UNIVERSIDADE FEDERAL DO RIO GRANDE DO SUL
INSTITUTO DE INFORMÁTICA
PROGRAMA DE PÓS-GRADUAÇÃO EM COMPUTAÇÃO

MARINA FORTES REY

Visualization-Based Interface for Clinical Trial Monitoring

Thesis presented in partial fulfillment of the requirements for the degree of Master in Computer Science

Advisor: Profa. Dra. Carla M.D.S. Freitas

Porto Alegre
June 2020

CIP — CATALOGING-IN-PUBLICATION

Rey, Marina Fortes

Visualization-Based Interface for Clinical Trial Monitoring / Marina Fortes Rey. – Porto Alegre: PPGC da UFRGS, 2020.

160 f.: il.

Thesis (Master) – Universidade Federal do Rio Grande do Sul. Programa de Pós-Graduação em Computação, Porto Alegre, BR–RS, 2020. Advisor: Carla M.D.S. Freitas.

1. Information visualization. 2. Clinical data visualization. 3. LINDA-BRASIL. I. Freitas, Carla M.D.S.. II. Título.

ACKNOWLEDGMENTS

First of all, I would like to thank my advisor Carla Freitas for the support through all these many years and for always believing in me, even when I didn't. I would like to thank the Federal University of Rio Grande do Sul (UFRGS), the Institute of Informatics (INF), CNPq and CAPES, for both the great infrastructure and funding, which made this work possible.

I would like to thank all specialists from LINDA that were essential for the development of this work, especially Maria Inês Schmidt, Bruce Duncan and Diogo Ferreira, who were always very supportive and present. I would also like to thank all non-experts and experts that participated in the evaluation process.

Finally, I would like to thank my family and Nicolas Kagami for all the support during these formative years.

ABSTRACT

Despite current technological advances, interactive tools to facilitate analysis of data collected during clinical trials are still not widely available. Such a scenario makes researchers rely on time-consuming extractions from databases and subsequent application of analytical methods by statisticians to obtain results from which they can get insights. Moreover, during clinical trials, researchers need to keep track of subjects' progress by monitoring their participation as well as the quality of the data collected at specific phases of the trial. In this work, we present a visualization-based interface that assists epidemiologists of a randomized clinical trial focused on the effects of lifestyle intervention in the development of type 2 diabetes for patients with Gestational Diabetes Mellitus (GDM). Coaches give the intervention, and research assistants collect data from hundreds of questionnaires and clinical exams. The clinical trial is still in the field and it is planned to be completed by the end of 2021. We adopted user-centered design principles, which allowed continuous improvements to the visualizations and interactive features during a year-long development process. Besides typical selection and filtering features, the visualizations we provide allow the research team to monitor each participant's progress as well as perform analyses that facilitate findings in and between subjects' histories. Two formal evaluations were also performed with experts and non-experts, where the visualization-based interface proved to be intuitive and useful for assisting coaching activities, monitoring the progress of data collection, and performing analyses. In this work, we describe the design process and the resulting interactive visualization-based interface that we developed. We then present a detailed usage scenario and the results of the formal evaluations.

Keywords: Information visualization. Clinical data visualization. LINDA-BRASIL.

Interface Baseada em Visualização para Monitoramento de Ensaio Clínico

RESUMO

Apesar dos avanços tecnológicos atuais, ferramentas interativas para facilitar a análise de dados coletados durante ensaios clínicos ainda não são amplamente disponíveis. Esse cenário faz com que pesquisadores precisem depender de extrações custosas para tirar conclusões a partir dos dados. Além disso, durante ensaios clínicos, pesquisadores precisam acompanhar o progresso dos participantes, monitorando suas atividades além da qualidade dos dados coletados em etapas específicas do ensaio. Nesse trabalho, é apresentada uma interface baseada em visualização que auxilia epidemiologistas de um ensaio clínico randomizado focado nos efeitos da intervenção no estilo de vida para o desenvolvimento de diabetes tipo 2 para pacientes com diabetes gestacional. Instrutores transmitem a intervenção e assistentes de pesquisa coletam dados de centenas de questionários e exames clínicos. O ensaio clínico ainda está em andamento e será completado ao final de 2021. Foram adotados princípios de design baseado no usuário que permitiram realizar melhorias contínuas nas visualizações e funcionalidades interativas durante um processo de desenvolvimento de um ano. Além de seleções e filtragens típicas, as visualizações criadas permitem que os pesquisadores monitorem o progresso de cada participante assim como realizem análises que facilitam descobertas nas histórias das participantes do ensaio clínico. Duas avaliações formais foram realizadas com experts e não-experts, onde a interface baseada e visualização provou ser intuitiva e útil em auxiliar atividades de acompanhamento, monitorando o progresso de coleta de dados e realizando análises. Nesse trabalho, o processo de design e a interface baseada em visualização desenvolvida são descritos. Também são apresentados um cenário de uso detalhado e os resultados das avaliações formais.

Palavras-chave: visualização de informações, visualização de dados de ensaio clínico, LINDA-Brasil.

LIST OF ABBREVIATIONS AND ACRONYMS

EHR	Electronic Health Records
DM	Diabetes Mellitus
GDM	Gestational Diabetes Mellitus
LINDA	Lifestyle INtervention for Diabetes prevention After pregnancy
IPAQ	International Physical Activity Questionnaire
BMI	Body Mass Index
PSQI	The Pittsburgh Sleep Quality Index
EDPS	Edinburgh Postnatal Depression Scale
DR	Dimensionality Reduction
PCA	Principal Component Analysis
t-SNE	t-Distributed Stochastic Neighbor Embedding
SUS	System Usability Scale
UEQ	User Experience Questionnaire

LIST OF FIGURES

LIST OF TABLES

CONTENTS

1 INTRODUCTION

Visual interactive technologies have become widely available in the last decade, allowing applications in several fields of human activity to take advantage of their features for improving human performance and accuracy. One of these fields is clinical research, where the huge volume of complex data is demanding considerable efforts in creating visual interactive, intuitive systems for gathering insights on collected data.

One of the most prevalent research topics tackled by clinical research is chronic diseases, which require periodic tests and observations over a long period of time. Such studies are known as epidemiological studies. They are based on following a sample of a population to provide information on the causes of some disease or condition of the whole population. Epidemiological studies focus on a particular population (the *source population*) followed over a particular period of time (the *risk period*) (PEARCE, 2012). Correlations between these longitudinal data are important to epidemiologists' decision making, which critically depends on visualizing the complete history of subjects in the sample, spotting trends, incidents, and cause-effect relationships between data (PLAISANT et al., 1996).

Clinical trials are experimental studies based on some intervention, belonging to the broad class of interventional studies, where the researcher intervenes in some aspect, and follows the outcomes of that intervention (THIESE, 2014). They often rely on time-consuming extractions from databases and subsequent application of analytical methods by statisticians to obtain results from which they can get insights. Therefore, these studies can benefit from flexible, powerful tools that enable and support exploration (PREIM et al., 2016). This exploration is vital for assisting researchers in keeping track of patients' progress, enabling dynamic methods for monitoring participation as well as assessing the quality of the data collected at specific phases of the trials.

Even though clinical trials can have many common characteristics, i.e., the separation of subjects in control and intervention groups and the segmentation in phases, they can vary significantly in the types of information gathered, the number of participants enrolled and the duration of the study. Moreover, the analysis of medical data often brings additional challenges compared to other fields of study, involving complex and disorganized information, and, as it accumulates, it is increasingly difficult to integrate and analyze. There are several obstacles connected to medical research (SHNEIDERMAN; PLAISANT; HESSE, 2013) and the analysis of cohort study data (MAY et al., 2015), many of which were encountered or taken into consideration during the development of this work:

1. Characterization and understanding of similarities on large databases to search for patterns
2. Visualization of comparative relationships to detect relevant information for medical intervention
3. Logging of operations, so it is clear to the user what operations were applied
4. Missing or incorrect data, possibly by denied answers to inconvenient questions or incorrectly entered data
5. Mixed variable types, such as numerical, linear and categorical values
6. Time-varying variables in longitudinal studies.

This work emerged as a collaboration with researchers from LINDA-Brasil, a multi-center randomized controlled clinical trial focused on investigating the effects of lifestyle intervention on the development of Type 2 Diabetes Mellitus (DM) after pregnancy with Gestational Diabetes Mellitus (GDM) (SCHMIDT et al., 2016). The trial specifically targets women who used insulin during pregnancy or presented intermediate hyperglycemia postpartum. These women are recruited and followed by coaches through regular phone calls and clinical visits to detect new-onset diabetes, reversion to normoglycemia, weight loss, physical activity, and collect other relevant information by the completion of questionnaires and clinical exams. The clinical trial is still in the field, and it is planned to be completed by the end of 2021.

1.1 Goal

Our goal was to investigate the potential benefits of interactive visualization techniques to the workflow of epidemiologists. We started our research with several meetings with the principal investigators of a large Brazilian longitudinal study, the ELSA-Brasil (Longitudinal Study of Adult Health) [1]. After developing and presenting some prototypes of visualizations using data from ELSA, we were invited to work with data from another study, the LINDA-Brasil clinical trial, that shares its principal investigator with the ELSA study.

We then re-targeted our research to investigate visualization techniques in the con-

[1] <http://www.elsa.org.br/oelsabrasil.html>

text of the LINDA-Brasil study. We aimed at integrating interactive visualization techniques in an interface to assist epidemiologists of the LINDA-Brasil study in keeping track of participants' progress as well as to discover similarities between their histories. We hypothesized that helping researchers discover patterns in the data about participants could enable the discovery of lapsed subjects to prevent them from leaving the study or develop diabetes.

We can state our general research question as "to what extent a set of interactive visualization techniques assists epidemiologists in a longitudinal study?". To answer this question, we created three views for user interaction, each contributing in different ways to the workflow performed by researchers. Besides typical selection and filtering features, the visualizations that we designed allow the research team to:

1. Track the participants' progression for the duration of the trial to assess the effectiveness of the intervention
2. Find similar participants based on data collected during the trial
3. Track the study's status and completion of each phase for each enrolled participant
4. Discover incorrect and missing data through the analysis of outliers

1.2 Structure of the Dissertation

In this dissertation, firstly, we present some concepts from the field of study that are essential for understanding our work and introduce the LINDA-Brasil clinical trial, which is our target domain (Chapter 2). Then, we review relevant works related to the context of medical data visualization (Chapter 3) and describe the requirements (Chapter 4) gathered through interviews with the LINDA-Brasil specialists.

In Chapter 5, we present the interactive visualization-based interface that we have designed and implemented. We then describe a detailed usage scenario (Chapter 6) and the assessments we performed for evaluating the tool (Chapter 7).

Finally, in Chapter 8, we summarize our conclusions, comment on lessons learned, and describe possible directions for future work. The Appendix contains all the details about the evaluations we performed.

2 DOMAIN CHARACTERIZATION

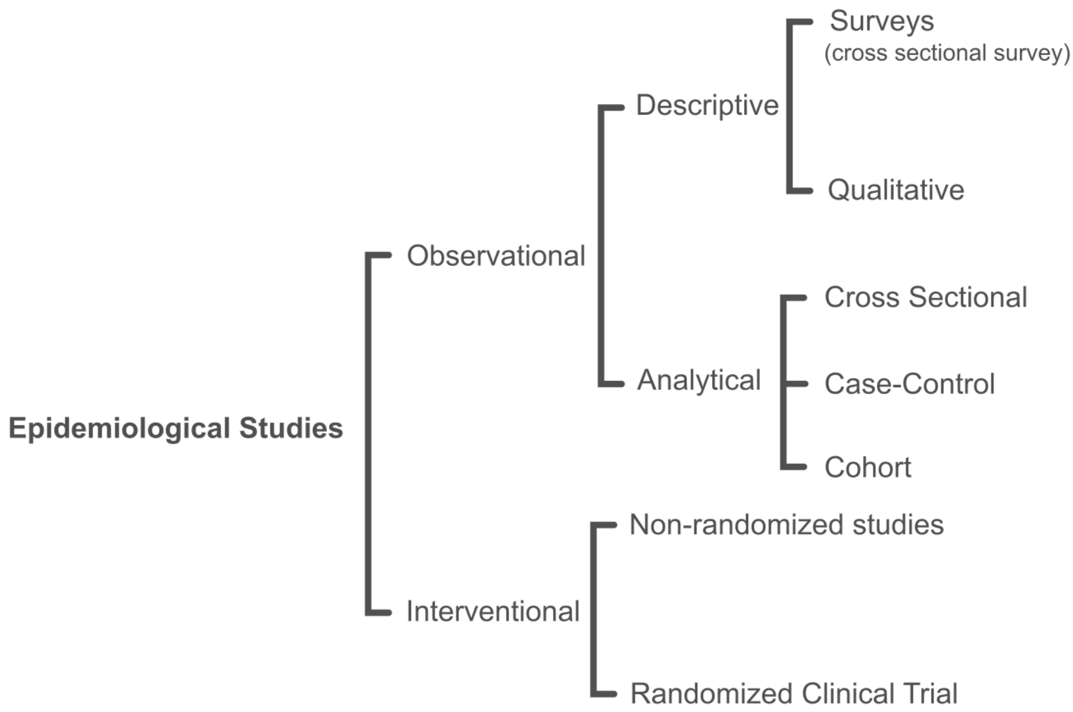
In this chapter, we review some concepts related to epidemiological studies, which is the general context where our work fits in. They are important for understanding our specific target domain as well as the research problem we aim to address herein. We introduce the LINDA-Brasil study and describe the most relevant data collected for each participant.

2.1 Epidemiological Studies

While clinical observations generate conclusions about individuals, epidemiological observations tend to relate to a particular group within a population from which conclusions are to be drawn (COGGON; ROSE; BARKER, 2003). Epidemiological studies are based on an analysis of a sample of the population to provide information on the causes of diseases and health conditions that affect a community. These studies can be conducted with prospective approaches (e.g., cohort studies), which investigate from cause to effect, or retrospective approaches (e.g., case-control studies), which investigate from effect to cause. Many types of research designs derive from epidemiology, as seen in Figure 2.1. Descriptive studies are used to generate hypotheses, while analytical studies test them.

