Improving Patient-Reported Outcome Measures Through Visual Analytics

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by

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This thesis has been done within the Center for Science and Technology of Visual Analytics (CVAST) at **Technische Universität Wien**

Figure 1: Center of Science and Technology of Visual Analytics

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Abstract

In this thesis the important role of visual analytics will be presented as it offers a better understanding of Patient-Reported Outcome Measures (PROMS). PROMS differ from the well-known medical measures, which are objective and quantitative such as blood pressure or blood levels among others, as they are questionnaires that assess aspects of patients' quality of life. The correct use of these data provides an improvement in healthcare practices, but this remains a research challenge. To fix the problem, the KNoVA project uses these data described from clinical trials, especially in an eye disease called Uveitis. The methodology of Visual Analytics in tackling this problem, and the design and evaluation performed in a prototype are discussed in detail. Intermediary results with Visual Analytics experts show promising uses of the developed solution.

Resumen

En esta tesis se presentará el importante papel de la Analítica Visual, ya que ofrece una mejor comprensión de las medidas de resultados comunicadas por los pacientes (PROMS). Las PROMS se diferencian de las conocidas medidas médicas, que son objetivas y cuantitativas como la presión arterial o los niveles de sangre entre otras, ya que son cuestionarios que evalúan aspectos de la calidad de vida de los pacientes. El uso correcto de estos datos proporciona una mejora en las prácticas sanitarias, pero esto sigue siendo un reto para la investigación. Para solucionar el problema, el proyecto KNoVA utiliza estos datos descritos a partir de ensayos clínicos, especialmente en una enfermedad ocular llamada Uveitis. La metodología de Analítica Visual que se usa para abordar este problema, así como el diseño y la evaluación realizados en un prototipo se discuten en detalle. Los resultados intermedios con expertos en Visual Analytics muestran usos prometedores de la solución desarrollada.

Resum

En aquesta tesi es presentarà l'important paper de l'Analítica Visual, ja que ofereix una millor comprensió de les mesures de resultats comunicades pels pacients (PROMS). Les PROMS es diferencien de les conegudes mesures mèdiques, que són objectives i quantitatives com la pressió arterial o els nivells de sang entre d'altres, ja que són qüestionaris que avaluen aspectes de la qualitat de vida dels pacients. L'ús correcte d'aquestes dades proporciona una millora en les pràctiques sanitàries, però això segueix sent un repte per a la investigació. Per solucionar el problema, el projecte KNoVA utilitza aquestes dades descrits a partir d'assajos clínics, especialment en una malaltia ocular anomenada uveïtis. La metodologia d'Analítica Visual que s'utilitza per abordar aquest problema, així com el disseny i l'avaluació realitzats en un prototip es discuteixen en detall. Els resultats intermedis amb experts en Analítica Visual mostren usos prometedors de la solució desenvolupada.

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1 Introduction

1.1 Motivation

Nowadays, huge amounts of data are currently being collected and stored. This increase in amounts of data offers great opportunities to promote technological progress.

Visual Analytics is the science that gives meaning to all data by combining the enormous processing power of computers with the exceptional perceptual and cognitive abilities of humans. Also, aims the understanding of large and complex data sets by intertwining interactive visualization, data analysis, human-computer interaction, as well as cognitive and perceptual science.

From [4] we extract that there are a lot of techniques from this science that are useful tools to support decision-making and cope with increasing data, particularly to monitor natural or artificial phenomena. When monitoring disease progression, visual analytics approaches help decision-makers to understand or even prevent dissemination paths.

Living in a pandemic situation makes us think of some options to optimize and to make easier sanitary conditions. So a good example for Visual Analytics could be a tool for monitoring COVID-19 dissemination. This tool will help to analyze the growth in the number of confirmed cases in some cities. Also provides information to decision-makers to think about strategies isolation policies according to the risk of dissemination.

1.2 Overview and goals

Focusing on healthcare, a visual analytic application, we can discover that patients take a really important paper on that. Their feedback gives us a lot of important information to take some health decisions as I mentioned before. This is called **PROM (patient reported outcomes resources)**. PROMs are a way of tracking changes in the progression of a patient's health. In other words, PROMs are a solution for quantifying patient data.

The patient is usually followed through a set of questions (questionnaires) to capture the patient's subjective perception of his or her own health. These questions are used to better understand the impact of a quality of life in a clinical trial, in new drug trials, etc. These questionnaires can be general or domain-specific. Following the paper, I will explain that in our case, it is about an ophthalmology clinical trial. As it is a job that the patient has to answer, we have to be very careful to program the task well because it would not be very useful nor would we obtain good answers if the patient had to answer hundreds of questions because we are looking for maximum quality. What we want to achieve is to improve the use of PROMs in medicine (clinical trials, treatments and research) with the help of Visual Analytics.

After patient answers all this questions, data is stored and has to be understood and clean in order to work with it in a visualization field and then the expert could have a quick result about those questions.

From CVAST (Center for Science and Technology of Visual Analytics) has been designed a triangle to approach what Visual Analytics is aim to taking into account three main aspects.

1. Characteristics of the data
2. Users (the ones who answers the questionnaires)
3. User's tasks (questionnaires)

This is an important piece of information that will provide us with much of the theory for the final evaluation.

1.3 Requirements and Specifications

For many software projects, keeping requirements on track needs an effective and efficient path from data to decision [5]. Visual analytics creates a path that allows humans to extract ideas by interacting with relevant information. Although there are various requirements visualization techniques, few have provided comprehensive value to practitioners. We follow the objective-question-metric paradigm to define the framework, shelving five conceptual objectives (user, data, model, visualization and knowledge), their specific operations and their interconnections. The framework allows us not only to evaluate existing new ones, but also to create tool enhancements in a principles-based way. We evaluate our improved tool through a case study in which massive, heterogeneous and dynamic requirements are processed, visualized and analyzed. Working together with professionals on a contemporary software project within its real-life context leads to the main conclusion that visual analytics can help address both open visual exploration tasks and well-structured visual exploitation tasks in requirements engineering. In addition, the study helps professionals make practical decisions in a wide range of areas related to their project, ranging from identifying issues and outliers, through requirements tracking, to risk assessment. Overall, our work shows how data analytics for decision-making can be improved by increasing the interactivity of requirements visualization.

1.4 Work Plan

[WP1]

Literature research and angular

An extensive literature research to get more familiar with the topic of Visual Analytics. Reading papers about the topic to be able to write about them in the final dissertation report.

[WP2]

Angular

After few meetings with my supervisor, I decided to sign up into an online course of Angular (a platform and framework for building single-page client applications using HTML and TypeScript) because it is the weapon they use. GitLab: architecture and D3.js.

This would help me if my team decided to visualize evaluation's results with this weapon or with Tableau.

[WP3]

Implementation and evaluation.

Reading of papers and research on what methodology use for the evaluation of the prototype created in the team for the clinical trial.
After researching the information, implement a good evaluation for the target audience that will participate in the evaluation of the system.

[WP4]

Write thesis.

Once evaluation is nearly done and we have tested all the evaluators, it is time to write all the important things seen during the evaluation and relate it with all the papers read by the moment.

[WP5]

Defense thesis.

After all the report is completed and decided how to show the evaluation's result, prepare the final presentation.

Figure 2: Work plan

These work packages summarize the most important points that have been carried out during the project. To clarify, WP1, WP2 and WP3 refer to the first three points of this thesis. The WP4 refers to point four of the thesis and finally, WP5 refers to the last points of the work.

The first part of the project consisted of reading a lot of technical papers from the team and getting acquainted with Visual Analytics.

Once I had a base of knowledge on the subject we proceeded to cooperate with the team to find the way of implementation and evaluation which took us more time than expected since we worked together with the clinical center.

The implementation and evaluation of the prototype also consisted of reading and searching for information on the subject because nowadays there are many ways to perform them and we had to find the way that best suited our needs but above all to the needs of the clinical center because in the end, the users who will use the tool are going to be them.
The following image shows how the work has been distributed on a monthly basis.

Figure 3: Timetable

This three mains aspects will be described in the third point of this project as they has been the main source of information consulted to move forward with the project. Still, we can talk about the data that we have on the process of Visual Analytics.

1.5 Gantt

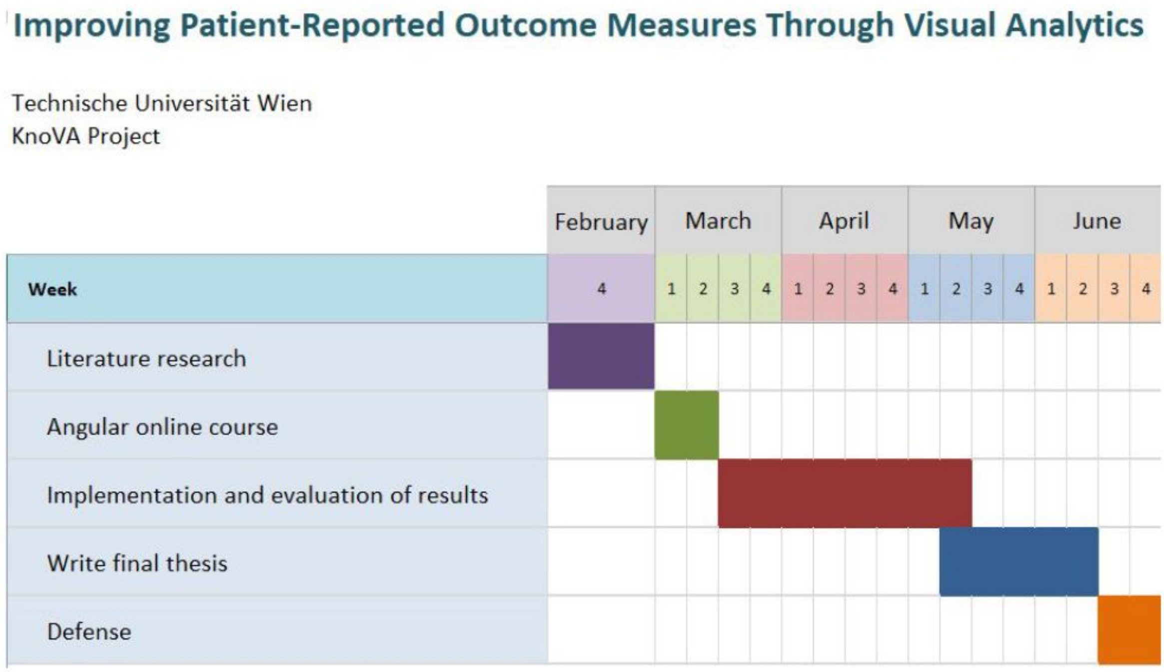

Figure 4: Gantt

1.6 Challenges

The team has been following up an eye disease called Uveitis with the help of a medical professional. The objective of this project is to help doctors to communicate with the patients. Is not always easy understand doctors' necessities and work with qualitative data and convert them into visualization tool but here is where Visual analytics appears and convert this into the main challenge.
As our team works in parallel with the clinical trials medical team, we are affected in terms of time. It is very important that the medical team gives us feedback from their professionalism so that we know how to implement the evaluation because we do not know about the clinical trial as they do. There are some weeks in which we cannot move forward until they inform us and correct us so, in terms of time, sometimes we go slower than we really would.
Otherwise, everything has being totally adapted and we have several meeting with the medical team and also two meeting a week with the CVAST team going correctly, we try to have a meeting with the medical team to keep us informed, although we also communicate through the Slack platform. Apart from time, some of the doctor's modifications have made us rethink our work and we have looked for ways to find new solutions. A solution was prepared was Gamestorming. Gamestorming is a visual thinking tool to solve bussines problems. Helps to interact with each other and with the medical team. These games are made to come up with new ideas, as a Brainstorming.

