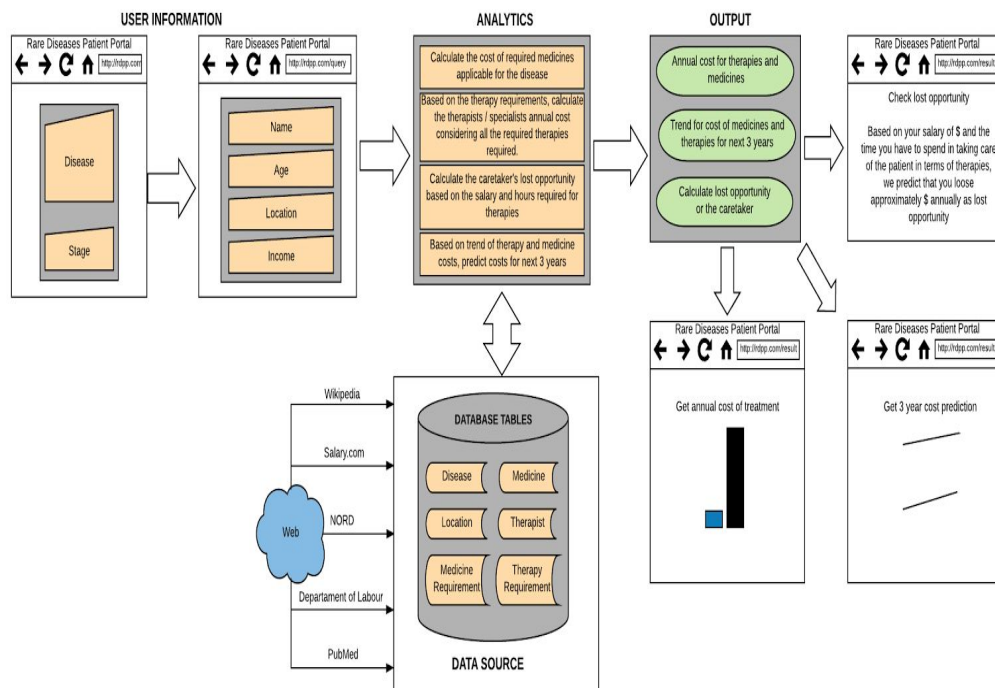
4   Database

There is no proper dataset available for this particular purpose so most of the information is scraped from the internet using web searches and web crawling.

Web Scraping.

Any medical information is considered confidential and is usually hard to find on the internet. With rare diseases, the task of finding the dataset is even harder. With no dataset available for the Rare Disease Patient Portal, the data has been gathered from different sources to create new datasets.

Diseases information was crawled from WebMD, Wikipedia, National Organization for Rare Diseases, PubMed and several scholarly articles. Medicine information was collected from Mayo Clinic, WebMD, Drugs.com. Therapists information was accumulated from Mayo Clinic, and salary information was gathered from Bureau of Labor Statistics and Salary.org. State-wise salary details were acquired from Wikipedia. Other details about medicine and therapy requirements were gathered from web searches.

The database for the application is a SQLite3 database and contains 6 tables as mentioned below.

Disease Table:

The disease table contains information about every disease in the system, including general description, newly diagnosed description, additional information about current research being done and encouraging words for newly diagnosed patients. and related links.

Location Table:

The location table contains all states of the United States of America, Therapy Cost Factor, Medicine cost factors for current year and following three years for each state.

Therapist Table:

The therapist table has the name of the therapy, description of the therapy, and cost for per session of the therapy.

Medicine Tables:

The medicine table has the name of the medicine, description of the medicine, and cost for per unit of the medicine.

Therapy Requirement:

The therapy requirement table serve as connecting piece between the disease and their therapies and includes sessions per year requirements for current year and next 3 years.

Medicine Requirement:

The medicine requirement table serve as connecting piece between the disease and their medicines and includes units per year requirements for current year and next 3 years.

5   Implementation

There are cost factors for the therapies and medicines that were estimated based on various factors as defined below and put into the database tables.

Cost Factor Estimation

There are 2 types of cost factors, medicine cost factor and therapy cost factor. To estimate the annual medicine cost factor, the average sales tax of United States was taken as the base and tax rates of every other state were compared with this and the cost factor was determined. For the therapy cost factor, the median average household income of United States was taken as the base and average income of every state was compared with this and the therapy cost factor was determined. For next 3 year projections, medicine cost factors for next three years were calculated based on the current inflation rates, and therapy cost factors were calculated based on the yearly increase in salary during previous years.