Often, a study population has some characteristics in common, such as the geographical location, occupation, and the diagnosis of a specific disease. Epidemiologists tend to work with numerical and categorical data, where its reliability depends significantly on its sample size and selection criteria (PREIM et al., 2016). The direction of the study is often based on a hypothesis formulated by researchers, and the resulting characterization of risk factors of diseases is often based on statistical analyses of the data acquired. The information obtained from the subjects is often genetic or environmental factors, lifestyle choices, and their overall health, usually collected in a mixture of interviews and clinical examinations. This data is often collected by different people, which hampers the rigorous standardization and quality control that are essential in epidemiology. All results from such studies should always be questioned for biased comparisons and non-causal relations (COGGON; ROSE; BARKER, 2003).

Figure 2.1: Epidemiological study designs and denominations



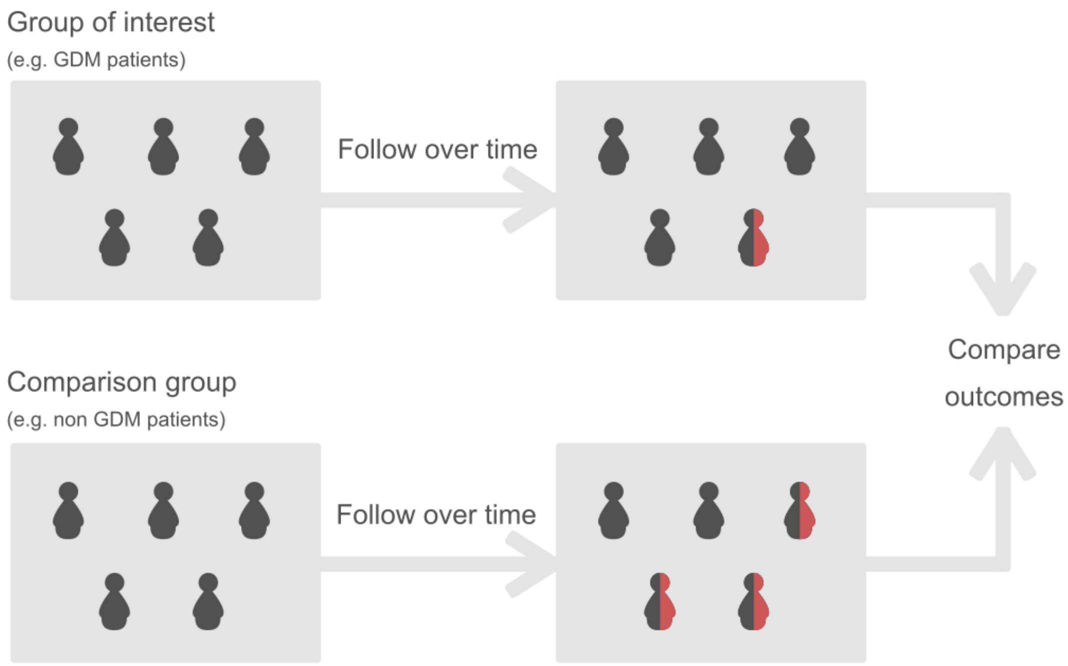
Source: Adapted from http://howmed.net/community-medicine/study-designs/

2.1.1 Cohort Studies

Cohort studies are a form of longitudinal study that samples from a population with a particular characteristic, collecting self-reported information and performing medical examinations in a large number of randomly selected individuals over a long period of time (PREIM et al., 2016). Self-reported information is usually acquired in the form of questionnaires and categorizations of continuous data. The characteristic that links the individuals being analyzed in the cohort is usually some significant life event that occurred in a given period, as, for example, a disease, employment, type of education, and year of birth. The purpose of the study is to identify the effects of changes in the dependent variable being analyzed, often separating the participants in two different groups, as the example in Figure 2.2 shows.

This type of study, when applied to chronic diseases such as cancer and diabetes, need a large number of participants to be followed for a long period to produce statistically meaningful results (COGGON; ROSE; BARKER, 2003). Since longitudinal cohort studies are strongly time-dependent, it is natural that individuals drop out for a variety of reasons. There is also the possibility that subjects respond with the most socially accept-

Figure 2.2: Cohort example with patients with GDM where the variable being analyzed is the intervention being applied to the groups.



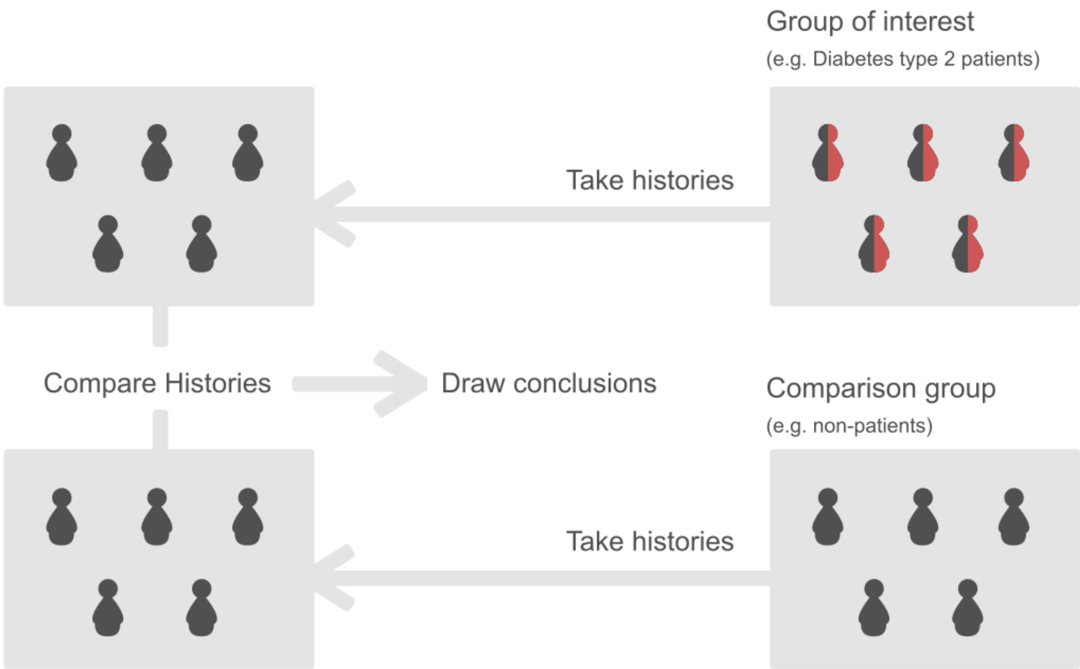
Source: adapted from SUNY Downstate

able answer instead of the truth. These facts generate incomplete or erroneous data that can cause misleading conclusions. Epidemiologists try to address these problems by improving the quality of data after collection and asking redundant questions to avoid false information (PREIM et al., 2016).

2.1.2 Case-Control Studies

Case-control studies investigate the cause of a disease after its occurrence by comparing the personal histories from patients with the disease already diagnosed and individuals without it, as seen in Figure 2.3. These two groups should be as similar as possible, except for their outcome on the disease being studied, to produce unbiased results. This type of study is cheaper to perform, especially when compared to a cohort study, as they are fast to produce results and do not need to follow the patient for an extended period. Nevertheless, the fact that the patient must self-report information from past events turns this type of research more prone to bias.

Figure 2.3: Case-control example where patients with diagnosed type 2 diabetes and non patients have their personal histories analyzed to determine what factors could have caused the disease.

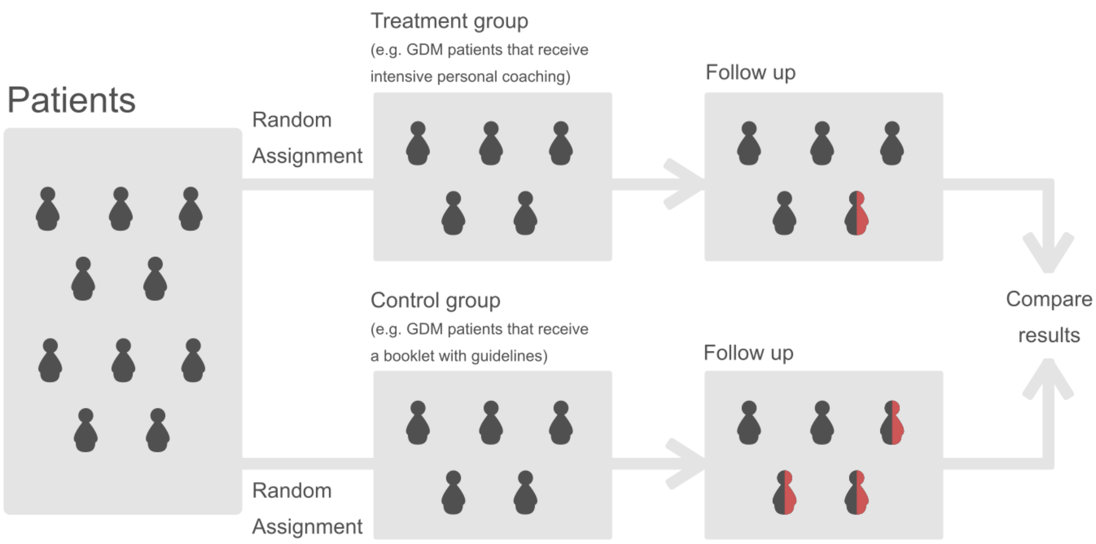


Source: adapted from SUNY Downstate

2.1.3 Clinical Trials

Clinical trials provide the most convincing evidence of the relationship between exposure and outcome since they can fulfill the criteria for causal inference (establishing a cause and effect relationship). In this type of trial, subjects are selected based on pre-specified criteria for their inclusion and exclusion. Then, subjects are randomized into different groups, shown in Figure 2.4, where each receives different types of therapy and are observed for a period of time. Clinical trials with control groups are called Randomized Controlled Trials. The control group receives the current standard treatment, while the intervention group receives the treatment being tested. The randomization plays an essential part in the reliability of these trials since they eliminate possible differences between the groups, thus removing bias.

Figure 2.4: Clinical trial example.



Source: adapted from SUNY Downstate

2.2 Diabetes Mellitus

Chronic Non-Communicable Diseases (NCDs), such as Diabetes Mellitus (DM), have been growing substantially over the years as the global population ages and is one of the main causes of deaths in most countries. As of 2017, approximately 451 million people live with DM across the world, and 374 million have glucose intolerance, which can lead to the development of the disease (CHO et al., 2018). 26 million of those diagnosed live in South and Central America, where a 64% increase in numbers are predicted for 2045. Brazil accounts for close half of that number as the fourth country in the world with the largest number of diabetics.

Diabetes Mellitus consists of a chronic condition that occurs when there are raised levels of glucose in the blood from the body's incapacity to produce enough or use effectively its insulin, an essential hormone that transports glucose from the bloodstream into the cells for energy conversion. The lack of insulin or its absorption causes Hyperglycaemia, i.e., high levels of blood glucose, which can lead to several life-threatening health complications (MAGLIANO; ZIMMET; SHAW, 2015). There are three main types of diabetes:

1. **Type 1 Diabetes:** an autoimmune reaction where the person's body attacks insulin-producing beta cells on the pancreas, leading to a shortage in insulin production. It can be triggered mostly by genetic susceptibility and environmental triggers.

2. **Type 2 Diabetes:** the most common type, defined by an inadequate production of insulin and insulin resistance strongly linked with obesity, aging, nutrition, and genetics. Around 50% of people with the disease remain undiagnosed throughout the world, possibly due to its symptoms not being acute and its asymptomatic phase lasting possibly many years (BEAGLEY et al., 2014).
3. **Gestational Diabetes (GDM):** hyperglycaemia that is first detected during pregnancy, usually during the second and third trimesters. This condition usually resolves once the pregnancy ends, but women that had this condition are at higher risk of developing Type 2 Diabetes within 5 to 10 years of delivery. It was projected that 21.3 million live births were affected by hyperglycaemia in pregnancy as of 2017 (CHO et al., 2018).

Even though the population aging has greatly affected the prevalence of Diabetes on a global scale, sedentary behaviors, lousy eating habits, and obesity are also responsible for the expansion of the disease (SCHMIDT et al., 2009). Data collected on a national survey with 12,423 individuals in Brazil indicated the association of age, education, marital status, obesity, sedentary lifestyle, demand for health services, comorbidity with hypertension and hypercholesterolemia with DM development (FLOR; CAMPOS, 2017).

2.3 Lifestyle INtervention for Diabetes prevention After pregnancy (LINDA-Brasil)

LINDA-Brasil is a multi-center randomized controlled trial study where pregnant women with Gestational Diabetes Mellitus (GDM) are recruited to analyze the effects of an intervention program to prevent Type 2 Diabetes (SCHMIDT et al., 2016). The study currently operates in 6 cities in Brazil: Fortaleza (CE), Rio de Janeiro (RJ), São Paulo (SP), Curitiba (PR), Porto Alegre (RS), and Pelotas (RS). Women must be aged 18 or older and have been identified as having recent GDM, using insulin during pregnancy, or presenting intermediate hyperglycemia postpartum. The trial started its recruitment and randomization in January 2015, and it is estimated that 740 women will participate, entering between 10 weeks during and 2 years after pregnancy. These women are to be randomized between conventional care and coach-based intervention, where habits such as breastfeeding, weight loss, healthy eating, and physical activity are encouraged and followed annually. The groups are defined as follows:

1. **Control Group:** Less intensive care where they receive a booklet about diabetes

prevention and guidelines with recommendations for breastfeeding, physical activity, and healthy eating.

2. **Intervention Group:** More intensive program that supports healthy behaviors that are usually linked to preventing diabetes. Women from this group receive personal coaching from the study by phone to prolong breastfeeding, control weight, adopt a healthy diet, and a proper amount of physical activity.

The study is based on lifestyle interventions and follows three stages. In the first stage, coaching activities aim at weight loss and healthy eating; the second is focused on increasing physical activity, and the third aims to maintain progress and monitor goals. These stages are conducted using motivational interviews, phone sessions, SMS texting, group sessions, and social activities. Phone sessions are the primary communication method, starting with three sessions of a weekly interval, then biweekly until weight goal is achieved, then monthly for about one year. Motivational interviews usually occur during the clinic visits, where other exams are also performed, and questionnaires are applied. The trial has currently randomized 460 women between control and intervention groups, which will be tracked for at least 18 months for a maximum of 5 years after childbirth or developing Type 2 DM.