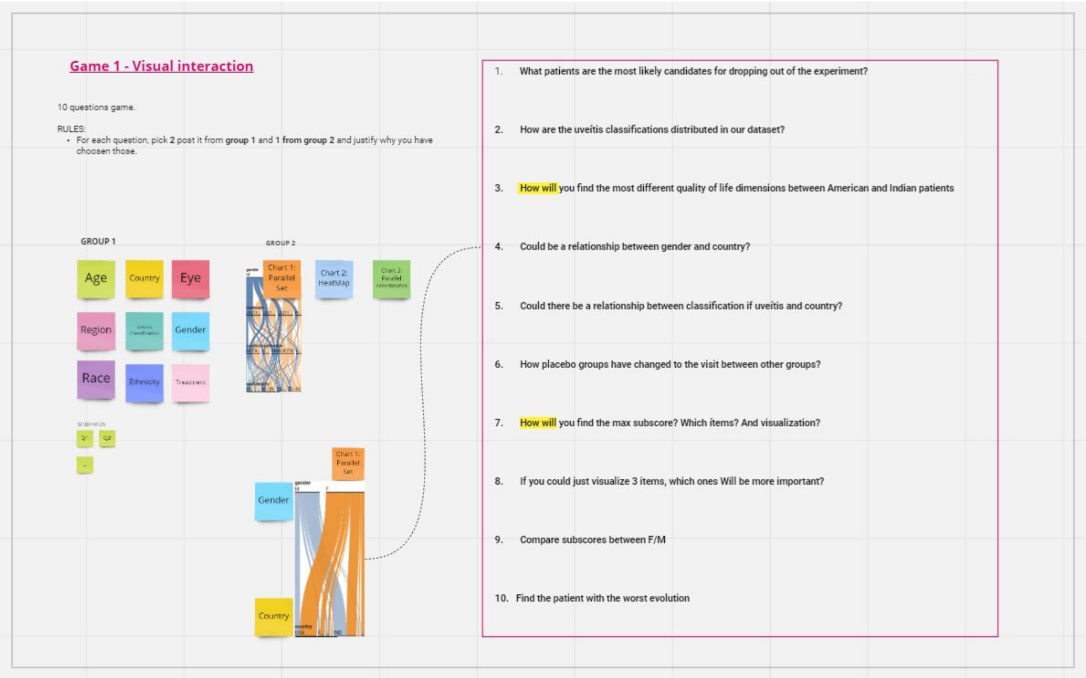

Figure 5: Gamestorming 1

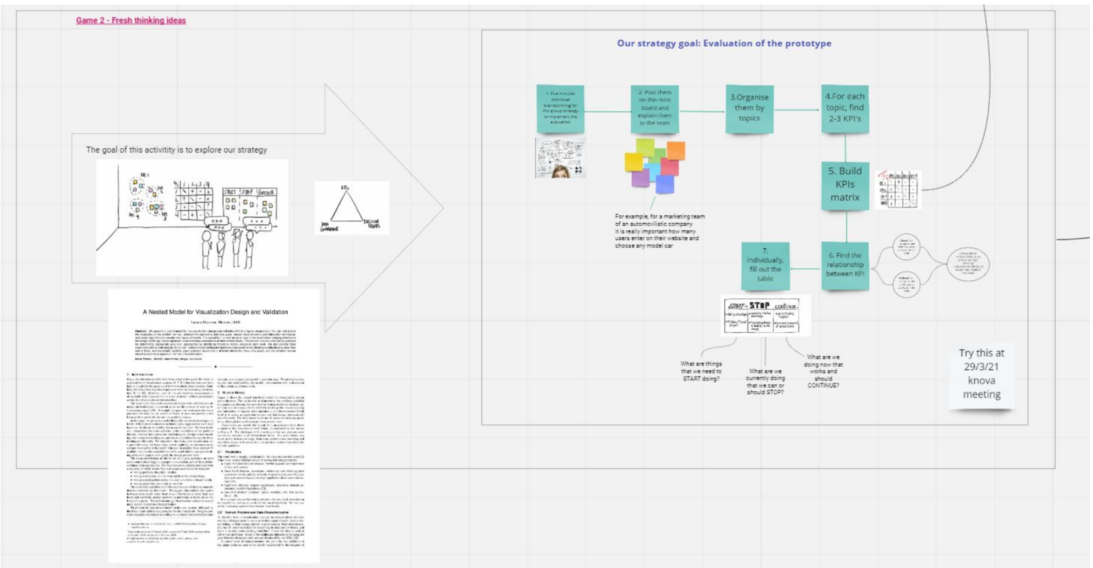

Figure 6: Gamestorming 2

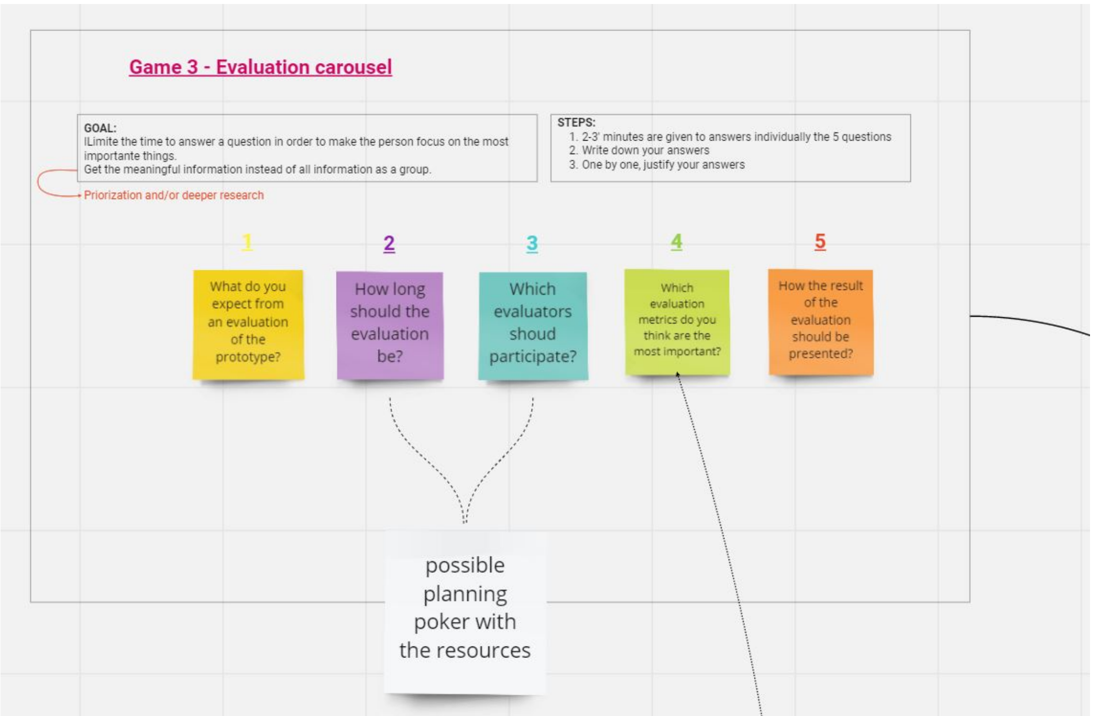

Figure 7: Gamestorming 3

2 Visual Analytics

2.1 Overview

Visual Analytics is the science that is responsible for making an analysis with interactive visual interfaces. In other words, visual analytics gives meaning to all data by combining the enormous processing power of computers with the exceptional perceptual and cognitive abilities of humans.

As we save and store data, we are faced with the obligation to extract useful information from it in many fields of study, such as health, biology, chemistry, social sciences, astronomy and physics. [6]. Information overload is the problem that arises when individuals try to analyze a number of variables that surpass thelimits of human cognition. Data analysis is part of the human visual system, as we are constantly contrasting objects on the net. This helps us to make decisions of all kinds in different fields. Many disciplines, such as visualization, statistics-based data analysis, machine learning, data mining, perceptual and cognitive sciences, are used to extract useful information so that users can generate reliable knowledge from unexplored data. The goal of visual analytics research is thus to turn the information overload into an opportunity by enabling decision-makers to examine this massive information stream to take effective actions in real-time situations.

The amount of data available to clinicians, administrators, and researchers in the healthcare system continues to grow at an unprecedented rate [7] In our case, what we want from the information that we extract from these data (PROM) is to be able to help professionals and to serve them this support as an aid for future research and future clinical trials since in this way, they can make decisions in a compact way taking into account the quality of life that the patient has had during the whole process of the drug.

In order to achieve this point, it is very important to know how to interpret and understand the database in order to be able to make a good representation of it using Visual Analytics. It is true that, although they are professionals in the medical field, the system is intended for clinicians with little or no knowledge of statistics, data mining,etc. Most of them are probably in contact with that kind of technological tool for the first time, so they must be able to use the tool, in our case, the dashboard, in an easy and understandable way. This tool is done to create, gather, and manage their information. Otherwise, they will not be able to make any reliable or confident decisions based on the representation and will lead to users ignoring, overlooking, or misinterpreting crucial information and doing wrong diagnoses.