Cost of Rare Disease Estimation.
Cost of rare disease included the costs of therapies and medicines combined:
- Annual Therapy Cost = Session Cost * Therapy Location Cost Factor * Sessions Per Year
- Annual Medicine Cost = Unit Cost * Medicine Location Cost Factor * Units Per Year
- Annual Cost = Annual Therapy Cost + Annual Medicine Cost

The unit cost is the cost of medicine per dose, which generalized the cost independent of nature. The location cost factors are calculated based on basic unit / session price and scaled using each state's sales tax. Units per year and sessions per year are dependent on the disease and its requirements.

Furthermore, for the three year prediction, different location cost factor has been used depending on each state's inflation rates, while the unit/session cost and the units/sessions per year remained static.

Lost Opportunity Estimation
To calculate the lost opportunity of the patient or the caretaker, we gathered the user input of their annual salary. We assumed that they work a full time job and since there are 2080 hours in a year for an average full time position, the annual salary was divided by 2080:
- Lost Opportunity = (Annual Salary / 2080) * Annual required Hours of Therapy

Here, the Annual Salary is what user will input initially or a default value of national average of $60,000. Number of hours of therapy is calculated based on suggested number of therapies annually.

Front End.
The application is a web application developed using Flask and bootstrap styling was used for better look and feel.

The web portal consisted of seven pages.
1. **Homepage**: This is the landing page for the rare disease patient, where the user is provided with general information about the portal and what it can do, as well as, the choice of rare diseases.

2. **Disease information**: After clicking on one of the diseases, the user will see the general knowledge of the disease, and will be prompted with two buttons for the stage of the disease: "Newly Diagnosed", "Known for a while". All of the chosen information by the user is saved as user input and sent to the result.

3. **Query**: Based on the stage of the disease, the user will see some information of either where to start and what to expect or recent research on the disease. Both stages will be recommended websites for their particular disease. Under all this text will be the user input fields: name, age, state, annual salary. Each one of these fields will have the reasoning behind those questions.

4. **Results homepage**: This page will provide information on medicine requirements and therapy requirements of the disease. Under it, there will be three buttons: "Get annual cost of treatment", "Get 3 years cost prediction", "Check Lost Opportunity".

5. **Annual cost**: This page will have a bar chart separated by medicine cost and therapy cost, under the graph there will be the breakdown of the cost. This contains the information of how a specific medicine or a specific therapy is required for the disease

along with the information about the doses of medicine or frequency of therapy requirements.

6. **3 year prediction**: Similarly to the annual cost page, this page will have a bar chart separated by medicine cost and therapy cost, however, this time there will be three times the bars. This contains the information of how a specific medicine or a specific therapy is required for the disease along with the information about the doses of medicine or frequency of therapy requirements.

7. **Lost opportunity**: This page will have the number of hours required for therapy throughout the year and calculated cost of lost opportunity based on the salary.

6 Results

Overall, the Rare Disease Patient Portal achieved all of the stated goals of this project and effectively solved the problem. This has been a successful proof of consent for cost prediction for rare disease based on various factors.

Homepage:

Has the 4 rare diseases in the "Rare Diseases" section and basic information about the portal in the "About" section of the page.
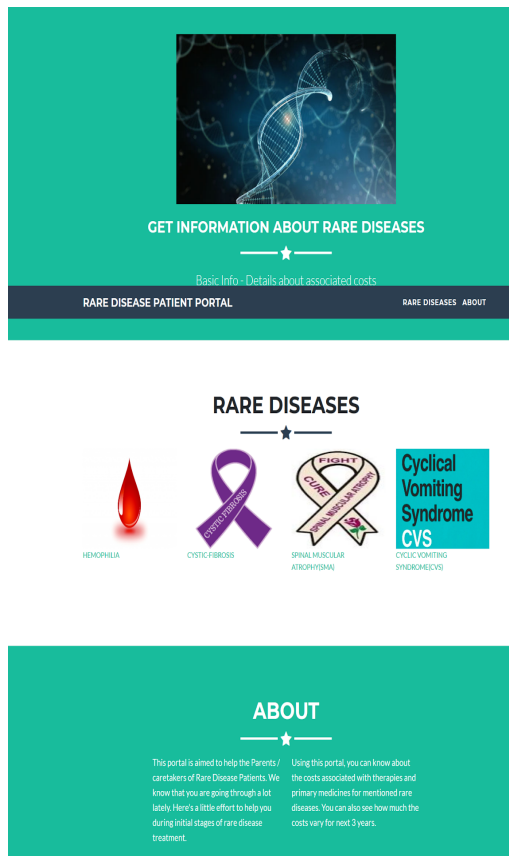
Disease information:

Has the basic information about the selected rare diseases along with appropriate buttons to get further information.

Query:

Shows information specific to the selected option in previous page, along with a query form to collect information.

Results homepage:

Shows the description of the medicines and therapies required for the selected disease based on the information provided by the user.