2.3.1 Data Collected During the Trial

Throughout the duration of the clinical trial, standardized questions are asked to collect the participant's profile and address risk factors for Type 2 Diabetes, such as eating and drinking behaviors, physical activity, sedentary habits, quality of life, depressive symptoms, quality of sleep, and medication use. Physical exams are also performed periodically, including blood pressure, waist, hip and arm circumferences, and weight. For measuring the participant's physical activity, she uses an accelerometer on the waist for seven days, and a six-minute walking test is performed on a thread mill.

The study was partitioned in 12 different phases, roughly translated as Recruitment, Initial Calls, Follow-Up Calls, Call 2 and Schedule, Basal 1, Basal 2, 6-Months Visit, 1-Year Visit, 2-Years Visit, 3-Years Visit, 4-Years Visit, and 5-Years Visit. The study's current database only has data until the 4-Years Visit phase. In each phase, several questionnaires are applied and should be concluded on that stage, depicted in Figure 2.7. Many questionnaires are repeated throughout the trial, which can be used to perceive the progression of each participant. The summarized definition of data collected by each recurrent questionnaire, identified by its acronym, is listed below:

1. **RCP:** information before performing exams, used in the reception of patients.
2. **ANT:** anthropometry, i.e., body measures such as weight, blood pressure, the circumference of hip, waist, and arm.
3. **BIA:** body fat measurements.
4. **SAU:** overall health, including medication, contraceptive methods, and cigarette consumption.
5. **AFI:** physical activity (questions are based on the International Physical Activity Questionnaire (IPAQ) (BOOTH, 2000)). Time walking, doing strong and medium physical activity, and cycling. It also contains information on sedentary behavior.
6. **SON:** sleep quality, i.e., the number of hours slept, how long it takes until falling asleep, and the time they got into and out of bed. It also contains questions from The Pittsburgh Sleep Quality Index (PSQI) (BUYSSE CHARLES F. REYNOLDS; KUPFER, 1989) to measure sleep quality.
7. **RVD:** computer and internet access and usage.
8. **QVD:** quality of life, measured by the perception of health and mental state.
9. **HAB:** eating habits of past month, including the frequency of intake of certain foods.
10. **FBB:** information about the baby. Its weight and size, gestation type, and breastfeeding.
11. **ACE:** information from the use of the accelerometer device during a week, including the average number of steps, and active and inactive periods.
12. **DSO:** sleep diary, where naps, sleeping, and waking times are recorded.
13. **TCM:** thread mill run of 6 minutes, corresponding to the cardiac frequency, the distance traveled, and the Borg Scale of Perceived Exertion (BORG, 1982), used to measure the perceived physical exertion.
14. **EDG:** Edinburgh Postnatal Depression Scale (EPDS) (COX; HOLDEN; SAGOVSKY, 1987), subject's emotional state in the last 7 days.
15. **FOR:** results from tests of the isometric force of both hands.
16. **ALB:** baby's feeding habits, if they are still only breastfeeding, and the intake of other liquids.

17. **AAF:** abdominal height and flexibility measures.

The transition between phases varies between weeks and a year, also depending on the availability of the participant. The overall timeline is shown in Figure 2.5. Although most phases are only applied once per participant, the Follow-Up Calls phase is applied multiple times for the same subject at different times of the study.

LINDA's Primary Outcome is the incidence of Type 2 Diabetes that is verified with laboratory exams for both control and intervention groups. This outcome cannot be accessed until the end of the study for all subjects, since it could interfere with how the intervention is performed. Therefore, we did not include this variable in our visualizations. The study's Secondary Outcomes are summarized below, emphasizing the ones that are analyzed in this work, selected with the help of LINDA's specialists:

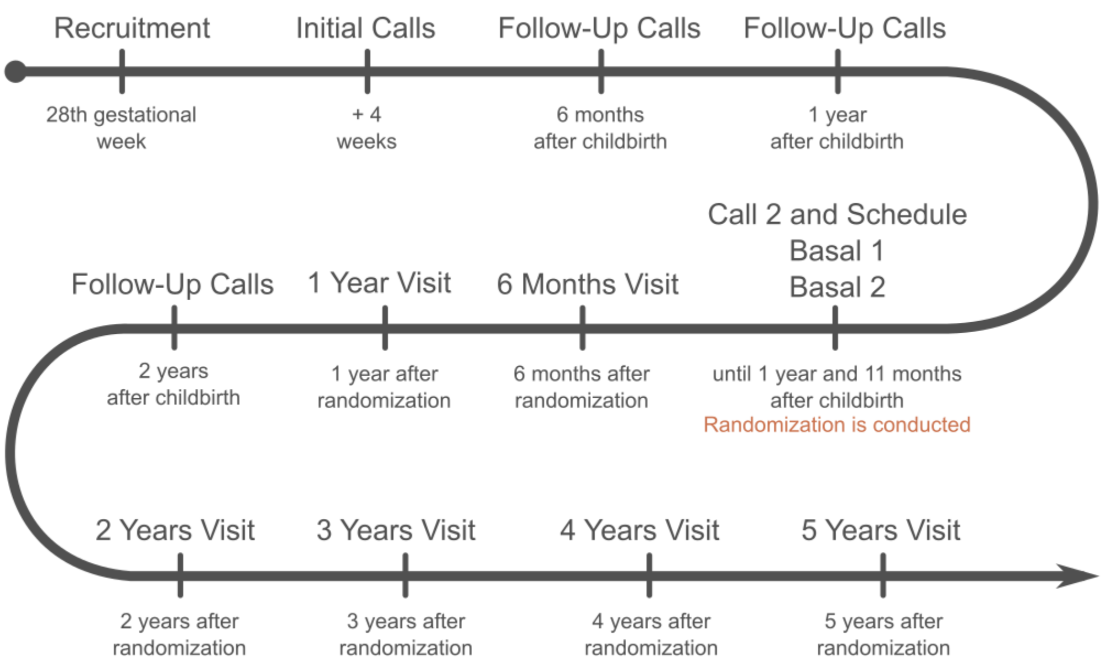
1. normalization of intermediate hyperglycemia
2. metabolic syndrome
3. mean insulin resistance
4. **mean weight loss and weight goal achievement**
5. **physical fitness**
6. **duration and rate of exclusive breastfeeding**
7. **quality of life**
8. **mean body fat (weight,** % body fat, **waist circumference, etc)**
9. **sleep quality**
10. perceived body image
11. **depressive symptoms**
12. infant growth
13. adverse events

2.3.2 LINDA-Brasil Database Structure

Participants' information from the LINDA-Brasil trial is stored in a PostgreSQL database where each questionnaire has its specific table and view [1]. Each view contains columns with the date the questionnaire was started, if it was finished or not, and the

[1]For preventing participants' outcomes from being known, we only had access to the available views as a security measure

Figure 2.5: Timeline of when each phase is expected to be presented to the participant. Dates are initially based on the gestational period of the subject until the randomization is performed, which is then used as a reference point for the next phases.



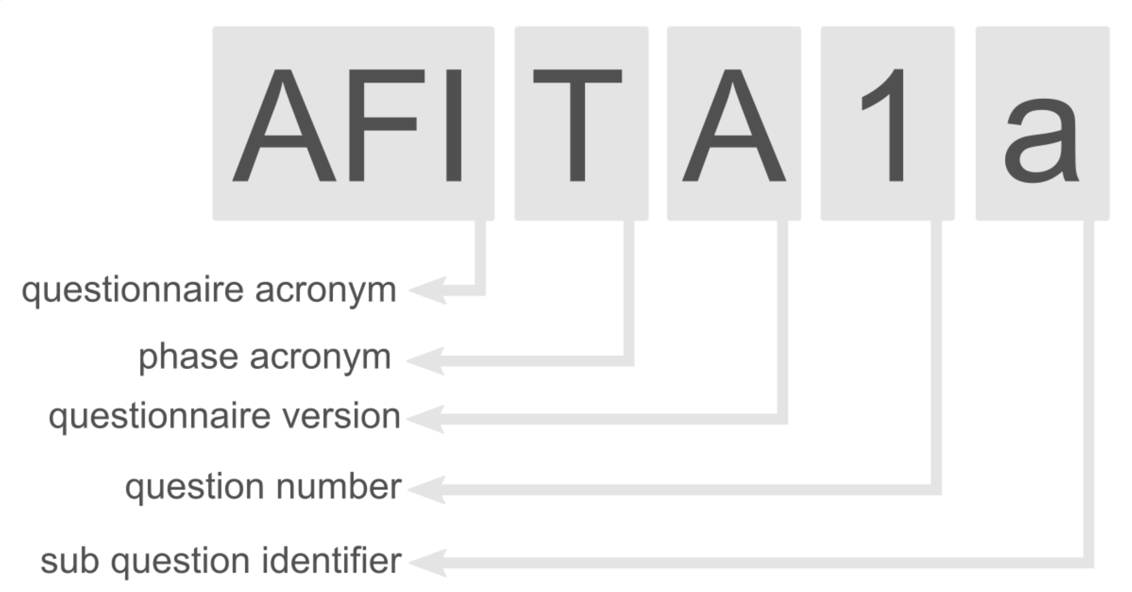
Source: Author

answers to all questions. Each questionnaire is identified with an acronym, and every question also receives a codification based on the questionnaire and position, as exemplified in Figure 2.6.

Even though the same questionnaires can be applied in different visits to the center, a different one exists for each phase on which it should be conducted (Figure 2.7). The questionnaire acronym then changes based on the phase it is assigned to, for example, the AFI questionnaire is named AFIU (AFI Um, as in 'one' in Portuguese) on the first-year visit, AFID (AFI Dois, as in 'two' in Portuguese) on the second-year visit, AFIT (AFI Três, as in 'three' in Portuguese) on the third-year visit, and so on.

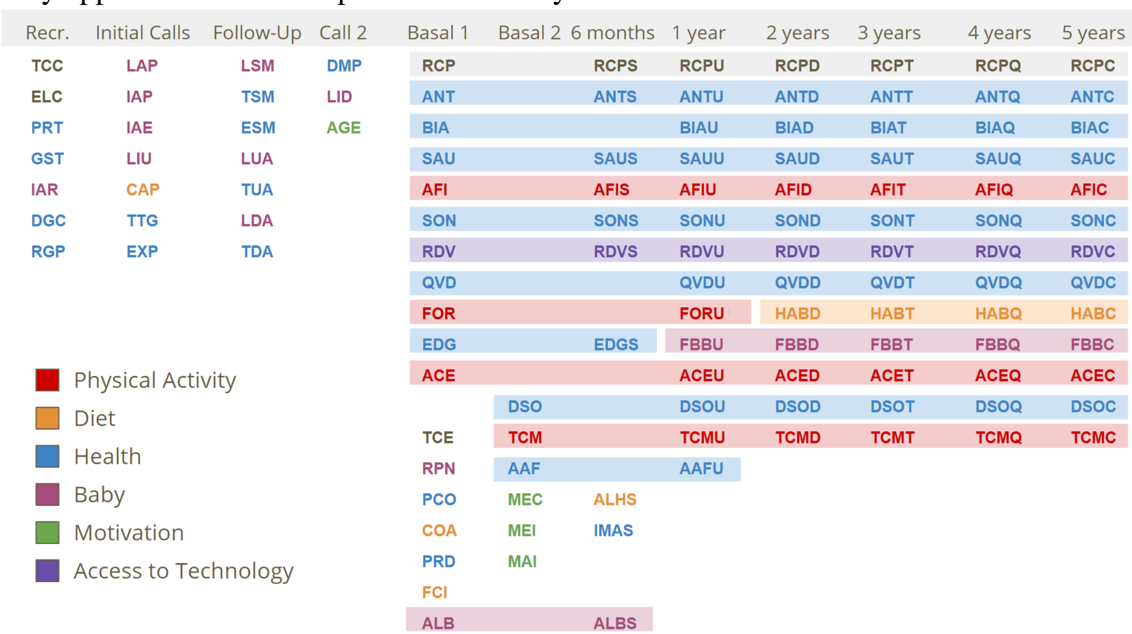
The variables collected for visualization were selected by their recurrence in different phases of the study and their importance to the outcome of the trial, and were selected based on requirements from the LINDA's researchers. The groups of recurrent data retrieved are briefly defined in Table 2.1 and further explored in Section 5.3.

Figure 2.6: Logic behind the naming of each question inside a questionnaire exemplified by a question from the physical activity questionnaire during 3 year Visit phase.



Source: Author

Figure 2.7: Phases of the study with their questionnaires. Each column represents a different phase, and each questionnaire acronym has been classified with a color that defines its variables' overall significance. Grouped acronyms are essentially the same, only applied at a different phase of the study.