That is why, the creation of the dashboard involves a lot of effort and understanding because whoever creates it, usually not in a professional in the field of medicine and at first it is difficult to understand the data of the clinical trial but once understood, you have to visualize it in a visually speaking, pleasant and easy way so that they can move and interact through it.

2.2 Visual analytics process

Visual analysis uses visualizations to perform tasks and obtain information. These tasks are often complicated and the process of obtaining information becomes difficult. Users find it complicated to play with and interpret data and to generate new insights from the data. As a result, the effectiveness of visual analytics and the quality of the results is greatly reduced.

User's support has been one of the main goals of visual data analysis and much research has been done on how to achieve this goal. It consists on to reduce the When the goal is to reduce the lack of knowledge of a new user, and to do that exists the "Onboarding" experience and the manuals are an example of it.

The purpose of using a manual is to encourage effective use of the analysis tools and to help users overcome any possible problems that may arise during the analysis. This is to encourage human interaction in the analysis process. Visual analytics can work as the interplay between data analysis, visualization, and interaction methods. Human factors (interaction, cognition, perception, collaboration, presentation, and dissemination) play a key role in the communication between humans and computers. In point five of this thesis, we focus on how we manage user guidance and the evaluation of the Knova prototype to accompany users in that process.

When developing Visual Analytics systems it is necessary to first start describing the problem by means of data, tasks, and users that are addressed.

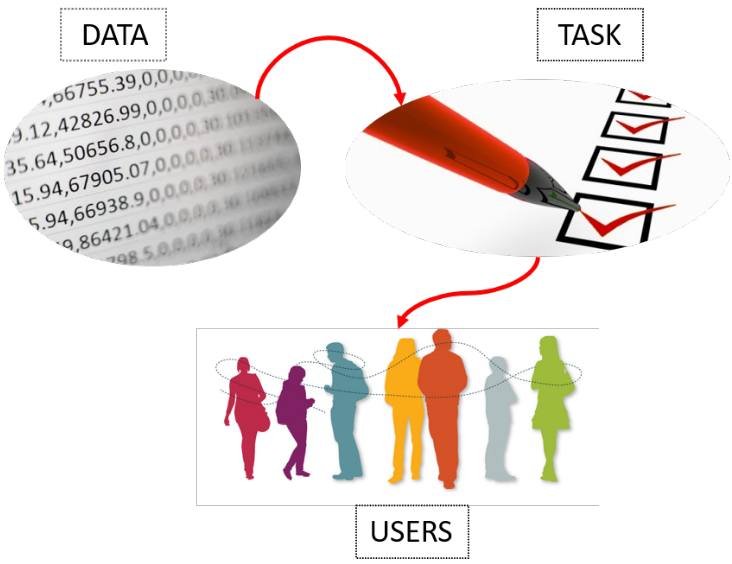

Figure 8: Data-task-users

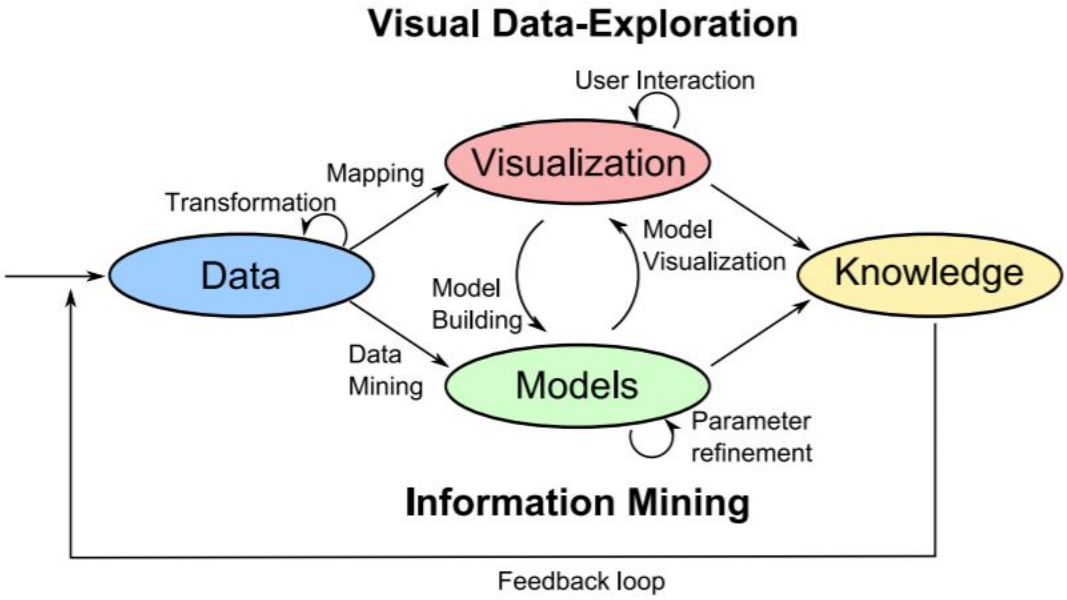

Figure 9: Visual Data-Exploration. The process of visual analytics is characterized by interacting between data, visualizations, models about data, and users to detect knowledge [2].

In the process of visual analytics we find the union of automatic analysis methods and visual analysis methods. The figure shows the different stages of the process. Usually, the sources used in visual analytics are heterogeneous, so before applying these analysis methods, the first step to be done is to preprocess and transform (clean, normalise,etc) the data to obtain meaningful data units (S=S1,...,Sm) in order to start with the main processing.

Continuing with this meaningful data, the analyst can select between visual or automatic analysis methods and maps this data to obtain knowledge that may or may not be the desired knowledge as user interaction is necessary to extract useful information.

The results of the visualisation can be reused to build a model for automatic analysis. Once the model is created, the analyst has the possibility to interact with the automatic methods by modifying parameters.

When alternating these two types of analysis methods, we obtain results that are prior to the final results and that in case they are erroneous in an intermediate step can be discovered in the next stage. (We will see this in the next point where the Nested Model is explained) this leads to greater confidence in the final results.

In the visual analysis process, knowledge can be gained from all these different points. The loop we see in the figure stores this knowledge and makes it possible for the analyst to draw faster and better conclusions in the future.

Visual analytics can be summarize in four importants steps:

1. Preprocess the data (cleaning, normalization, grouping, among others) and btaining information from the data. This step is very important and costly because, as we have mentioned before, these are usually data that a Visual Analytics professional is not used to seeing, so they are from a completely different field and it can be complicated to understand what each thing means or what is related to each other. Here, we could highlight the importance of communicating with the medical team so that they can guide us to the information provided to process.

2. Formulate and test which methods can be more useful, visual, or automatic once the data has been mapped.

3. Visual methods are necessary for user interaction and to reveal information. Once these are built, you can interact with the automatic methods such as modifying the analysis algorithm. The visual methods serve to verify the results of the automatic methods. Somehow, with both methods we are interpret results and fixing errors.

4. Discover new knowledge.

3 State of the art

As a stepping stone two required papers were proposed by my advisor.These two papers presented in this section, both belong to the visual analytics research center at TU Wiena University (CVAST). They have been the main source of motivation and inspiration for the evaluation done with the KNOVA team for the Uveitis Clinial Trial. They are two ways of approaching the visual analytics process, especially taking into account aspects such as what type of user it is, what data is used and what tasks you want to ask the user to perform. All these points have been very important when choosing what type of evaluation to do as there are many options and approaches available.

3.1 Related work

3.1.1 Applying a data–users–tasks design triangle to visual analytics of time-oriented data

As explained in the section on Visual analytics, one of the points of the process is to describe what we mean by data, tasks and users that the tool will address.

From Vienna's Institute of Software Technology and Interactive Systems it is proposed a design triangle, which considers three main aspects to ease the design: (1) the characteristics of the data, (2) the users, and (3) the users' tasks.

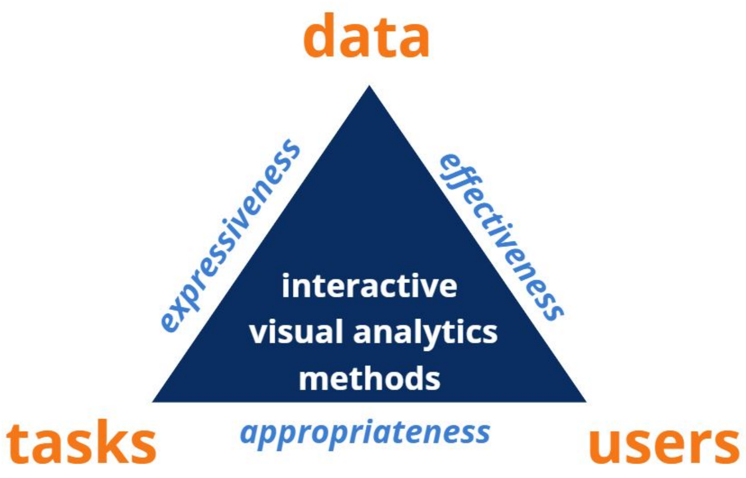

Figure 10: Triangle design

After considering the three importants aspects of the design,it is also proposed some questions related to each aspect in order to guide Visual analytics designers:

1. **Data**
   What kind of data are the users working with? After this question is it important to follow Visual Analytics process steps in order to end up with a good database to work with.

2. **Users**
   What users are participating? In our case, for the evaluation, Visual analytics professionals who will receive the tasks and whose response and defense mechanisms to these tasks will be collected and analysed to make changes in the prototype.

3. **Tasks**
   What are the users' task? It is necessary to know well what type of task is going to be once the group of users has been selected, since it can depend a lot and especially because there are many types of tasks that can be asked to be performed and not always all types are of interest. We will get in more detail about this last point on the Evaluation part as we had to think some low-level and high-level task for the users.

By getting answers to these questions, we can determine which type of representation is most useful for that database.

The sides of the triangle show the main quality criteria for the visualization with which useful results are obtained:

1. Expressiveness: quality that refers to the visualization of all the information provided by the data.

2. Efficiency: quality referring to the cognitive capabilities of the human visual system.

3. Appropriateness: quality related to the evaluation of the visualization process.

In conclusion, this triangle brings together the main features of a Visual analytics design which are, the data, the users and their tasks. It offers a very easy working structure to achieve the expected design and above all, very easy to solve for both users and professionals.