HERE IS SOME IMPORTANT INFORMATION FOR YOU

Most people with cystic fibrosis live a normal daily life, with the challenge of incorporating daily medications, airway clearance techniques, and other treatments and medications. Children with CF grow up, go to school, have friends, have hobbies, and can exercise and play sports. Many go to college. Many marry and have families.

Cystic Fibrosis Foundation-accredited care centers work closely with people with CF and their families to create individualized treatment plans.

Proper nutrition – including a high-fat, high-calorie diet rich in vitamins and minerals – is vital for people with cystic fibrosis, especially children. Thick mucus often gets in the way of proper digestion and the disease can rob children of the nutrients they need to grow.

We recommend following websites:

Cystic Fibrosis Foundation

Learn more about navigating insurance

Learn more about coping while caring for someone with CF

FILL BELOW DETAILS TO GET MORE INFORMATION ABOUT

CYSTIC FIBROSIS

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FILL BELOW DETAILS TO GET MORE INFORMATION ABOUT

CYSTIC FIBROSIS

---★---

Please let us know your name.

> Gaurav Joshi

The costs of medicines and therapies may vary according to patient's age.

Please let us know the patient's age.

> 26

The costs of medicines and therapies may vary according to the location because of difference in salary of therapists and the tax applicable.

Please select your State.

> North Carolina ▼

We would like to help you figureout the lost opportunity according to your salary. Please let us know your Annual Salary (We don't store or use this information anywhere else)

If you are not ok with giving your salary details, we will use $60000 as the average salary

> 60000

[Check Results]

REQUIRED MEDICINES AND THERAPY DESCRIPTION

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MEDICINE REQUIREMENT:

ADYNOVATE

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly.

DESMOPRESSIN

Can be used to promote the release of von Willebrand factor (with subsequent increase in factor VIII survival secondary to vWF complexing) in patients with coagulation disorders such as von Willebrand disease, mild hemophilia A.

THERAPY REQUIREMENT:

HEMATOLOGIST

A hematologist is a specialist in hematology, the science or study of blood, blood-forming organs and blood diseases. The medical aspect of hematology is concerned with the treatment of blood disorders and malignancies, including types of hemophilia.

ORTHOPAEDIC SURGEON

An orthopaedic surgeon is a physician devoted to the diagnosis, treatment, prevention and rehabilitation of injuries, disorders and diseases of the body's musculoskeletal system.

PHYSICAL THERAPIST

Physical therapists, sometimes called PTs, help injured or ill people improve their movement and manage their pain. These therapists are often an important part of the rehabilitation, treatment, and prevention of patients with chronic conditions, illnesses, or injuries.

PEDIATRICIAN

Pediatrician is a child's doctor who provide preventive health maintenance for healthy children & medical care for children who have short-term or long-term sickness. Pediatricians manage the physical, mental and emotional well-being of their patients, in every stage of development.

MEDICAL GENETICIST

A medical geneticist is trained in general medicine, genetic diagnosis, and the treatment of patients with genetic disorders. They employ molecular genetics, cytogenetics, and biochemical tests to diagnose patients in a comprehensive molecular and clinical approach.

CLICK ON BELOW BUTTONS TO GET COST INFORMATION

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[Get annual cost of treatment]   [Get 3 years cost predictions]   [Check Lost Opportunity]

Annual Cost:

This page show the graph with annual medicine and annual therapy costs, the user can see both the costs or can select any one cost to focus on that.The users can also download the charts for future reference.

Next 3 Years Cost:

This page show the graph with annual medicine and annual therapy costs for next 3 years. Other details are similar to the annual cost page.

Annual Cost for Medicines and Therapies

Costs are based on sales tax in your State of residence and medicine and therapy requirements for the disease

● Annual Medicine cost   ● Annual Therapy cost

Highcha
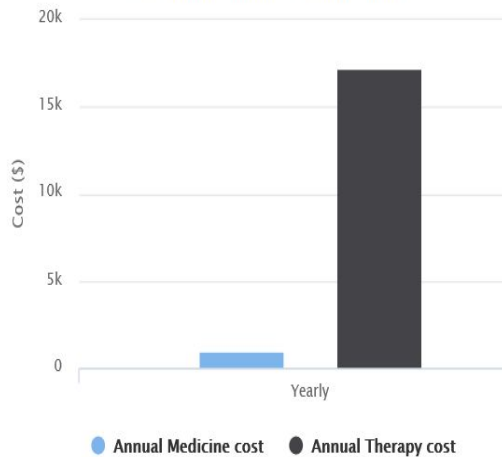
COST OF MEDICINES: $1426, INCLUDES BELOW MEDICINES

GENTAMICIN:

Used to treat bacterial infections in patients who suffer from cystic fibrosis. One dose is to be taken

PIPERACILLIN:

This medication is given by injection into a vein as directed by your doctor. Usually on an average once eve

ACETYLCYSTEINE:

Used to help thin and loosen mucus in the airways. Usually has to be taken daily.