Source: Author

Table 2.1: Summary of the temporal variables collected from participants

	Variables	Details	Surveys
Physical Activity	• Minutes/week walking/walking for locomotion • Minutes/week riding a bike for locomotion • Minutes/week of intense physical activities (running, gym) • Minutes/week of medium physical activities (swimming, sports for leisure)	Collected by asking the participant how many times per week and with what intensity she performs certain physical activities. Questions are based on Part 4 (Recreation, Sport and Leisure-time Physical Activity) of the International Physical Activity Questionnaire (IPAQ) (BOOTH, 2000)	AFI AFIS AFIU AFID AFIT AFIQ
Sedentary Behavior	• Minutes/week sitting down during the week/weekend • Minutes/week watching TV or other screens during the week/weekend • Minutes/week in front of a screen for work or studying during the week/weekend	Based on Part 5 (Time Spent Sitting) of IPAQ. According to IPAQ's scoring protocol, data from sitting should be presented as median values and interquartile ranges since there are still no well-accepted thresholds for data presented as categorical levels.	AFI AFIS AFIU AFID AFIT AFIQ
Thread mill	• Distance covered in meters • Initial and final time of the run (should always total 6 minutes of activity) • Cardiac Frequency • Final Borg Scale of Perceived Exertion	A thread mill test of around 6 minutes is performed. The Borg Scale of Perceived Exertion is a scale based on how much exertion a subject feels after physical activity. Participants rate their exertion between 6 (none) and 20 (very, very hard) (BORG, 1982).	TCM TCMS TCMU TCMD TCMT TCMQ

Continued on next page

Table 2.1 – *Continued from previous page*

	Variables	Details	Surveys
Accelerometer	• Average number of steps per day • Average physical activity per day • Average time inactive per day	Participants wear a belt on their chest for one week. The study considers a participant inactive with less than 5,000 steps a day, somewhat active between 5,000 and 7,500, active between 7,500 and 10,000 and very active with more than 10,000 steps a day. As for physical activity, the trial considers participants with no exercise to be inactive, participants with between 10 to 149 minutes/week to be somewhat active, and more than 150 minutes/week to be active.	ACE ACEU ACED ACET ACEQ
Weight	• Weight in kg • BMI (Body Mass Index)	The Body Mass Index is calculated using the reported height of the subject and the measurements of weight collected. Weight values are also collected on previous phases and can be seen on the Participant's Dashboard (Section 5.2).	ANT ANTS ANTU ANTD ANTT ANTQ
Blood Pressure	• Systolic blood pressure • Diastolic blood pressure	Systolic and Diastolic blood pressures are measured three times each, and only the last value is taken into consideration.	ANT ANTS ANTU ANTD ANTT ANTQ

Continued on next page

Table 2.1 – *Continued from previous page*

	Variables	Details	Surveys
Body Measures	• Waist circumference • Arm circumference • Hip circumference	The ratio between waist and hip measures is one the methods used to indicate obesity.	ANT ANTS ANTU ANTD ANTT ANTQ
Health and Quality of Life	• 36 quantitative variables with values between 1 to 5, 1 to 3 and 0 to 1.	The questions gather information about how the participant perceives her health, the participant's limitation in doing physical activities, and how the her physical and emotional health affected her life	QVD QVDS QVDU QVDD QVDT QVDQ
Eating Habits	• Frequency of bad eating habits: drinking soda, eating chocolate and adding sugar to coffee or tea • Frequency of good eating habits: eating vegetables and eating steamed vegetables	The eating habits collected were chosen by researchers because they better represent changes in a participant's nutrition.	HABD HABT HABQ
Quality of Sleep	• Time trying to sleep • Total sleep time • Time went to bed / got out of bed • Sleep problems (14 questions)	Values can be used to calculate a score using The Pittsburgh Sleep Quality Index (PSQI) (BUYSSE CHARLES F. REYNOLDS; KUPFER, 1989). The scale varies from 0 to 21, where values above 5 imply bad quality of sleep.	SON SONS SONU SOND SONT SONQ
Postnatal Depression	• Edinburgh Postnatal Depression Scale (EDPS) (COX; HOLDEN; SAGOVSKY, 1987)	A survey with questions about feelings of guilt, sleep disorders, levels of energy and suicidal thoughts that are used to calculate a score. This score can range between 0 and 30, where scores above 10 indicate signs of depression.	EDG EDGS

Continued on next page

Table 2.1 – *Continued from previous page*

	Variables	Details	Surveys
Breastfeeding	• If the baby is breastfeeding / only breastfeeding • The age the baby started taking other liquids	Even though breastfeeding data is also collected in questionnaires LAP, LSM, LUA, LIU and LID, only values from phases Basal 1 and 6 Months Visit are used.	ALB ALBS

3 RELATED WORK

The first visualizations devoted to showing medical information date back to 1858, when Florence Nightingale created a polar-area diagram to demonstrate the correlation between sanitary conditions and deaths of soldiers (NIGHTINGALE, 1858). Since then, many advances have been made on the field, mainly using standardized charts to indicate the need for intervention by medical professionals (WEST; BORLAND; HAMMOND, 2015).

In the '90s, Lifelines (PLAISANT et al., 1996) was another pioneer work, which used a timeline to depict events in a patient's life employing colors and lines. After that, many tools for analyzing medical data were created, where patient information was presented as a time series related to the same axis (BADE; SCHLECHTWEG; MIKSCH, 2004; BRODBECK; GASSER; DEGEN, 2005; RIND et al., 2011a; FAIOLA et al., 2012; FAIOLA; NEWLON, 2011).

In 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act promoted the adoption and meaningful use of health information technology, as well as addressed the privacy and security concerns of such information. This act caused various improvements in previous tools and the development of new ones, mostly interactive techniques that allow the user to explore data in one visual display (WEST; BORLAND; HAMMOND, 2013).

In this chapter, we describe previous works on the visualization of medical records and epidemiological data. For further reading, we recommend Rind et al. (RIND, 2013) and West et al. (WEST; BORLAND; HAMMOND, 2015) surveys on interactive visualization systems for electronic health records. From these surveys, we selected the most relevant works to this dissertation and added others, more recent ones, which will be further discussed in the next sections.

3.1 Time Series with Common Time Axis

Timelines are one of the most common visualization methods used to represent Electronic Health Records (EHR). Laboratory results and medical events (e.g., symptoms, doctor appointments, treatments) often occur periodically and can be more easily understood when temporally represented. In this section, we present some relevant works depicting time series in EHR.

3.1.1 Lifelines

Lifelines (PLAISANT et al., 1996) is a tool that provides a general visualization environment for personal histories such as medical and legal data. Medical conditions are displayed as individual timelines in a one-screen overview, where icons indicate events such as medical consultations and symptoms (Figure 3.1). Line color and thickness are used to illustrate relationships between events and their significance. There are also rescaling and filtering tools that allow for a more detailed view of the information. When there is too much data compressed on the overview page, the interface is simplified. The lines are drawn closer, labels are removed, or even all lines are clumped together. Also, unusually large records can be shown as a mere colored shadow of the record. The benefits of this tool include the reduced chances of missing information from using an overview method of data visualization, the spotting of anomalies, trends and patterns, the access to details on demand, and the acting as a navigation menu for the stored information.

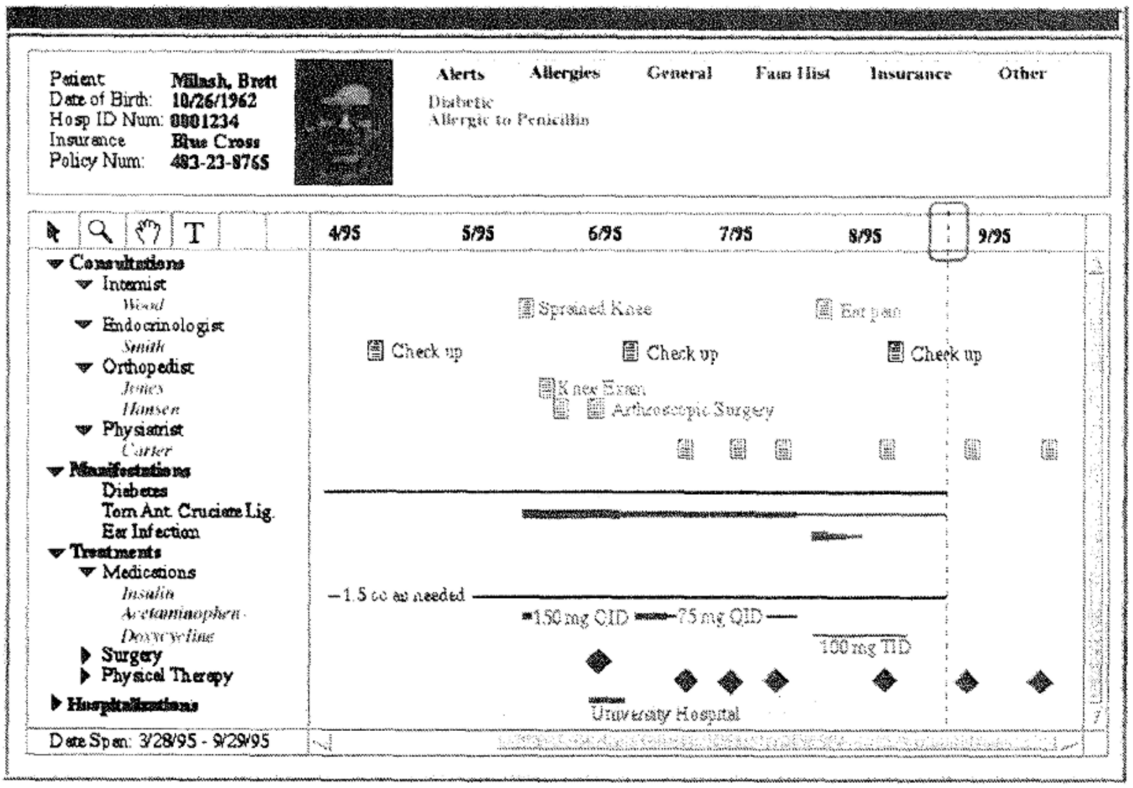
However, users can only see information from one patient at a time and, when there is a lot of data to be displayed, there is often overcrowding in certain regions of the interface while others remain empty. Users of the tool also reported possible bias from the color and thickness of the lines.

3.1.2 Lifelines2

Lifelines2 is an extension of Lifelines designed to display selected subsets of the records of multiple patients, while the original focused on displaying the entire history of a single person (WANG et al., 2008). The authors propose a prototype to visually explore multiple records of categorical temporal data, allowing for its alignment with sentinel events that are relevant to medical professionals. This alignment can be useful for comparing patient medical histories close to the event being analyzed, to discover trends and insights. In Figure 3.2, we can easily visualize the difference between analyzing a subject's record chronologically and by a relevant event. The result is an interactive visual tool that provides the alignment, filtering, and ranking of results while also being able to visualize estimates of validity intervals of the data. The tool can be useful for aiding observational research with existing data and patient recruitment during clinical trials, helping find subjects with particular medical histories.

However, the work only focuses on displaying patient events, needing manual con-

Figure 3.1: Lifelines interface, showing a medical record overview. The dashed vertical line marks the current time, so that markers placed after it indicate future scheduled events. A tree structure on the left works as an axis for the data displayed, separating the information between medical consultations, manifestation of diseases, treatments and hospitalizations.



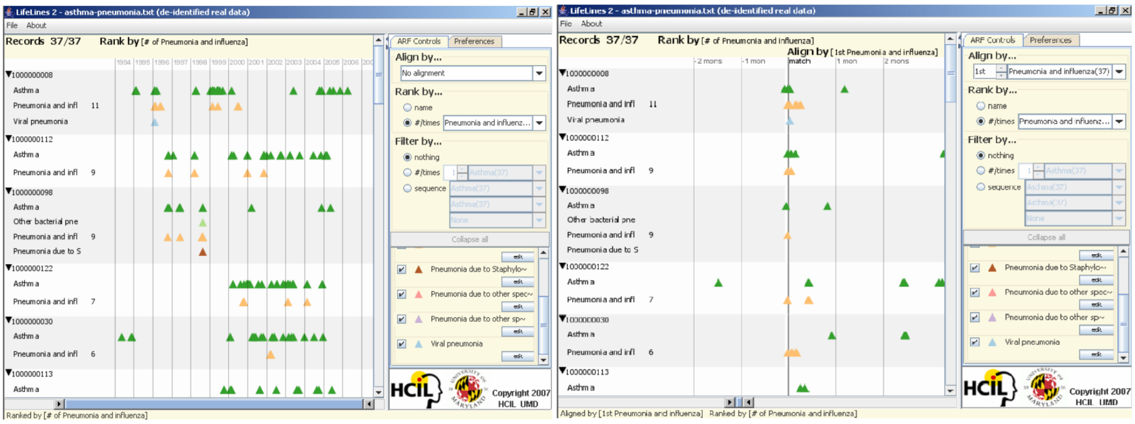
Source: (PLAISANT et al., 1996)

version to show metrics from medical exams, and other results. There were also problems with representing their duration since the size of the marker, or the line can be interpreted as the time span.

3.1.3 Medical Information Visualization Assistant (MIVA)

The Information Visualization Clinical Decision Support System (IV-CDSS), also known as Medical Information Visualization Assistant (MIVA) (FAIOLA et al., 2012; FAIOLA; NEWLON, 2011), utilizes separate plots that share the same axis to visualize numerical patient data over time. Each plot can be panned and zoomed and contains the numerical variable's normal range indicated by a gray band, facilitating the assessment of a value's meaning (Figure 3.3). On the right of the interface, the current value for each plot is emphasized and colored according to its positive or negative meaning, while also showing an overview of recent values. Some categorical data can also be presented by

Figure 3.2: Lifelines2 interface, where each row shows a different patient. Each triangle represents an event, showed chronologically and ranked by number of pneumonia and influenza events. On the left, markers are represented without alignment by event, shown in chronological order. On the right, all patient records are aligned by the first pneumonia and influenza marker.



Source: (WANG et al., 2008)

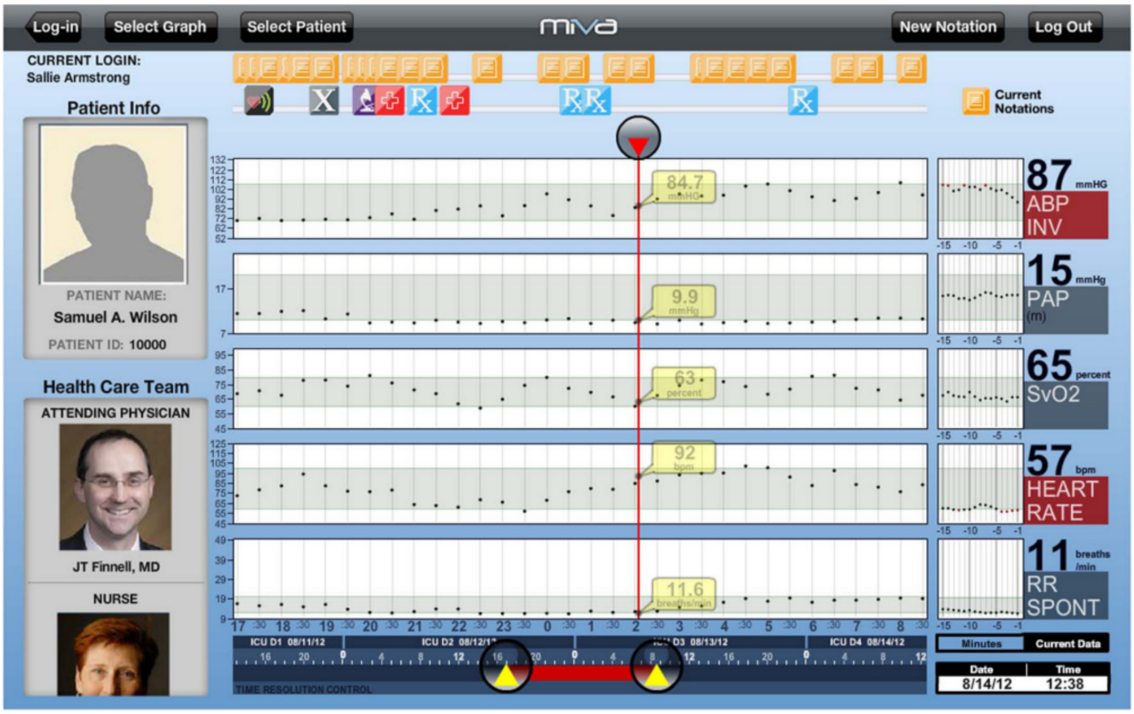
using icons to represent text notes and events in the timeline. On the bottom of the screen, a timeline is available for selecting the time period being viewed, which can be used to navigate the data and provide a method for zooming on specific parts of the dataset.