3.1.2 A Nested Model for Visualization Design and Validation

In this point is going to be explained an evaluation methodology model. The most remarkable thing about this model is that it allows analysts and designers to identify the four levels and be able to see threats or errors in some specific levels and thus be able to clean level by level for future validity. So as I mentioned, splits visualization into four different levels as the picture below. This four levels are:

1. Characterize the tasks and the data in the vocabulary of the problem domain.
2. Map those into abstract operations and data types.
3. Design visual encoding and interaction techniques to support those operations.
4. Create algorithms to execute the techniques efficiently.

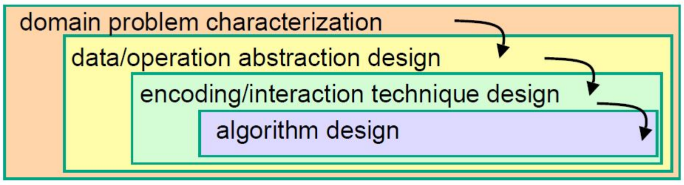

Figure 11: Nested model

As it can be seen from the picture, this nested model stands out for that the output from an upstream level above is input to the downstream level below. This is a important thing to take into account as all the error from the up level cascades to all the down levels. What is meant with that is, that any error for example in characterization level even exists a really good algorithm design, this won't delete the error from up levels.

If we go level by level describing their main characteristics we can highlight:

For the highest level, domain problem characterization, it is important that designers learn about the data and vocabulary for the domain that is working for. If not, some assumptions and marking and this means losing information.

From the second level from the top, operation and data type abstraction, is about to convert the vocabulary of the specific domain into a generic description.Amar, Eagan, and Stasko have also proposed a categorization of low-level tasks as retrieve value, filter, compute derived value, find extremum, sort, determine range, characterize distribution, find anomalies, cluster, correlate [8] In this level is where designer has to be really carefully extracting the information because sometimes some important information is skipped and they assume a design problem that maybe doesn't have relationship with the real one.

At third and fourth level are about interaction design and the algorithm to carry it out.

Once the four level are described, it is important to be sure what we understand for validating each one. As we know, exists a correlation between all the levels so they will have strong dependencies in terms of validation.

We refer to validation, when we study whether the right and adequate product has been achieved, but it does not mean that the implementation is being verified.

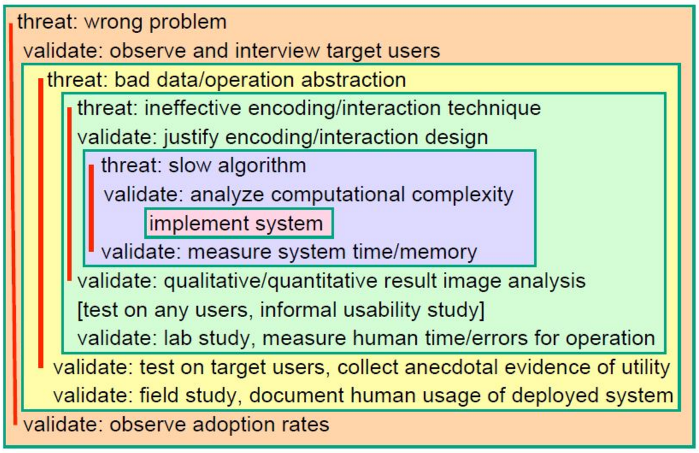

Figure 12: Validation at each level

It is proposed a classification of the evaluation into three levels taking into accout "when" to use different kind of evaluations.

1. Formative evaluations: to give feedback to the designers in order to improve a system. Can I make it better?
2. Summative evaluations: intended to measure the performance of a system. Is it right?
3. Exploratory Evaluation: done in order to make understable all the possible information. Can I understand more?

Our evaluation was going to be a mix of the three options since the main objective we had was to be able to understand all the information through the evaluation methods. Later on we will see that at the beginning the tasks were more summative but throughout the evaluation they end up being open response tasks so we could say that it ends up being exploratory method.

3.2 Uses

This section will explain what has been extracted from each of the methodologies described in the documents. These two methodologies exposed were very useful in the preparation of the evaluation. For example, from the second paper, it stands out for taking into account the vocabulary, since it is very important for a correct evaluation. As we have seen, the tool has to be useful for any type of professional, that is, if we are in the case that the evaluation is going to be done by a person who does not understand the fields of medicine, such as a professional in the world of Visual Analytics, he/she will be able to use the tool because he/she will understand its operation well but will not know how to relate concepts and therefore we could not get good feedback from him/her to know where to improve the prototype. In the opposite case, we could have a professional person in the world of medicine but without any idea of how the technological part works, i.e. the dashboard, therefore, he would understand the tasks of the evaluation but probably would not be able to relate concepts due to lack of knowledge in terms of knowing how to use the visual tools. In these two cases, I would also highlight the time it would take that person to perform the tasks proposed for the assessment because even if it is one case or the other, both lack knowledge about one of the areas. Therefore, it is extremely important to be able to find a point in between and to know how to train any person in a reasonable amount of time.

From the first paper we draw the conclusion that before preparing an evaluation we must be clear about the three groups: users, tasks and data. This last group, once the steps already explained in the Visual Analytics section on how to treat the data and obtain a good data base have been carried out, is the most intuitive to have, although, as already explained, the process to clean the database is not always very easy. Another important decision is the users, in our case evaluators, are the people who will receive the tasks and whose response and defense mechanisms to these tasks will be collected and analyzed in order to make a decision about the Visual Analytics tool. As for the tasks, it is necessary to manage well what type of task is going to be and its length once the group of evaluators has been selected, since it can depend a lot and especially because there are many types of tasks that can be asked to be performed and not always all types are of interest. In conclusion, you should look for that type of task from which a good conclusion can be drawn and which fulfills the purpose of the prototype.

4 Methodology

4.1 Introduction

The clinics or centers in charge of clinical trials collect enormous amounts of data for each treatment, with which they then have to make extremely important decisions about whether the drug is valid for that disease or not. It is also important because it is being tested on humans, so the decisions have a very important weight in this part of the medical process. In this case we are dealing with a clinic which is conducting a clinical trial on the drug LX211 to see how it reacts to the eye disease called Uveitis.

From the Oftalmologic Spanish Society, Uveitis it is defined as: Diffuse uveitis or panuveitis is one in which all intraocular structures are affected, with inflammation in the anterior chamber of the eye, vitreous cavity and retina and/or choroid and/or retinal vessels. They are the most severe processes and are often related to general diseases. (https://www.oftalmoseo.com/patologias-frecuentes-2/panuveitis/)

From here, is going to be described in detail the methodology that was used to create the prototype and the effects of the type of tools used in the final evaluation as user will be fully time interacting with it. It may sound strange but studies have shown that the part that handles computer-human interaction has a lot to do with the tool they are using. That is to say, humans, for example, with the visual system we are guided by images, which would be a strong point in terms of evaluation and therefore, it is something to be measured.

However, it is true that there are other types of studies that say otherwise. In this article, [9], it is said that humans can be fooled by digital images. This paper was useful to be able to analyze from our prototype, which part of the tool is misinterpreted and used for certain situations for which it was not defined. This is interesting because it is important that end users use the tool with a clear objective.

4.2 Data base

So as we have seen in the introduction, this data set is about a rare eye disease called Uveitis. The data set comes from a study that evaluated the efficacy of a certain drug, especially LX211 as a treatment for uveitis patients.These patients suffer one of this Uveitis type:

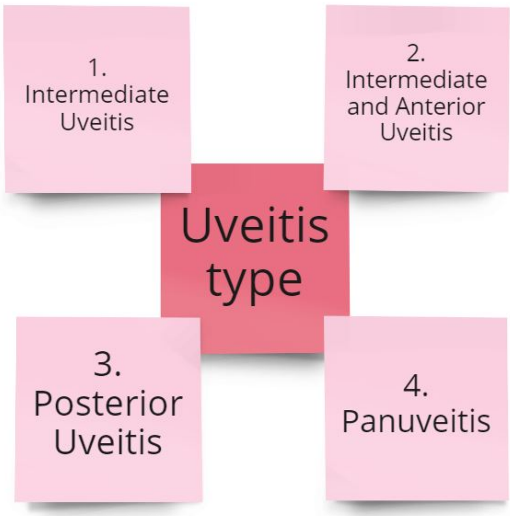

Figure 13: Uveitis-type

These patients are also divided into four different treatment groups:

1. Placebo (no medication)
2. High dose
3. Mid dose
4. Low dose

These patients, during six months they visited the doctor regularly in order to have under control general health of this patients. In three of these visits to the doctor, patients were asked to fill out two different questionnaires. The questionnaires were about patient's quality of life. This answers as we have seen, are called PROM and is where most of the data base comes from, the other one is about personal patient's information.

On the pictures below we can see the different questionnaires, one is about 25 questions and the other 36 questions. The 25-one assesses how vision influences quality of life including aspects like emotional well-being, social functioning or general health. And the other one about 36 questions, it subscores correspond to health concepts (limitation in social activities because of physical or emotional problems, or bodily pain,vitality).

The surveys are available here: https://www.rand.org/health-care/surveystools/mos/36-item-short-form/survey-instrument.html

36-Item Short Form Survey Instrument (SF-36)

RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:
- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?
- 1 - Much better now than one year ago
- 2 - Somewhat better now than one year ago
- 3 - About the same
- 4 - Somewhat worse now than one year ago
- 5 - Much worse now than one year ago

SF-36 Resources

Terms and Conditions for Using the SF-36

MOS 36-Item Short Form Survey Instrument (SF-36) (English PDF)

MOS 36-Item Short Form Survey Instrument (SF-36) (Arabic PDF)

Scoring Instructions for MOS 36-Item Short Form Survey Instrument (SF-36)

Figure 14: Visual Function Questionnaire (VFQ-25)

For each of the following statements, please tell me if it is definitely true, mostly true, mostly false, or definitely false for you or you are not sure.

(Circle One On Each Line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
20. I stay home most of the time because of my eyesight.....	1	2	3	4	5
21. I feel frustrated a lot of the time because of my eyesight..............................	1	2	3	4	5
22. I have much less control over what I do, because of my eyesight.	1	2	3	4	5
23. Because of my eyesight, I have to rely too much on what other people tell me. .	1	2	3	4	5
24. I need a lot of help from others because of my eyesight..............................	1	2	3	4	5
25. I worry about doing things that will embarrass myself or others, because of my eyesight..............................	1	2	3	4	5

Figure 15: Short-Form 36 Questionnaire (SF36)

In the data base we also find the data related to the patient, such as age, country they come from,region, uveitis classification, gender, race, ethnicity, treatment and affected eye.