COST OF THERAPIES: $11105, INCLUDES BELOW THERAPIES

RESPIRATORY THERAPY:

Required to do Chest physical therapy (CPT or Chest PT) is an airway clearance technique (ACT) to drain the lu devices available to do this procedure. Usually have to visit the therapist every week.

PHYSICAL THERAPIST:

Physical therapists, help injured or ill people improve their movement and manage their pain. Usually 1 therap required.

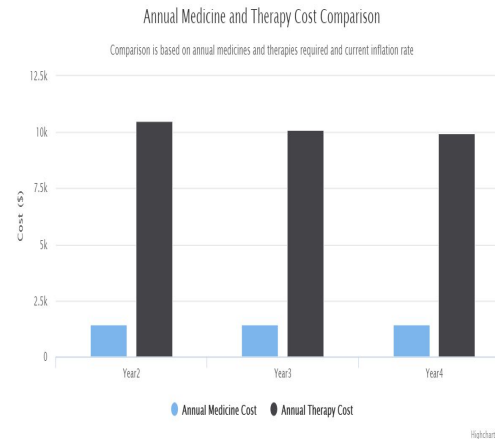**PULMONOLOGISTS:**

Diseases commonly evaluated and treated by pulmonologists include asthma and Cystic Fibrosis. Usually 1 sea required.

THE BELOW GRAPH SHOWS THE 3 YEARS COST PREDICTIONS FOR MEDICATION AND THERAPIES REQUIRED FOR CYSTIC FIBROSIS

Annual Medicine and Therapy Cost Comparison

Comparison is based on annual medicines and therapies required and current inflation rate

● Annual Medicine Cost   ● Annual Therapy Cost

Highchart

COST OF MEDICINES FOR NEXT 3 YEARS IS: $1447, $1444 AND $1452, INCLUDE BELOW MEDICINES

GENTAMICIN:

Used to treat bacterial infections in patients who suffer from cystic fibrosis. One dose is to be taken daily.

PIPERACILLIN:

This medication is given by injection into a vein as directed by your doctor. Usually on an average once every 15 days.

ACETYLCYSTEINE:

Used to help thin and loosen mucus in the airways. Usually has to be taken daily.

COST OF THERAPIES FOR NEXT 3 YEARS IS: $10507, $10120 AND $9937, INCLUD BELOW THERAPIES

RESPIRATORY THERAPY:

Required to do Chest physical therapy (CPT or Chest PT) is an airway clearance technique (ACT) to drain the lungs. You ca devices available to do this procedure. Usually have to visit the therapist every week.

PHYSICAL THERAPIST:

Physical therapists, help injured or ill people improve their movement and manage their pain. Usually 1 therapy every mor required.

Lost Opportunity:

This page Includes the textual information about the total hours of therapy required and the cost of lost opportunity calculated based on the salary of the caretaker.

THIS SECTION SHOWS THE LOS
OPPORTUNITY IN TAKING CARE O
PATIENT WITH HEMOPHILIA

⭐

THE PATIENT REQUIRES AROUND 58 HO
OF THERAPIES THROUGHOUT THE YEA

BASED ON YOUR SALARY OF $120000 A
THE TIME YOU HAVE TO SPEND IN TAKI
CARE OF THE PATIENT IN TERMS OF
THERAPIES, WE PREDICT THAT YOU LO
APPROXIMATELY $3346 ANNUALLY AS L
OPPORTUNITY

✖ Close

7 Future Work

Even though, all of the goals decided for this project have been met, there is still a lot of room for a lot of improvement and potential to be built upon. One of the biggest improvements that could be made is having a dataset and information about diseases. We were not able to find the proper dataset that can be used for this project, so most of the information being used right now is gathered from the internet. If there is a possibility of having a better dataset, all of the potential rare disease could be added to the database, as well as, their medicine and treatment requirements. This would add a bigger scope to the application and ensure that it's being used by real users.

Currently, the app only provides information in US Dollars and bases the location on the United States. To create an accessible and internationally recognized application, the rare disease patient portal could have a bigger dataset of locations and currencies.

One of the other changes that could be made is tweaking the algorithm for lost opportunity prediction to also take into account the amount of hours spent taking care of the patient outside of treatment. Currently, there was not enough information provided online on how much the caretakers spend on taking care of the patient and the portal couldn't expect the users to input this information since some of the patients were newly diagnosed.

Consulting with the domain experts and the families of patients can be really helpful as the figures mentioned in the application right now are gathered from various resources but only a domain expert can give proper details of the medicine and therapy requirements for a particular disease.

This application can be integrated with the hospital rating portal or the insurance portal to get the information about the hospitals available for a rare disease treatment in a particular area and to get help related to health insurance for rare disease patients.

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