Although MIVA's interface can be a simple solution for plotting multiple numerical data, it can only visualize one patient at a time and is limited when representing categorical information. Is also does not provide any intuitive means of finding patients by their medical histories.

3.1.4 VisuExplore

VisuExplore (RIND et al., 2011a) is a design study of information visualization methods for medical data. The focus of the study is a Diabetes outpatient clinic, where patients are examined at the clinic at scheduled intervals, and several quantitative and nominal data are collected. This data is then plotted using different well-established visualization techniques, including line charts, bar charts, event charts, and timeline charts (Figure 3.4). All variables are drawn in different rows and share the same time axis. New rows can be added on demand by the user, which can select different types of visualizations for the same data. Users can also interact with the visualization in several ways, including changing the position of each row, panning and zooming on the timeline and measuring the time between events, and showing tool-tips for each entry. It is also possible to use a tool for measuring the time interval between different data entries, which can

Figure 3.3: Screenshot of MIVA's user interface, consisting of a timeline with multiple plots sharing the same temporal axis. Each row shows a different intensive care data, where a grey area in the background indicates the normal range of values. On the right, labels show the current status of the patient and its most recent history for the variable. On the top, icons show clinical text notes and events.



Source: (FAIOLA; NEWLON, 2011)

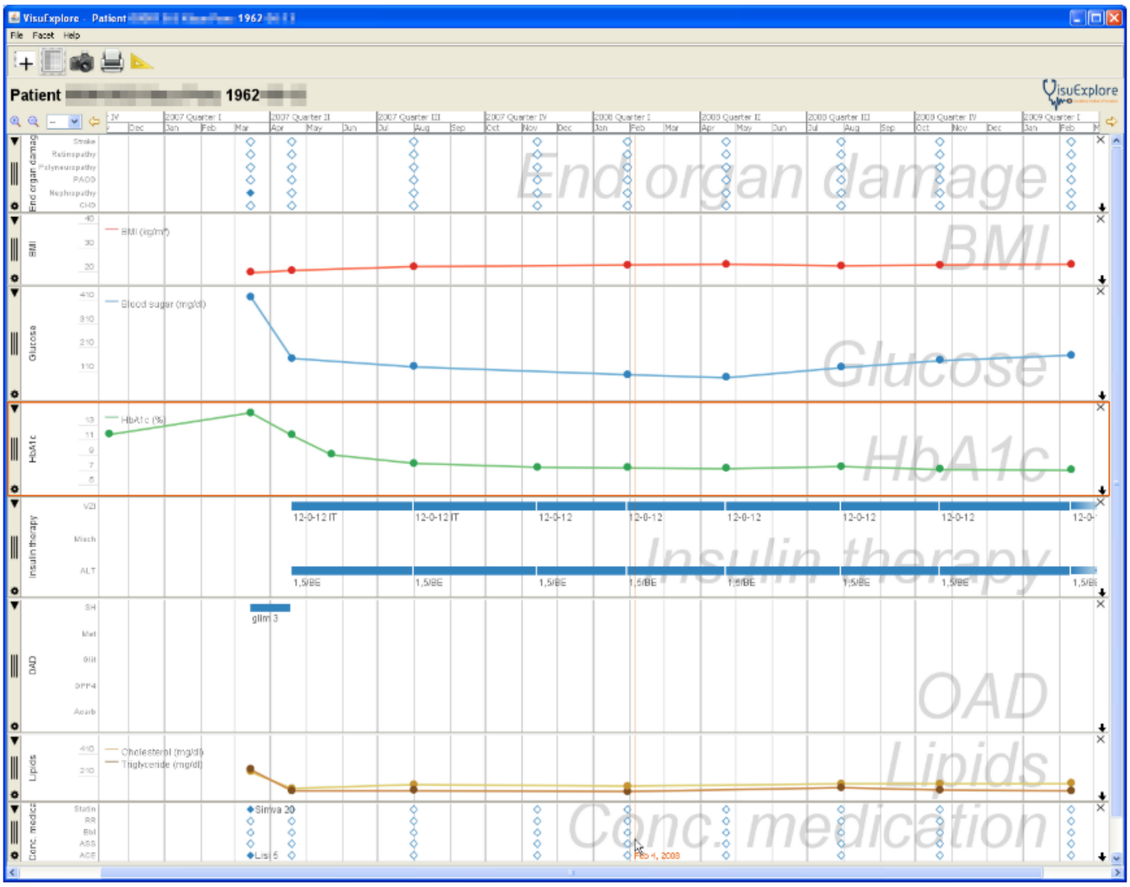
be useful when analyzing treatment outcomes and correlations between laboratory data.

Even though the tool provides an easy-to-learn and intuitive overview of complex data, it is not capable of comparing multiple patients. Most users also criticized the zooming and panning feature, because the function fails to zoom in the selected item, zooming in the middle of the time axis.

3.2 Dashboards

Dashboards are one of the most used approaches of data visualization in healthcare (WU et al., 2019). Patient information often needs to be quickly accessed during medical appointments and emergencies, where a dashboard can be a powerful tool for providing an overview of all relevant information. In this section, we review some relevant medical dashboards found in the literature.

Figure 3.4: Screenshot of VisuExplore's user interface. Variables are displayed in multiple rows using different visualization techniques, sharing the same time axis.



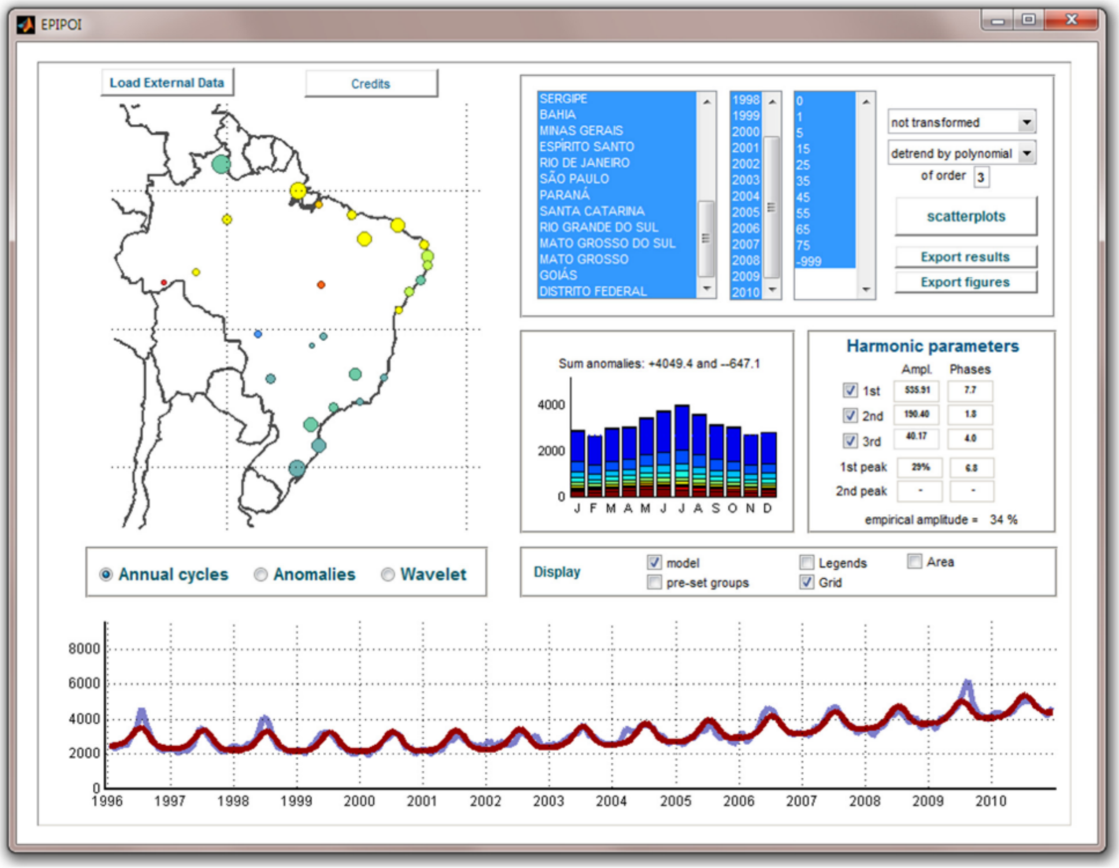
Source: (RIND et al., 2011a)

3.2.1 EPIPOI

EPIPOI (ALONSO; MCCORMICK, 2012) is a freely available tool created in Matlab that presents a user-friendly comparative analytical tool for creating visualizations of epidemiological time-series data. It focuses on the exploration and extraction of parameters for describing trends and anomalies, combining several specialist tasks into a single interface and offering insights by the comparison of time series. The time series (Figure 3.5) is described in three components: *trend*, that checks for long term patterns of diseases, e.g., if their incidence is increasing or decreasing through long periods of time; *seasonality*, that checks for seasonal recurrences of diseases that could be caused by environmental factors or associated behaviors; and *anomalies*, which checks for abrupt changes in expected patterns possibly caused by a severe epidemic.

Even though the tool provides interesting features, it still has several imposed limitations, since time-series data must be entered using a spreadsheet with no data gaps and sorted in ascending chronological order. Additional variables correlating to the time series, such as geographical information and any additional categorization, must be loaded using separate files. Furthermore, the tool does not provide all the relevant analytical features that would be needed to keep it as user-friendly as possible.

Figure 3.5: Screenshot of EPIPOI's user interface showing dataset for influenza and pneumonia mortality data in Brazil. In the map, circle sizes show the number of causalities, and their color shows the timing of peaks of the seasonal signal. In the timeline on the bottom of the interface, the blue line represents raw data, and the red line indicates the model trend and seasonality. The central histogram shows the average mortality for each month of the year.



Source: (ALONSO; MCCORMICK, 2012)

3.2.2 PatientExploreR

PatientExploreR (GLICKSBERG et al., 2019) produces interactive and dynamic patient dashboards from cohorts generated by user queries using clinical concepts. It is capable of creating visualizations for a common format of EHR data using 5 main components: (1) a login and landing page for secure authentication that can be maintained by institutions or individual groups, (2) a patient finder tool that queries EHR vocabulary with logical operators to identify patients, (3) an overall patient report of their full clinical history data and background, (4) an interactive timeline where users can visualize the distribution of clinical encounters and (5) a data explorer feature where users can explore categorical and numeric data in a number of different plots.

However, the tool possesses a few drawbacks, including only being possible to visualize data from a single patient and that users must be familiarized with EHR concepts to make effective use of the tool.

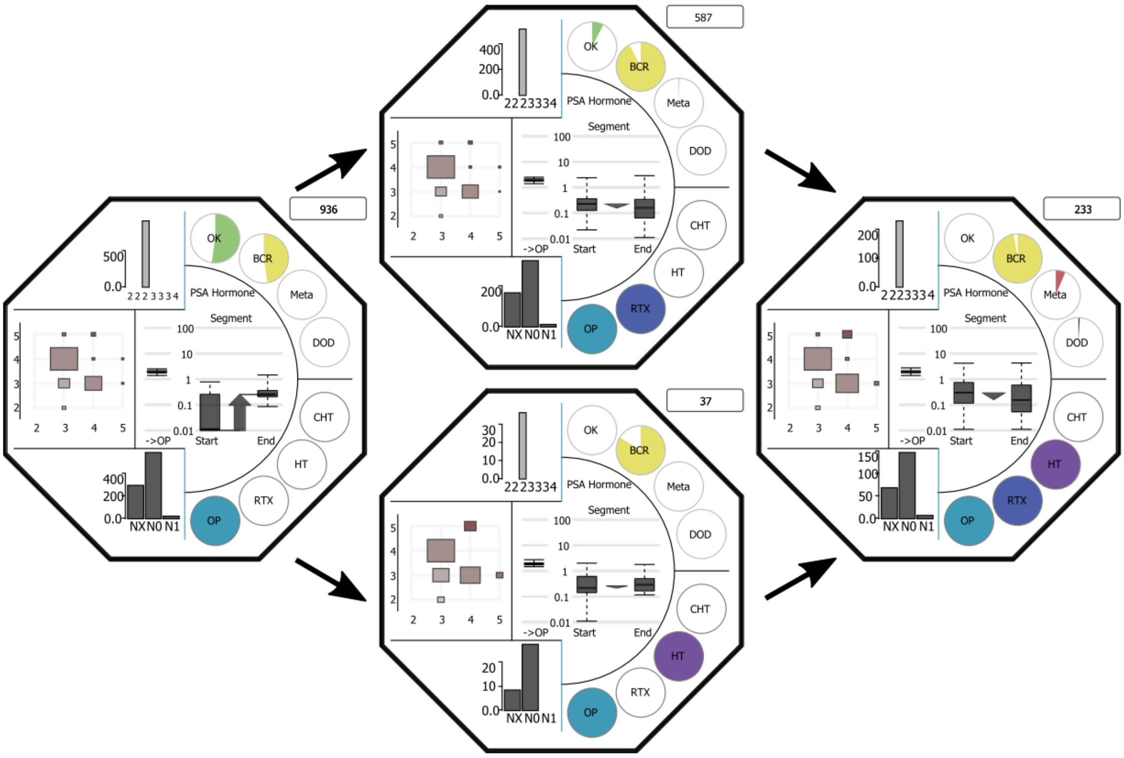
3.2.3 Using dashboard networks to visualize multiple patient histories

Bernard et al. (BERNARD et al., 2019) presents a compact static dashboard for the visualization of aggregated patient histories represented by a series of symbols and plots. The work was a collaboration with the Department of Prostate Cancer at the Universitätsklinikum Hamburg-Eppendorf (UKE), where several thousands of prostate cancer patients are accompanied during their treatment. The clinic gathers their demographic data, blood and histological samples, clinical data, and surveys to improve the quality of care. The tool focuses on a visual comparison of histories from different patient cohorts (Figure 3.6), creating an overview focused on strategic planning for health professionals since it presents longitudinal patterns of disease progression and comparison of cohorts.