Figure 16: Patient-related-data

So in general, we could say that the data set has two main parts. The first one is about the patient and the second one that comes from PROMS, answers to the questionnaires. This last part, that is made for each patient in three of their visits, are sub-scored from 0 to 100 in order to use them in the visual tooling of the prototype. This sub-scored will be explain it better in the next section where is going to be explained all the charts used in the prototype one by one explaining it's objectives and how information arrives to the user using each one of it because each one needs different user's interaction.

4.3 Prototype

This is a general view of the prototype that KNOVA team are using for the evaluation of this clinical trial. Visualization can be seen as a process that transforms data into a visual form. [10] This prototype was nearly finished and developed by a Master student once I arrived but I was available to follow it.

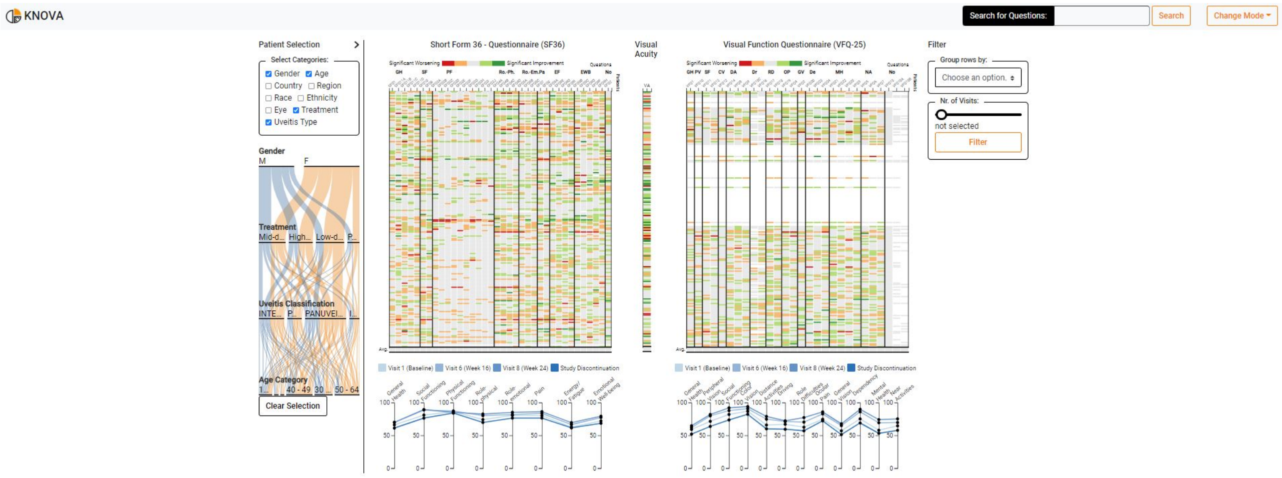

Figure 17: Patient-related-data

There are three different types of tools or charts that have been used in the prototype and in the next page will be described.

4.3.1 Charts

1. **Heatmap**

   The left one represents the questionnaire of 36 questions about health concepts and in the right is the one of 25 questions about quality of life, we can see how each answer for each patient have changed from the first visit to the last one. The columns are the questions and each row represents a patient and the colours indicate how the answers improved (green), worsened (red) and grey (no change).

Figure 18: Heatmap-chart

2. **Parallel-set-chart**

   The parallel set shows the distribution of the different patient characteristics. It has three main objectives:

   (a) Get to know the set of patients.

   (b) See their distributions among the categories.

   (c) Input for the heatmap .

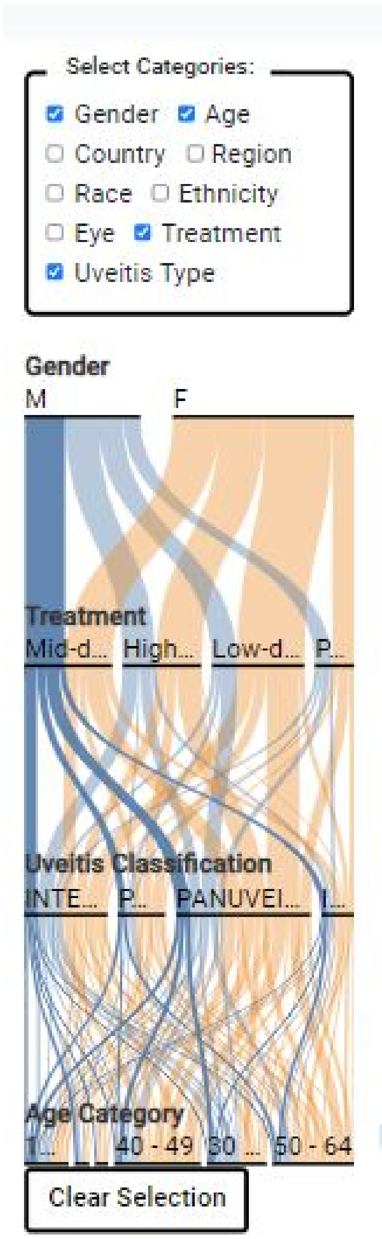

Figure 19: Paralle-set-chart

3. **Parallel-coordinates-chart**

   Then the last visualization is the parallel coordinates.We use parallel coordinates [11] both for visualizing data and for grouping and filtering It shows how the different subscores of the questionnaires have changed so each line is one type of visit and the average subscore value of all patients is shown.

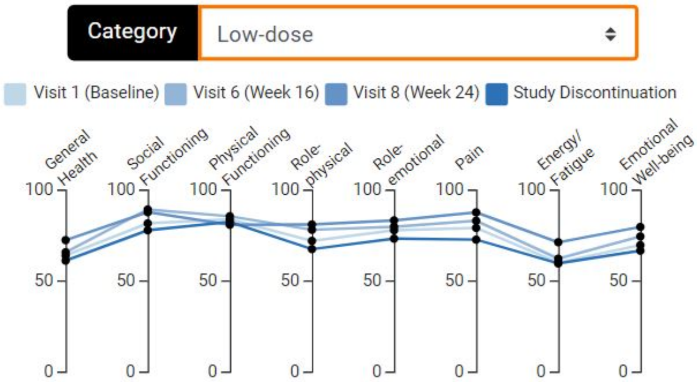

Figure 20: Parallel-coordinates-chart

5 Evaluation

Before deciding on the type of evaluation, an exhaustive search was necessary to find the type of evaluation that best suited our needs and, above all, the needs of the doctor in charge of clinical training, who gave us feedback each time we improved the prototype in order to make it ready to be used for the evaluation. The exhaustive research was to read a lot of documentation of Visual analytics evaluations and above all, to be guided by examples and systems that have already been evaluated.
The gamestorming explained in the first section, was used at this point of the project in order to find out from the whole database which points were more important, more remarkable for all of us and above all, to find among the members of the KNOVA team which things were not understood or which doubts came up when we played with the database.
These games, seen in section one, were played along with the prototype and gave us a lot of ideas and options as to the method of evaluating the prototype. In fact, they were played with the doctor so that we could discuss from both professional points of view: ophthalmological and visual technician and extract from her which points she considered the most importants in the evaluation.

5.1 Main steps

Figure 21: Main steps from the evaluation

Evaluation has become a fundamental part of visualization research, and many approaches have been studied from the field of human-computer interaction (task performance measures, think-aloud protocols, and interaction log analysis and als eye tracking for analyzing users' visual strategies in this context). This has added more data, requiring special visualization techniques to analyze these data.

Once the games were done, we came to conclusions that were quite feasible for the evaluation. Some doubts arose once we finished the games with which we were developing schemes to see what solution we had to evaluate the prototype. As always, we used the Miro tool which is super visual and can make a good interaction with the team. With the diagrams, everyone gave their opinion and we were discarding doubts to get closer to our approach.

From the games, we asked ourselves two main questions: what resources we have available for evaluation and what tasks we could set for it. After reading many papers, we concluded that the best way to make an evaluation was making the evaluators do some tasks. In our case, tasks are synonym of questions. We had the idea of brainstorming the questions to ask in the evaluation and classify them by Task 1,2,3,4 in increasing order from closed to open questions and also classifying them into quantitative or qualitative question.

This ideas are from a cientific paper called "Exploratory visual analysis: A literature review and evaluation of analytic provenance in tableau" where explains all the importants point of an evaluation idea. The main one was the measurament of task performance. [3] Our way of evaluating is always focused on assessing how users use the tool to answer certain questions that have been studied in depth, i.e., each one has a different objective and causes the user to find himself in situations of doubt from which he has to play with the dashboard.

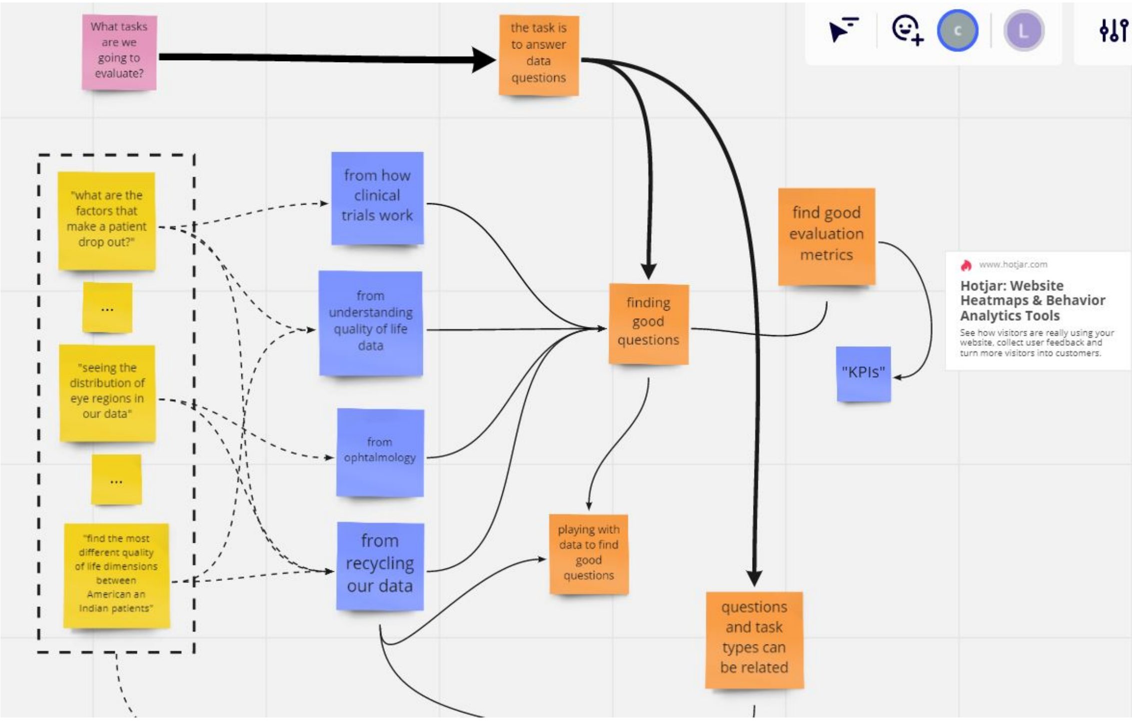

Figure 22: Map-conclusions

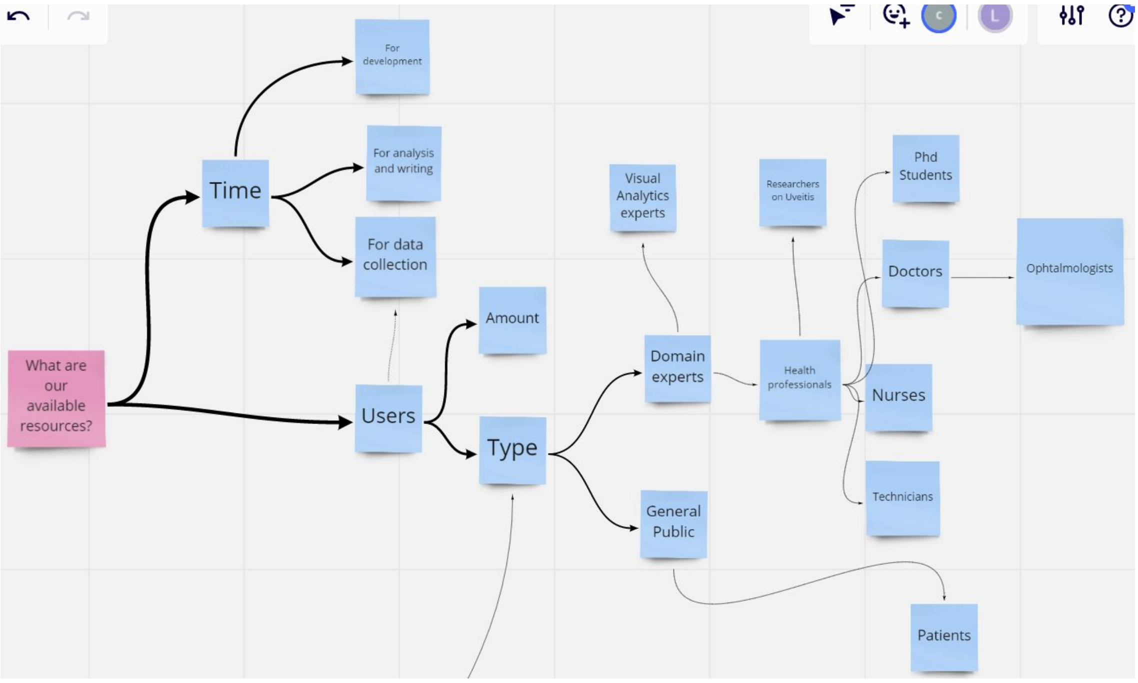

Figure 23: Evaluation-Resources

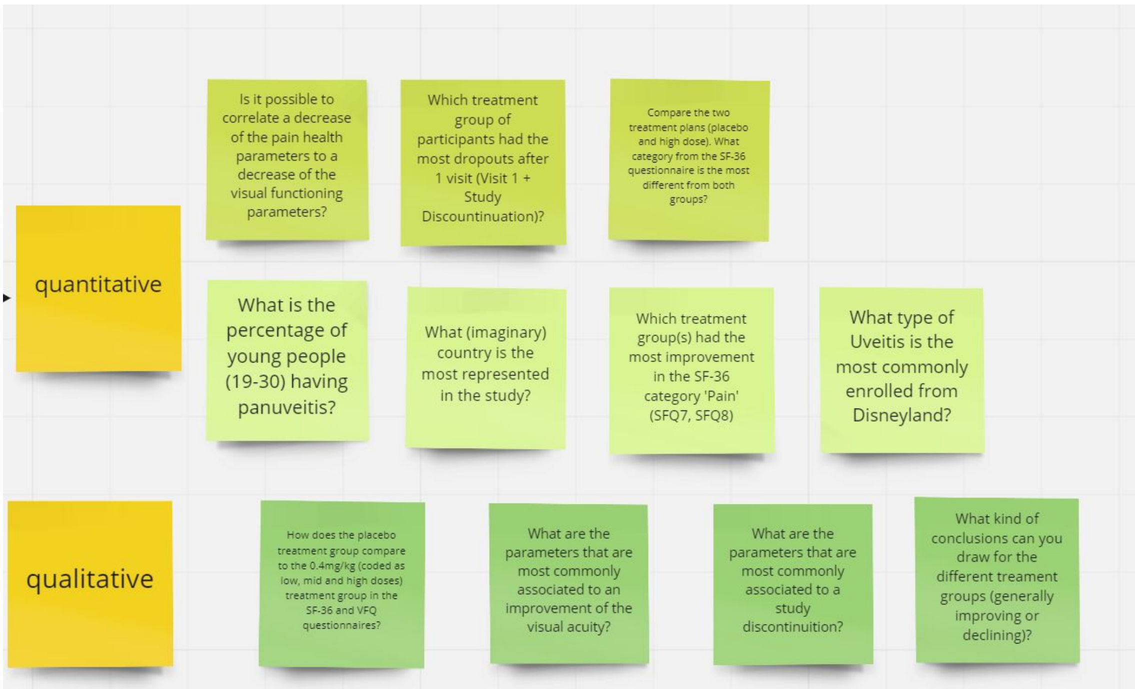

Figure 24: Evaluation questions

Dataset	Subtask	Prompt
Birdstrikes	T1	Consider these four parts of the aircraft: engine 1 ([Dam Eng1]), engine 2 ([Dam Eng2]), the windshield ([Dam Windshield]), and wing/rotor ([Dam Wing Rot]). Which parts of the aircraft appear to get damaged the most?
Birdstrikes	T2	Which aircraft classes ([Ac Class]), if any, appear to be more susceptible to damage ([Damage]) from animal strikes? Note that [Damage] also records when no damage has occurred.
Birdstrikes	T3	What relationships (if any) do you observe involving weather conditions ([Precip], [Sky]) and strike frequency, or counts over time ([Incident Date])?
Birdstrikes	T4	What are the most common conditions for an animal strike? Note that this is not limited to weather conditions, any dataset columns that are interesting to you can be included.
FAA	T1	How do cancelled flights ([Cancelled]), diverted flights ([Diverted]), and delayed flights ([ArrDelay], [DepDelay]) compare in terms of counts or frequency?
FAA	T2	What patterns (if any) do you observe in the count of flights over time ([FlightDate])? If any patterns are observed, what deviations (if any) do you see for individual airlines ([UniqueCarrier])?
FAA	T3	What relationships (if any) do you find involving flight distance ([Distance]) and arrival delays ([ArrDelay])?
FAA	T4	Suppose Delta Airlines wants to expand 3 airports. Based on your analysis of the data, which 3 airports would you recommend to Delta Airlines (airport code DL)? Existing Delta Airlines airports, and/or airports that Delta doesn't cover, can be included in your analysis.
Weather	T1	Consider the following weather measurements: Heavy Fog ([Heavy Fog]), Mist ([Mist]), Drizzle ([Drizzle]), and Ground Fog ([Ground Fog]). Which measurements have more data? Which weather measures (if any) would you remove from the dataset?
Weather	T2	How have maximum temperatures ([T Max]) and minimum temperatures ([T Min]) changed over the duration of the dataset (i.e., over the [Date] column)?
Weather	T3	How do the wind ([High Winds]) measurements compare for the northeast and southwest regions of the US?
Weather	T4	What weather predictions would you make for February 14th 2018 in Seattle, and why?

Figure 25: Evaluation questions [3]

This visual analytics questions or ubtasks are treated in eparate categories

1. Data quality assessment (T1)
2. Evaluation of patterns and relationships between variables (T2, T3)
3. Causality and prediction analysis (T4,open-ended).

Once we had the outlines clear and the questions more or less thought out, what we did was to try it out on ourselves. The whole KNOVA team started to answer the questions with the prototype to see what doubts came up during a hypothetical evaluation. We also timed ourselves to see how long each person took approximately. From there, we modified questions and/or vocabulary for a more successful evaluation.

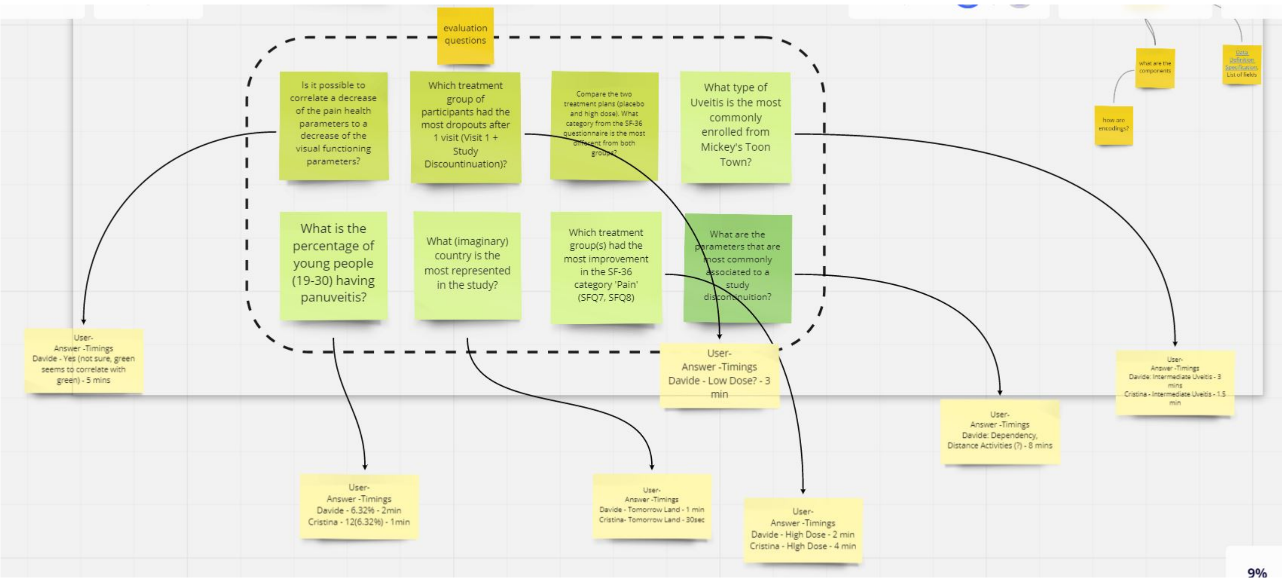

Figure 26: Knova-evaluation

Once we all evaluated ourselves and saw which doubts and things we did not understand or did not understand, that is, which stimuli we understood from the prototype and which we did not, we decided that the best option was to first do a little training for our evaluators, since they would be professional visual analytics professionals. Here comes into play my main task of the project and where I had all my maximum responsibility. This training is called onboarding, which refers to summarize all the important concepts of the prototype and above all, to clarify the technical vocabulary of the medical field so that anyone can feel comfortable with it. It was to compile all the information extracted from the internal evaluation of the group and translate it into a dashboard or manual to be useful for any type of person and above all to be self-taught because in the end the tool has to reach everyone and has to be resolvable without our help or without our presence.