The generated dashboard with four different chart types (pie charts, bar charts, box plots, and a heat map) was based on numerous interviews with medical professionals. These dashboards are considered as an aggregation of segments from multiple patients, where each can represent a different combination of treatments. Color in the visualizations can represent a distinctive variable displayed or depict the intensity of measures shown.

The design brings some limitations for its static nature and scalability issues when presenting more diverse cohorts. The dashboards can only be compared visually, lacking methods to highlight changes. Since each dashboard presents distinct variables simultaneously, comparing each for every cohort being analyzed is not a trivial task. Also, the design is limited in its scalability as the number of patients and different treatments increases, especially when users must compare each variant.

Figure 3.6: Comparison between cohorts of prostate cancer patients using static dashboards proposed by Bernard et al. (BERNARD et al., 2019). Patients progression after procedures and medication use is analyzed by comparing changes in the generated dashboards. The number on the top right indicates the number of patients in each.



Source: (BERNARD et al., 2019)

3.2.4 IDMVis

IDMVis (ZHANG; CHANANA; DUNNE, 2019) is an open-source browser-based interactive visualization tool that helps clinicians perform temporal inference tasks on type 1 diabetes patient data. Health professionals are able to interpret blood glucose measurements based on other relevant patient data such as diet, exercise and overall behavior. Data shown in the visualizations are integrated by multiple sources into a central database. The tool is encapsulated in a single view application with no scrolling, avoiding occlusion of information.

The interface is based on Shneiderman's user interface guideline (SHNEIDERMAN, 1996), showing a 14-day timeline overview, a detail view of a single day and a summary statistics view (Figure 3.7). The overview timeline is separated in days in order to identify trends in the blood glucose levels, which are commonly associated to day-to-day patterns. Data shown in this view is color coded based on range categories for glucose levels and its axis can be modified to align with a single or multiple temporal events such as the time a patient had breakfast or dinner. Alternatively, events can also be featured by mouse-over, which triggers the highlight of all similar events. When selecting a day from the overview, the single day detailed view shows the selected day with additional readings information. Finally, a statistics summary panel is also available, presenting events by their insulin and carbohydrate intake using quartile-labeled violin plots. The two top visualizations show the distribution of basal and bolus insulin. The events shown on the other plots show the distribution of insulin values (middle) and carbohydrate intake (bottom) for meal times and bedtime events that are also marked in the overview visualization. These plots help clinicians make treatment decisions based on the variability of insulin and carbohydrates eaten across meals.

The system has limitations on the number of variables that can be shown on the timeline, as well as not including a substantial part of clinician work by only covering tasks relevant to data analysis. The tool is also focused on the comparison of events which can be hard to discern since they are represented by the same identical token, which was noted as a drawback by clinicians evaluating the tool. The unfamiliarity with violin plots can also be a problem when considering users with little previous knowledge on more complex visualizations.

Figure 3.7: Screenshot of IDMVis's user interface. (A) 14-day timeline overview (B) Detailed view of a single day (C) Summary statistics panel.

Source: (ZHANG; CHANANA; DUNNE, 2019)

3.3 Similarities Between Patients

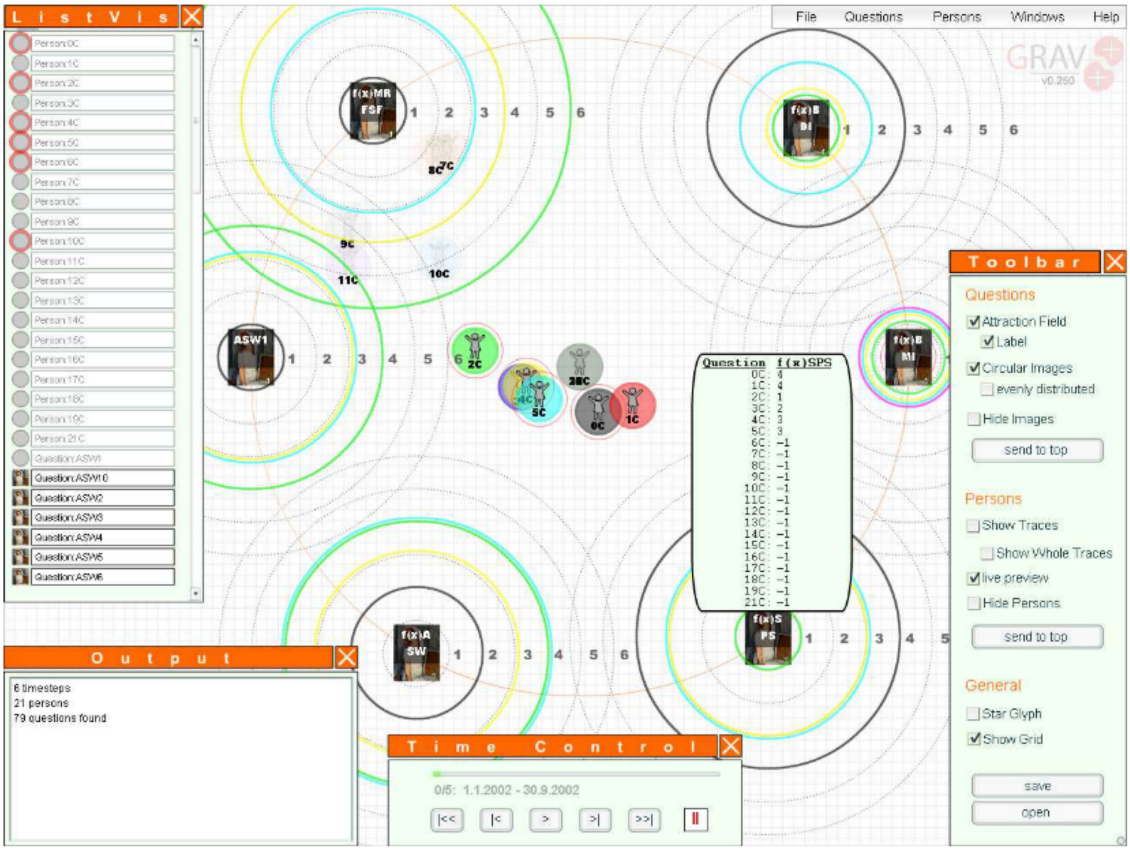
Characterizing and understanding similarity is instrumental in helping clinicians regarding their treatment decisions (SHNEIDERMAN; PLAISANT; HESSE, 2013). Patient information is often assessed individually or by manual comparison of multiple patients by specialists, which can be a time-consuming task when searching for people with similar medical histories. The ability to find such similarities can aid in comparing treatments and their results to be applied to patients with a comparable history. In this section, we describe works that focus on finding similarities between a cohort of patients' medical histories using information visualization tools.

3.3.1 Gravi++

Gravi++ (HINUM et al., 2005) is an interactive visual clustering information visualization method to support a psycho-therapeutic study on anorexic girls from the Department of Child and Adolescent Neuropsychiatry, Medical University of Vienna. The study deals with time-oriented, high-dimensional data where patients, their parents, and therapists must answer an extensive set of questionnaires. The visualization consists of icons representing the patients on the center and questions positioned around them (Figure 3.8). The position of each patient is based on the answers to each question shown, being placed closer to questions where the answer had a higher value. The size of the icon can also be related to an additional parameter. Changes over time are represented by animation or traces for each timestep. These methods can help find predictors to whether a treatment path has been successful by allowing specialists to analyze differences between questionnaire answers from all timesteps. Traces that are not a favourable outcome in the therapy are color coded in red, while traces with positive therapy progress are marked in green. Any missing value is represented by altering the color and opacity of the patient's icon, but such incomplete data can still cause problems when defining a subject's positioning.

The tool is limited to a restricted selection of different questions and patients since the influence of each question is difficult to be perceived as the number of variables increases, and person icons tend to overlap easily. With a large number of individuals plotted, values of the rings surrounding each question would be indistinguishable as values would be drawn next to each other.

Figure 3.8: Gravi++ screenshot. Patients are represented by the icons on the center, and questions are positioned around them. The circles around each question show the value of each patient's answer

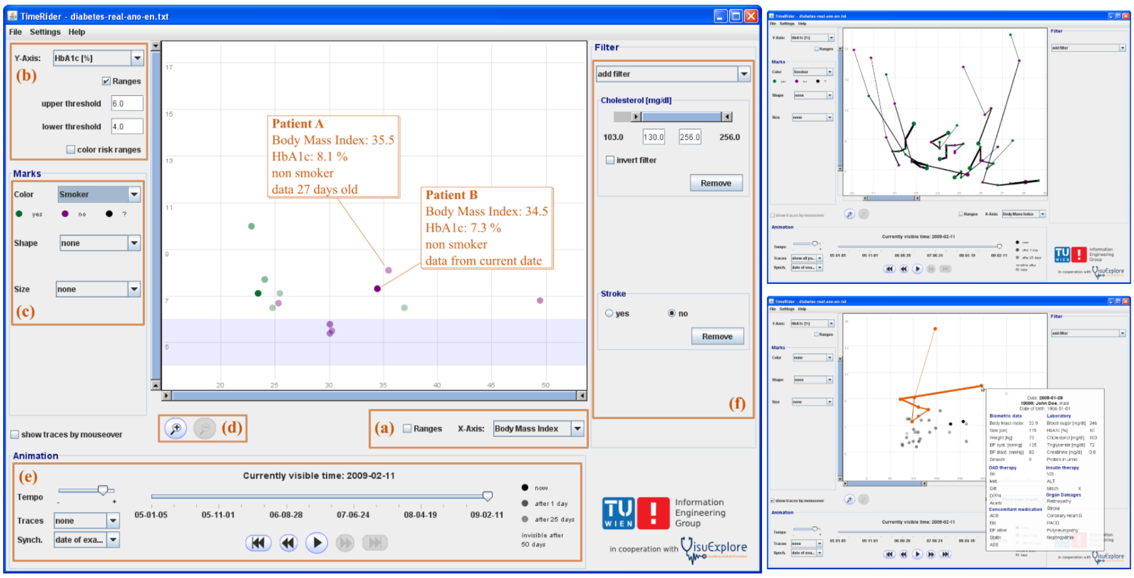


Source: (HINUM et al., 2005)

3.3.2 TimeRider

TimeRider (RIND et al., 2011b) is a visualization tool created to help the exploration and analysis of data from a diabetes outpatient clinic. It displays trends in patient cohorts using an animated scatterplot, where each axis represents a categorical or numeric variable (Figure 3.9). Other values can also be assigned to color, shape, and size of points. Changes through time can be shown with animations or tracing past values on the plot. The latter creates a line connecting all points representing the same patient through time instead of gradually presenting data through animation. This solution allows for an overview of patient history.

Figure 3.9: TimeRider screenshots. Each point represents a patient according to selected variables. On the bottom of the screen, users can control which moment in time the data represents and play it as an animation. The screenshot on the top right shows temporal information by tracing patient information and connecting it in a line. Each line can be highlighted and show a pop-up with complete information about the patient, as seen on the bottom-right screenshot.



Source: (RIND et al., 2011b)

Even though the tool plots a limited number of variables at a time, the position of each entry can be understood by users since it is directly related to variable values. The tool also has some limitations, including complex navigation and control/usability problems such as the filtering interface. TimerRider's tracing strategy was also proven to be challenging to analyze, especially when points overlap in the plot.

3.3.3 Lineage

Lineage (NOBRE et al., 2019) is an open-source visual analysis tool tailored for the study of complex diseases by comparing genealogical similarities. The tool creates a genealogy view where families can be visualized using a tree-like structure, while attributes from each individual or branch of individuals is shown in the attribute table on the right, based on a linearization method applied to the tree structure (Figure 3.10).

The genealogy view follows traditional geographical graph layouts, presenting males as squares and females as circles and crossing out deceased individuals. However, nodes are not plotted by generation, instead being positioned by birth year. A phenotype of interest can be defined dynamically, which is used in the aggregation algorithm when creating the linear layout. Each node of interest will be represented by a row in the attribute table, while its aggregate branches will be shown in an aggregated row.

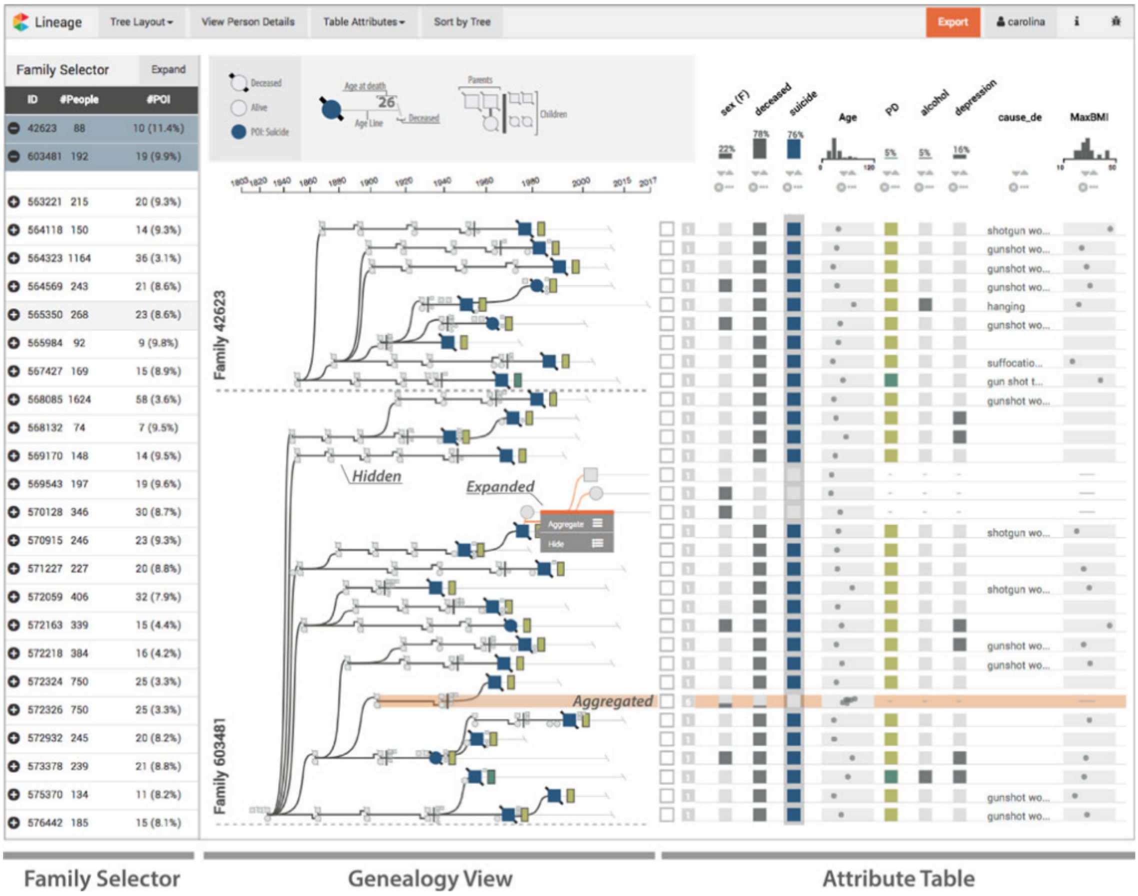
The table visualization was designed to show both single individuals and aggregates with multiple subjects. Attributes shown can be selected by the user, where numerical, categorical and multivalued categories are shown in different representations. Color coding is avoided in order to enable its use for highlighting elements.