5.2 Related work for onboarding implementation

In this little subsection, a relevant finding is described in order to ease the reader into the onboarding part of the project. Reference is made to the steps to create an onboarding extracted from a scientific paper which was very useful to know how to move forward.

5.2.1 Visualization onboarding [1]

Data visualization aims to help humans deal with very large and complex scales of information. Without this help, it would be difficult to explore and interpret them and it would not be so easy to discover new knowledge and therefore, consequently, to make decisions. It often happens that when you offer the visual tool to users, they do not know how to read and interpret the visualization data, especially when they are not from the technological field, i.e., it is their first time seeing a digital visualization tool. We are not only talking about the lack of confidence with the digital tool but often there is a great lack of knowledge about the data. That is why the concept of ”onboarding” was born to help users learn about the tool and teach them more deeply all kinds of features about it.

We take full advantage of onboarding, i.e., visualization onboarding methods, when users are not familiar with the subject matter because they may make poor decisions or have misconceptions about the data. Therefore, in this case we get the most out of power of visual characterization.

The scientific paper proposes to structure the design environment of visualization onboarding along the five W's and one how. Why, Who, What, How, Where and When. Also, combines the theory of the nested model explained in the Start of art section (point three) with some additional aspects. It is a good combination as it offers a way to evaluate from the beginning to the end taking into account many aspects of user experience.

Thinking back a bit, nested model divided the design into four levels and combined them with typical evaluation methods. In this case, the new variable is to combine all of the above described in point 3 along with automated data analysis and visual coding components.

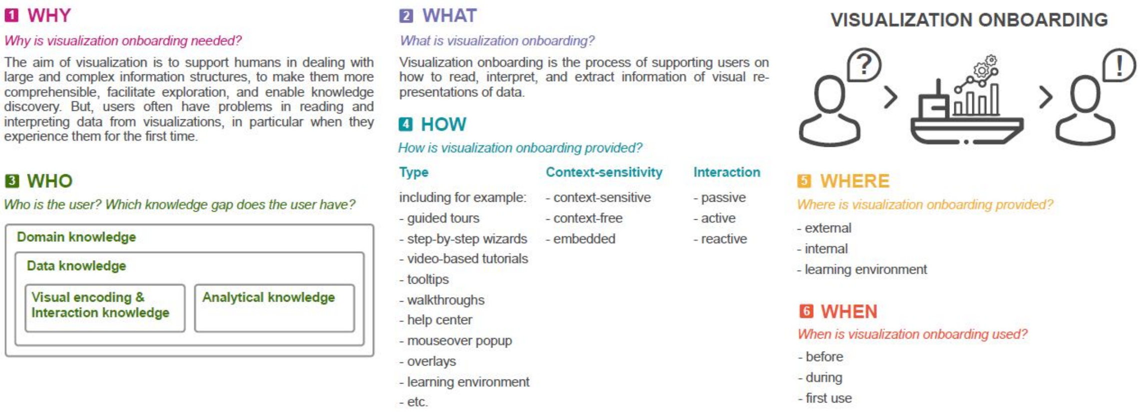

Figure 27: Onboarding overview extracted from [1]

In the figure we can see the different levels of knowledge necessary for users to understand the representations and that also, system designers have to take into account when incorporating new concepts. As explained in previous points, it is important that both onboarding and evaluation take into account the previous knowledge of these users in order to adapt the system well. This knowledge can be:

1. Domain knowledge
2. Data knowledge
3. Visual encoding knowledge
4. Interaction knowledge
5. Analytical knowledge

With that we have described "**What** is visualization onboarding".

The figure below, shows the visualization process in which there are three areas of data and analytics and visualization and user. We have two sides, left, which refers to the computer side and right to the user side. The data (D) is transformed with analysis methods (A) and displayed (V) according to a specification (S). From the left side an image (I) is sent to the right side where it is communicated to the user. The user perceives and processes (P) this image which leads to new knowledge (K) through interaction (E).

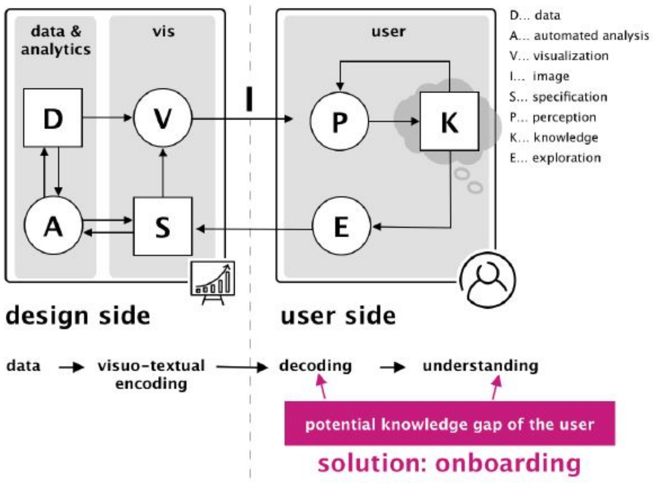

Figure 28: Onboarding overview extracted from [1]

From there on, depending on the type of user we are dealing with, we will use one domain or another. With this we answer the question of **"Who is the user?"**.

Type, sensitivity to the environment and relationship are important points in the question of **how** visualization onboarding occurs. The help system should be intended to direct users through a demonstration in its own interface environment. It has been developed an approach to grant a new framework for integrating collectively sourced contextual support into web application. In this framework for visualization onboarding has three main aspects:

1. Type: onboarding can be given in different ways as tutorials, manuals, etc.
2. Context Sensitivity: small helps during the evaulation as tooltips, instructions on the interface, etc.
3. Interaction

Fernquist [12] raises certain questions such as **"Where** is visualization onboarding provided?". He also explains the importance of incorporating help systems in learning envir onments so that the user can become familiar with the tool. Tied to the **Where**, we can talk about **"When** is visualization onboarding used?" as it can be used either before visualization tool or also during as a support tool.

In conclusion, we see that there are no specific steps for a good onboarding since there is still a lot of research and study to be done, but it is clear that there are some very basic steps to ensure that the user receives all the necessary information and feels as comfortable and confident as possible with the support to make a good evaluation.

So after that, we could summarize that for orientation in Visual Analytics we find this different steps:

1. We summarize and classify the main aspects of the prototype, also representing what constitutes a guide in the first place and explaining the main steps.

2. We communicate ways to provide different types of guidance to users, as they can perform analytics tasks with different levels of experience and with different forms of interaction. We also discuss how the user reacts to the different stimuli that he receives from the prototype so that we can finally draw conclusions about the prototype and together with them we can improve it for a better result and a better user-prototype interaction because once you get familiar with understanding of users' analysis it is easier to improve the design of these visualization tools to promote effective outcomes. An example would be timing how long it would take a person to complete a task to see if the tools they use to answer that question are efficient.

5.3 Practice

The above scientific paper gave us many ideas on how to do our onboarding.Especially with regard to the first approach. We discussed among the whole team the five W's and How and then we discussed more specifically the type of evaluation and how to carry it out.We also mixed ideas and knowledge obtained from the two scientific papers described in the State of the art section and finally we generated a very useful onboarding with very good feedback, although it is true that after each evaluation small things were tweaked to improve it more and more so that the user understands it in a better way.

For the evaluation with the participants, we decided to prepare an orientation manual so that before they started answering the questions they would feel comfortable and familiar with the database and the vocabulary they would encounter both in the questions and on the dashboard. In order to do so, it was important to know the database well and to know the relationship of each parameter or variable, since the first step of the manual is to place the user in the environment in which the evaluation will be made and to give him a small scheme so that he can get a mental idea of the data with which he will be working. This would correspond to the point "What is data about" of the manual, where the characteristics of the database explained in point 4.2 are explained in a summarized form. Secondly, what was proposed is to take as an example three questions similar to those of the evaluation and explain step by step how they would be answered from the prototype. The purpose of this part of the manual is to make the user feel comfortable when it is his turn to answer the questions since he will have seen three good examples previously explained step by step.

As we have seen in previous points, there are people from different countries/regions who, in a particular country, follow some pattern when answering the questions, which we can relate to some socio-cultural issue. That is why in this evaluation, so that the countries are not treated differently because sometimes because of the steorotypes that we have, we are going to name them all with fantasy legend names so that they are anonymous.

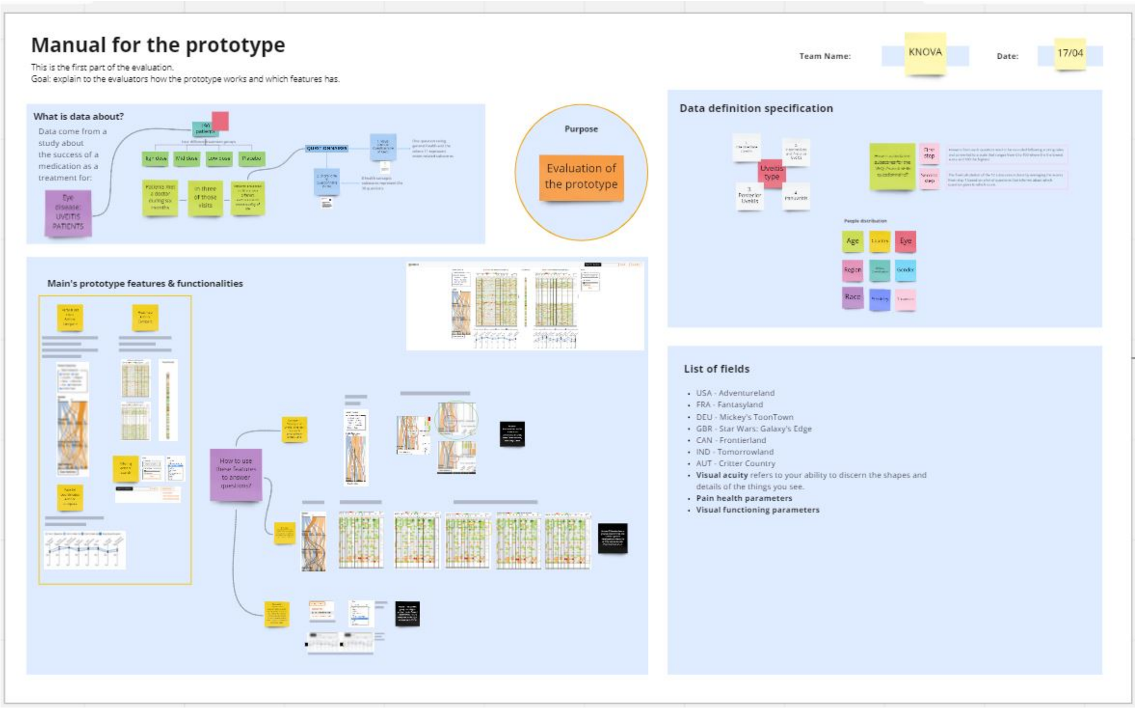

Figure 29: Orientation-manual

Once the manual was prepared and validated by all team members, we prepared a mural where you could find the onboarding and the evaluation part of the project, that is, the eight questions that participants had to do.

Following the triangle model, user, data and tasks, at that moment we had already defined what kind of data and what kind of tasks we would use to carry out the evaluation. Therefore, the only thing we needed to do was to decide what kind of users we wanted to participate in the evaluation and what kind of opinions we needed as feedback to improve the system. As a first option we had the whole clinical trial team which would be in charge of sending the evaluation to the responsible doctor who joined us with the medical team. This option at first seemed to be the most decisive since they are professionals in the medical field and, at the end, they are the users who will use this tool, and they could help us a lot with their reviews. Anyway, we could not coincide with them in terms of time so we looked for plan b and this was, to turn to colleagues in the visual analytics field who had already contributed their grain of sand when the project began so they were already a little aware of what was going on. However, when the medical team has more time this evaluation will reach them too, but so that the master and degree students who are in the team can carry out the evaluation we were left with the option to evaluate the colleagues which was also very useful because they, for example, of the medical field do not know as much as medical professionals and we could see in which aspects the subject was weaker and needed more help.

So this is how we proceeded. We saved five free slots in our diaries to do the onboarding part and to watch how the evaluators carried out the evaluation. This last part described above was recorded so that we, once we had finished all of them, could watch them again and analyse again from beginning to end how the evaluator developed during the evaluation process.

The onboarding part was customised for each of the evaluators. That is to say, we wanted to try to do the onboarding part in different ways each time to see which of them was the most effective and in which of them the evaluator felt more comfortable and more confident with the prototype tools to be able to answer the 8 questions with almost no doubts.

In fact, in the first one what we did was to read the manual (the examples too) and the questions but the first contact the evaluator had with the tools was directly in the evaluation, so at a technical level he had more doubts about the prototype, but in terms of vocabulary and data distribution he was quite clear.

In the second one, what we did was to read the manual but explain it to him/her from the prototype, that is to say, in a much more interactive way where the evaluator was seeing how to defend himself/herself with the tool. The examples were explained from the prototype so that the evaluator paid a lot of attention to how the tool worked but had more doubts about the characteristics of the data.

The other three evaluations were a mixture of what was explained. Not everything from the manual, not everything from the prototype. We wanted to do a mix of reading and teaching from the prototype and we also added that the evaluator would play with the tool before proceeding to the final evaluation, which turned out to be a very good idea and we got very good results.

These different ways of doing the onboarding part were reflected in the way each of the evaluators answered the questions and the time each of them spent on the tasks. Even so, we will see later that what we wanted to get out of these evaluations is the analysis of how the person interacts and defends himself with the prototype, the time we did not take into account but it was reflected when the person understood well the examples with the onboarding or not.

6 Experiments and results

Once the five evaluations were finished, the first thing we could observe was the time it took each of them to complete the whole evaluation. This is related to how many screens they used to do the evaluation. Because who has two, was much easier to read the tasks and be able to answer at the same time without wasting minutes changing tabs. However, we wanted to analyse how people solve the tasks, timing wasn't our concern.

Evaluator	Total time evaluation(minutes)	Onboarding time (minutes)
Evaluator 1	37	20
Evaluator 2	28	25
Evaluator 3	22	22
Evaluator 4	22	22
Evaluator 5	30	25

Table 1: Evaluation timing

In the table above you can see how much time in total each evaluator took to complete the evaluation and how much of the total time was spent on the onboarding part of the evaluation.

The 8 questions were ordered from closed to open, so we could see a clear increase in time from the first to the last one.

Evaluator	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8
Evaluator 1	4'22"	1'31"	12'	4'	3'	5	6	1'46"
Evaluator 2	1'	1'30"	5'50"	2'31"	40"	6'27"	3'44"	7'
Evaluator 3	36"	26"	1'30"	2'41"	1'	4'	3'32"	9'
Evaluator 4	37"	38"	2'12"	1'	1'26"	2'15"	4'	3'15"
Evaluator 5	42"	28"	1'27"	2'26"	30"	2'45"	4'46"	7'

Table 2: Questions timing

Related to this, we could also see on the table 2 that those who were onboarded in a more interactive way and shown the examples from the prototype, felt confident in answering the first four questions with the same tool and in a very easy and safe way. From evaluator three, the way of the onboarding part was totally interactive and the person was shown the examples from the prototype and also played before the evaluation.

We also found the parallel set chart to be the visual tool that was easiest for the evaluators to use. Not because the questions were closed and quick to answer, but because from the onboarding it was very clear what its main function was.

Also it can be seen on the table 2 because the first three-four questions can be answered using the parallel set and once the evaluator get the function was really easy to respond to the task.

On the other hand, the tool that was more difficult to understand was the Heatmap, as it is the one that contains more information and is more difficult to familiarise oneself with.

Therefore, we concluded that the onboarding part was essential in the process, but we could improve it by making it more interactive with the evaluator, for example allowing him/her to play with the tool and feel comfortable before starting the evaluation. Also we found some vocabulary that all the evaluators had doubts about. As I mentioned in the Nested Model vocabulary is a really important part of the evaluation because we can conclude with bad decisions due to the bad understanding of some medical domain words. So, after the five evaluations we saw some medical parameters that were not clera at all and all the evaluators gave us as a feedback. The main one for example was the kind of discontinuation that the patient has during the process.

7 Budget

In this section the costs related to the development of the project will be explained. As the final result is neither physical nor a closed prototype, that is to say, it is research on the subject, the working hours of the student and the supervisor of the Technical University of Vienna will be taken into account, and no material costs will be included, as the home office and the computer at our disposal will be taken into account.

As explained above, the main cost of the development of the Visual Analytics research corresponds to the working hours of the student and the two university supervisors/teachers. One from Barcelona and the other from the host university in Vienna.

The supervisor of the TU attended at least 2 hours per week through the communication platform we use, Slack, to have a personal follow-up with my work and every 2 weeks an online meeting of approximately one hour. We consider 18 weeks of work (2 weeks in February and 4 months) plus the extra hours to correct and evaluate, so we count that approximately 36 hours of work plus 10 hours of online meetings, so 46 hours in total. For the UPC supervisor, the hours of correction of the three deliverables (proposal plan, critical review and final) are taken into account and also coordination hours, so we count approximately 20 hours in total.

	Number	**Salary/hour**	**Hours**	**Salary**	**Total**
Supervisor TU	1	50	46	2.300	2.300
Supervisor UPC	1	35	20	700	700
Student	1	15	450	6.750	6.750
BUDGET					**9.750**

Table 3: General budget

8 Conclusions and future development

8.1 Conclusions

The most important part of this project has been to understand and participate in how to study, interpret and represent the data because nowadays, for almost everything we use a lot of data that we do not know how to use and that if we did, we could make very good decisions and very useful conclusions in our daily lives.

As we have seen, the use of Visual analytics in the medical field is one of the best options as it gives way to great opportunities. In particular, the use of Dashboard as the one implemented in the KNOVA team is the most suitable tool to display medical data. With it, medical professionals can speed up the decision making process and above all, the amount of work is streamlined as the communication between data and doctors is much closer.

With PROMS, we know the patient's feedback on your health status, both physical and psychological, and with this we can study in more detail the disease being treated in that clinical trial. Visual analytics plays a big role as patients are not trained with this type of medical information compared to medical professionals so using a connecting thread between these two is a very advantageous strategy. As we have seen, the use of Dashboard is one of the best options to inform patients and for medical professionals to quickly interpret the entire database. With PROMS, patient-doctor rapprochement is gained as better patient care is gained and most importantly, important decisions are made with a high chance of success on diseases.

8.2 Future development

One of the future paths of this project will be that the tool will reach the medical team and that they themselves, in a self-taught way, will use it for future clinical trials.

This will be very useful for streamlining medication processes as well as decision making on patient patterns and doses. In fact, once we were able to test the evaluation and it came out as expected, the tool was sent to the medical team who proposed to create an application that not only serves clinical trials but that can be adapted to all types of medical needs and above all that is compatible with all types of databases. So it would be a good option for this type of dashboard to be universal for all types of clinical trials and above all to be available in many clinical centers because, as we have seen in this pandemic period, decisions can be made quickly and very effectively in terms of health.

As a future personal academic development, I would like to be able to put all this theory and learning into practice and to create a tool for the health field useful to help health centers, because given the situation in which we live, we see that it is important to be able to make quick and good decisions about diseases and give a good treatment to the patient knowing him more with the use of PROMS.

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