The tool has a few limitations, especially regarding the use of the genealogy tree. Aside from performance issues when visualizing more than thousands of individuals, families with offspring from multiple partners can have their association lost. The attribute table also has a few drawbacks in its representation, not facilitating the discrimination between viewing different numbers of individuals in each row and removing direct associations with the tree when a row aggregates a group of subjects. The system also lacks export capabilities and search features for individuals or families.

3.4 Cohort Comparison and Analysis

Besides similarities between patients, another relevant topic in medical research is the comparison of cohorts to characterize differences between groups of patients (SHNEIDERMAN; PLAISANT; HESSE, 2013). Clinical trials and other epidemiological researches often need to compare between control and intervention groups of subjects, making use of software that provides analysis and comparison between these cohorts. In this section, we describe tools that focus on this comparison.

Figure 3.10: Lineage screenshot. Families can be selected from the family selector list on the left. Each selected family has its family tree plotted on the genealogy view. On the right, attributes from these individuals are shown in the attribute table.

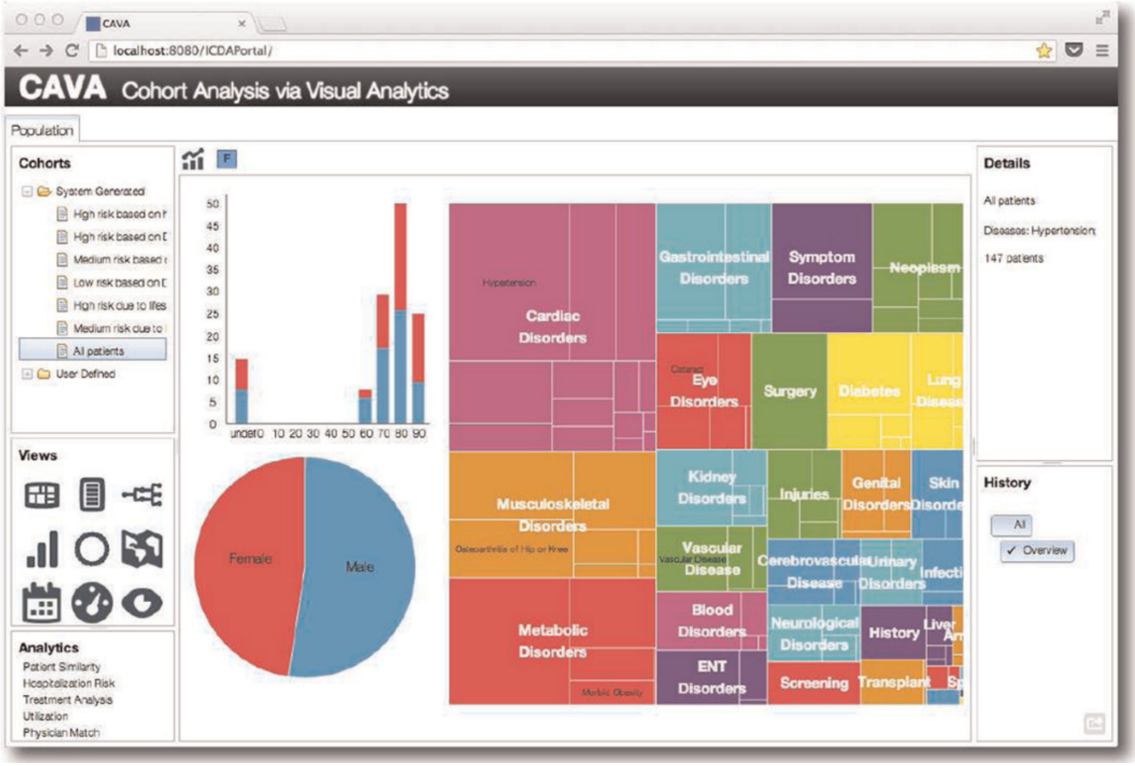


Source: (NOBRE et al., 2019)

3.4.1 CAVA - Cohort Analysis via Visual Analytics

Cohort Analysis via Visual Analytics (CAVA) (ZHANG; GOTZ; PERER, 2015) is a web-based platform that provides for the iterative analysis of user-refined cohorts using interchangeable, flexible visualization methods for large population-oriented datasets. It is centered around three primary types of artifacts: *cohorts* (set of people and their properties), *views* (interactive visualization components), and *analytics* (computational elements to enhance the cohort). A collection of multiple cohorts is stored, and groups of people are separated depending on their characteristics. Both *views* and *analytics* are functional components that generate an output cohort based on a previous one. The analytic component can add or remove members of a particular cohort based on their attributes or use them to alter or create new measures. The calculations performed are separated into interactive, when they block user interaction while calculating, used for fast calculations, and batch, where calculations are performed in background, while the user analyzes other

Figure 3.11: CAVA screenshot showing a cohort overview with age, gender and diagnostic distributions.



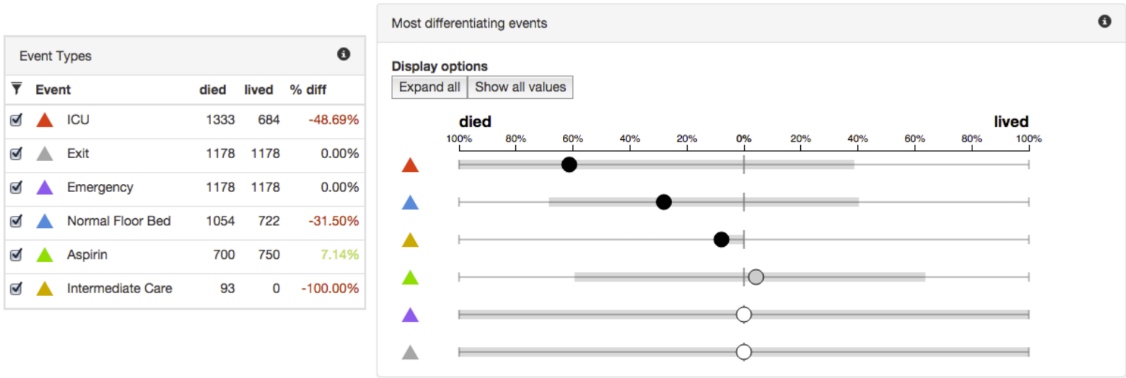
Source: (ZHANG; GOTZ; PERER, 2015)

data. While the analytic component uses computations to alter and filter entries, the viewing component relies on user interactions to modify the cohort. The generated cohort can be exported at any moment. These components have many different implementations depending on the current use-case, separated by different plug-ins that can be deployed. While the tool allows for a meaningful overview of cohorts, it still shows a limited amount of unstructured patient detail.

3.4.2 Cohort Comparison (CoCo)

Cohort Comparison (CoCo) (MALIK et al., 2014) is a visual analytics tool for comparing cohorts of event sequences that balances automated statistics with user-driven analysis to guide users to significant, distinguishing features between cohorts. It consists of a number of rows displaying the value of each metric or sequence of events being analyzed for each cohort, comparing the difference between the two values, as shown in Figure 3.12. A circle marker shows the difference between the values in the direction of whichever is the highest metric. The significance of the result defines the color of the

Figure 3.12: CoCo visualization. Each triangle represents one event and each row shows the prevalence of the event in the "died" and "lived" cohorts.



Source: (MALIK et al., 2014)

circle.

Its primary benefits include a better collaboration among colleagues, meaningful outcomes presentations, and an easy way of discussing intermediate results. However, the tool lacks in providing a clear overview and visualization of the actual data, mainly focusing on the analytical analysis and comparison between cohorts.

3.5 Discussion

In this section, we discuss similarities and differences between the works found in the literature. We also point out how our work compares to the discussed ones. We present three tables based on the ones shown in the survey by Rind et al. (RIND, 2013) to create an overview of the discussed works. The table only includes works discussed in this chapter, some of them surveyed by Rind et al. The recent works we found were added to the table and are marked in bold. Table 3.1 shows a summary of all works presented in this chapter regarding their ability to display categorical and numeric data, the number of variables per view, and whether the tool shows a single or multiple patients. Table 3.2 shows the type of medical data being displayed, whether it is from tests, diagnoses, or treatments of patients. Table 3.3 describes user intent features and interaction in all works reviewed herein. It includes information on the selection, exploration, reconfiguration, encoding, abstraction/elaboration, filtering, and connection between patients.

Lifelines, Lifelines2, MIVA, IDMVis and VisuExplore are some of the works that focus on timelines relative to a single time axis for the display of medical data. These systems present information in a temporal manner, but usually lack an overview of patient information besides the data shown in the timeline. Our work also creates a timeline with variables collected periodically. However, since the clinical trial on which our work is focused on is based on six phases, the generated timeline is considerably smaller, in terms of events, than in other works. Moreover, the timeline is also not the focus of our interface, which encouraged us to create smaller compact plots with denser information than those used in other systems described in the literature. The majority of works featuring timelines show information from a single patient or group data, to create a single line. Our work, on the other hand, creates multiple lines for each selected participant, facilitating the comparison of a handful of patients simultaneously.

Table 3.1: Summary of 12 systems, adapted from Rind et al. (RIND, 2013). Systems not present in Rind's version of the table are marked in bold.

		Categorical data	Numerical data	No. of variables per screen	One patient	Multiple patients
single EHR	Lifelines	●	○	~25	●	
	MIVA	○	●	~5	●	
	VisuExplore	●	●	~10	●	
	PatientExploreR	●	●	~6	●	
	IDMVis	●	●	~17	●	
EHR Collection	Lifelines2	●		~10		●
	Gravi++	●	○	~6		●
	TimeRider	○	●	2-5		●
	Lineage	●	●	20-40		●
	EPIPOI	●	●	~9		●
	Bernard et al.	●	●	~16	●	●
	CAVA	●		~27		●
	CoCo	●		~8		●
	Our Work	●	●	~90	●	●

●: full support, ○: partial support, “ ”: no support.

Dashboards are one of the most common methods of presenting information from a single patient or a cohort overview. EPIPOI, IDMVis, PatientExpoloreR and Bernard et al.'s work focus on such display. Although these works may contain timelines, the visualizations are simpler than others found in works displaying timelines, mainly showing simplified trends from a single variable while depicting other important factors in auxiliary visualizations. The majority of these tools utilize dashboards as their main view, needing to provide means of filtering, comparison, and analysis of data in a single interface. On the other hand, our work uses a simple dashboard for the visualization of a single participant, only focusing on the display of very specific data that is relevant to the clinical trial. Other important features for medical researchers are provided in another section of the tool, easily accessible at any time.

Another relevant method of analyzing a dataset of patients' information is by discovering similarities between their medical histories. Works such as Gravi++ and TimeRider show patients as points in a plot based on variables chosen by the user. The proximity between points indicates patients with a similar medical history for the analyzed parameters. Our work also provides this feature, using Dimensionality Reduction (DR) methods with variables chosen by users to create a scatterplot of the clinical trial's participants. DR techniques are important methods for analysing high dimensional data, generating simplified versions of a dataset while maintaining its characteristics (CUNNINGHAM; GHAHRAMANI, 2015). Similarly to these tools, our work can set variables to be color-coded and to watch their progression through time by the use of animations. While TimeRider plots a single variable for each axis, DR techniques, such as Principal Component Analysis (PCA) (HOTELLING, 1933), can create graphs with an unlimited number of variables while still maintaining their relevant features. Gravi++, on the other hand, uses a spring-based method for arranging the points, placing patients (the points) closer to variables where they have high scores. This method works similarly to DR solutions while also providing more meaning to the scatterplot's axes. However, as the number of variables grows, the forces influencing the position of points increasingly overlap the representation zones of other variables. Compared to other DR techniques, Gravi++'s tokens also tend to clutter the screen, while our work maintains a stable relationship between distance and data similarities, allowing a more intuitive understanding when scaling to a high number of variables. Lineage also relates to the comparison of subjects, but using very different techniques compared to what we provided in our work. One common strategy, though, was using histograms to overview variables and showing an individual's position inside it as a visualization of its value.

Table 3.2: Medical information types and medical scenarios that have been demonstrated on 12 systems, adapted from Rind et al. (RIND, 2013). Systems not present in Rind's version of the table are marked in bold.

		Tests	Diagnoses	Treatment	Details
single EHR	Lifelines	●	●	●	Events and intervals for diverse medical information
	MIVA	●		●	Tests and treatments recorded in intensive care
	VisuExplore	●	●	●	Tests, concomitant diseases, and treatments in chronic disease care
	PatientExploreR	●	●		Clinical indicators, clinical encounters, disease diagnoses and lab values in OMOP format
	IDMVis	●	○		Diet, behavior and blood glucose measurements
EHR Collection	Lifelines2	●	●	●	Test, diagnoses, and treatment events. Numerical test events needs to be first converted to categories.
	Gravi++	●	○	○	Questions and indicators in cognitive behavior therapy
	TimeRider	●	○	○	Tests, concomitant diseases, and treatments in cohorts of long-term diabetes patients.
	Lineage	●	●		Genetic information and disease diagnoses
	EPIPOI		●		Epidemiological information on disease diagnosis through time
	Bernard et al.	●	●	●	Post-operative prostate cancer patients' attributes
	CAVA		●		Male hypertensive patients between 60 and 80 years of age
	CoCo		●	●	Records from patients admitted to the emergency room
	Our Work	●	○		Surveys, indicators, diagnoses for GDM patients with DM type 2 risk

●: full support, ○: partial support, " ": no support.

The comparison between groups of patients is a relevant feature when analysing epidemiological studies and large databases of medical data. CAVA and CoCo provide the analysis of user-refined cohorts using visualization and analytic methods. In this aspect, CoCo shows a straightforward comparison of cohorts for a single metric, i.e., the number of patients that lived or died from each hospital admission type, or treatment used. Alternatively, CAVA shows an overview analysis of a cohort of patients, generating graphs on primary information, such as age and gender, and disease diagnosis. While our work does not provide a dedicated method for the comparison of multiple cohorts, it grants filtering methods for the creation and visualization of a meaningful cohort of participants. Our interface also shows an overview of cohorts by displaying graphs representing the distribution of all selected patients' data for each phase of the trial as well as questionnaire completion rates. Overall characteristics of subjects are also plotted, where each visualization can also be used as a filtering method, i.e., the percentage of patients from intervention and control groups.

Table 3.3: User intent support for interactive exploration and querying of EHR for 13 systems, adapted from Rind et al. (RIND, 2013). Systems not present in Rind's version of the table are marked in bold.

		Select		Explore			Reconfigure				Encode		Abst./Elab.			Filter			Connect		
		Keep track	Manage groups	Navigate in time	Add/remove parameters	Add/remove patients	Reposition items manually	Sort items	Adjust axis	Other techniques to avoid occlusion	Switch representation technique	Vary visual encoding	Parameter abstraction	Temporal data binning	Show details of items	Patient status	Development over time	Development with time constraints	Patient/group relationship	Brush in other representation	Brush other parameters
single EHR	Lifelines		n.a.	•	○	n.a.						•	•	•	•	•			n.a.		
	MIVA	•	n.a.	•	•	n.a.	•							•	•				n.a.		•
	VisuExplore	•	n.a.	•	•	n.a.	•	○	•		•		○		•				n.a.		
	PatientExploreR		n.a.	•	•	n.a.			•		•	•			•	•			n.a.		
	IDMVis	•	n.a.	•	•	n.a.			•	•		•			•			○	n.a.		
EHR Collection	Lifelines2	•	•	•	•	•		•	•	•	•	•		•	•	○	•	○		•	
	Gravi++	•		•	•	•	•		•	•	•	•	•		•					•	•
	TimeRider	•		•	•						•	•			•	•					
	Lineage	•	•	○	•			•		•	•	•	•		•				•	•	
	EPIPOI			•	•		•				•		•	•				•			
	Bernard et al.		○		•								•	•							
	CAVA	•	•		•	•	•				•	•	•		•		•	•	•		
	CoCo	○			•			•					•		•		•		○		
	Our Work	•	•	○	•	•	•	•		•	•	•	•	•	•	•	○		•	•	•

•: full support, ○: partial support, " ": no support, n.a.: not applicable

In conclusion, we present a tool that aims at providing different features from previous works for the analysis of a clinical trial progression in a single integrated interface. Compared to previous works on the field of medical information visualization, where most tools separate views of single or multiple patients (Table 3.1), our work presents a hybrid approach, allowing users to interact with a cohort of participants while viewing specific information from each subject of the study. Table 3.1 also shows how most tools are limited to presenting a few data in a single screen, while our work can show an overview of approximately 90 different variables. Most of the tools briefly surveyed herein work with data from health clinics to assist doctors in reaching a diagnosis or treatment (Table 3.2). In contrast, our work is more focused on the progression of patients to perceive the effectiveness of a treatment (*i.e.* a healthier lifestyle). Our work's main features include the creation of a cohort of patients by the filtering and selection of specific parameters, while also creating a visualization of similarities between subjects inside the cohort. Additional time-series visualizations show how these participants are similar and whether the collected measures have a positive or negative impact on their health. The plots are also useful to provide an intuitive way to discover participants with unusual measurements and to summarize a patient's progression on the clinical trial. These features are presented in an interface intending to give larger support to users compared to other works (Table 3.3), especially regarding the connectivity and coordination between representations. The work also stands out by its approach to data selection, creating auxiliary visualizations to assist users in understanding the distribution and amount of data available for each variable of the study.

4 INTERFACE REQUIREMENTS AND DESIGN PROCESS

As learned from the review of literature, information visualization techniques can be powerful tools for the analysis of patient data and the progression of clinical trials. However, to achieve relevant results, it is essential to understand the needs of researchers and medical professionals.

In this chapter, we discuss the tasks that need to be performed periodically by epidemiologists and researchers working on the LINDA-Brasil trial. Based on this information, we gathered a set of requirements for the tool that should be met to provide meaningful results. We describe these requirements and the design process we adopted for conceiving the visualization techniques.

4.1 Gathering Requirements

Inspired on the In-depth Long-term Case Studies evaluation method (SHNEIDERMAN; PLAISANT, 2006), a series of meetings were conducted with the clinical trial's epidemiology team over the span of a year to assess the necessities of researchers and learn about general use cases of an information visualization tool in their context. In the first meeting, we talked to 3 specialists that presented the main goals of the trial and its overall structure. When asked about what kind of method could aid their work, they mostly complained about lacking means of checking information from participants without intervention from other teams. Since there is no system for interacting with data collected during the study, the statistics and information technology (IT) teams are required to constantly produce reports that are used by researchers and coaches to perform several tasks necessary for tracking the trial's progress.

4.1.1 High-level Tasks

Each coach working on the trial has a number of participants that need to be contacted periodically to collect information or schedule appointments for future visits. Before performing these phone sessions, the specialist must first acquire a set of basic information regarding the participant receiving the call, such as her weight history, medical issues, contraceptive methods, and relevant dates to the study.

Another task is the management of patients' data during the intervention to perceive improvements in healthy habits and weight loss. The trial has 12 different phases with a total of 127 questionnaires, each collecting a variable amount of information. Many of these relate to the same measurements, only collected at different moments of the study. Some of those variables suffer direct intervention from the study and are the focus of the researcher's attention, such as physical activity, weight, body circumference measures, and breastfeeding, considered as secondary outcomes of the study. Other collected variables can help perceive the progress of the intervention but are not directly influenced by intervention protocol, such as sleeping patterns and self-reported motivation. The latter is especially important to be analysed as insights for why patients might have abandoned the trial. Only participants randomized as Intervention are analysed and followed closely during the trial.

It is also important for the research team to be able to accompany the study's progress, such as the number of participants enrolled from each center and the number of questionnaires completed for each phase of the trial. One of the most impacting issues to the development of a clinical trial is the enrolled participants that leave the study. Specialists must be able to identify the loss of contact with these women, since most of them fail to report their lack of interest in remaining on the trial.

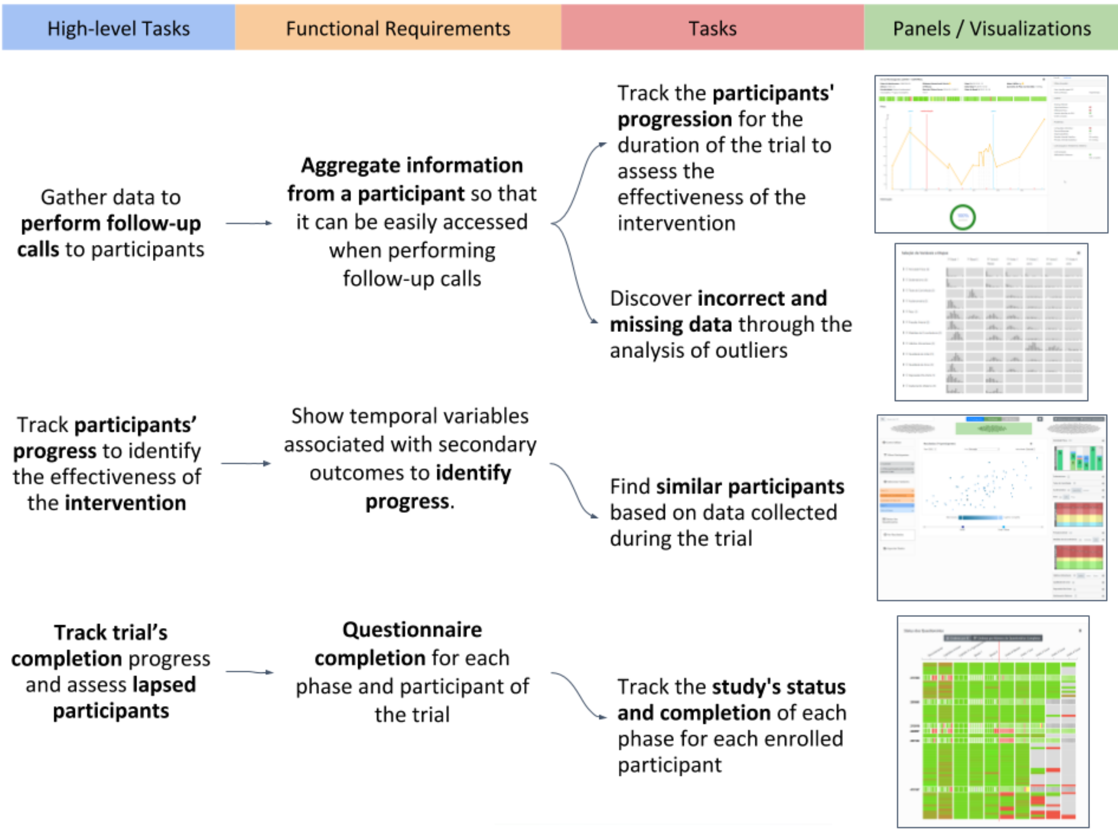
4.1.2 Functional Requirements

Based on the identified tasks, we established three main functional requirements for the tool, to support visual analytics of the data being gathered during the clinical trial:

1. Aggregate data of a single participant so that it can be easily accessed by the researchers when performing follow-up calls
2. Show temporal variables associated with secondary outcomes to identify progress, being able to filter participants and compare them according to parameters established by the researcher
3. Accompany the completion of questionnaires for each phase of the trial for each participant enrolled

These functional requirements created a number of tasks that were essential in the design of panels and visualizations used in the system. Figure 4.1 shows an overview of this workflow.

Figure 4.1: Workflow from high-level tasks to functional requirements, that helped define tasks that were essential when designing the interface.



Source: Author

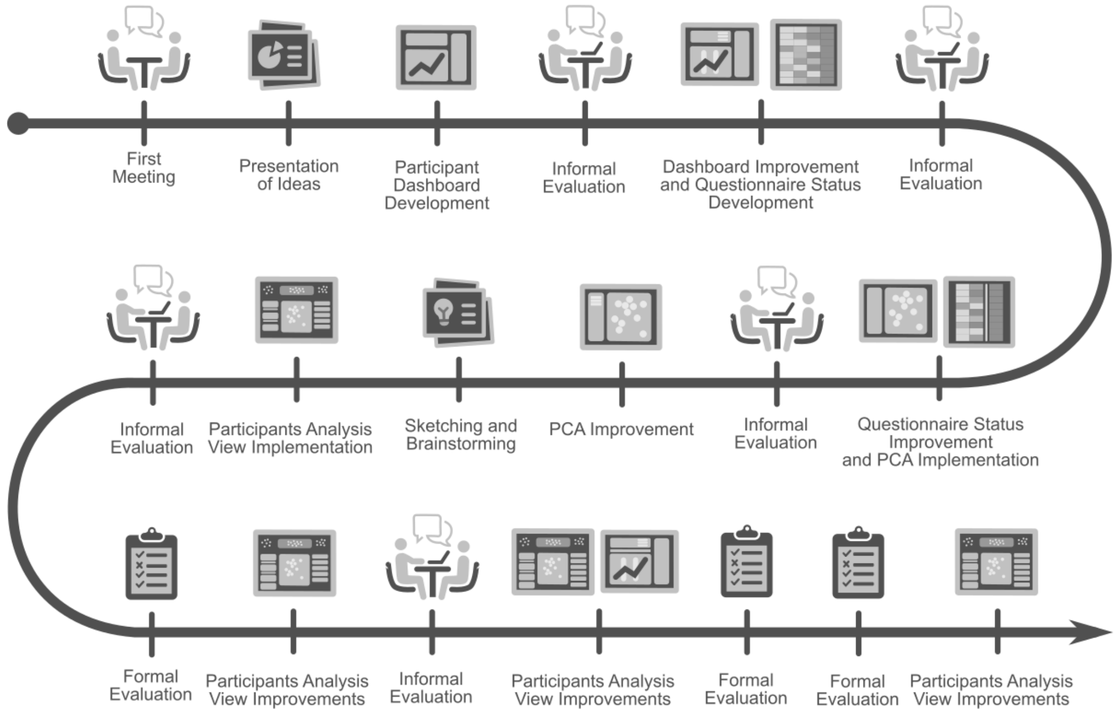
4.2 Design Process

With these requirements in mind, we gathered a number of different ideas that could allow achieving these goals and draw some ideas, starting the design process that is summarized in Figure 4.2.

We presented these ideas and prototypes to the trial's researchers. They were particularly interested in a dashboard where all data currently present in the manually generated dossier could be accessed as well as a chart showing weight measurements. We developed a prototype of such a dashboard, which was presented to the specialists for informal evaluation in another meeting. They suggested a number of small improvements to the interface, such as new information to be displayed and lines indicating labor and randomization dates. We also discussed a new visualization for creating an overview of the questionnaire status for all participants, which was considered very important for managing the trial.

After implementing it, another informal evaluation meeting was conducted where

Figure 4.2: Design Process of the tool. Development was done in an iterative process where each developed feature was evaluated in informal meetings and improved based on their feedback.



Source: Author

they suggested removing one of the phases of the trial from the view, since it was considered optional. They also suggested adding a line in the timeline to indicate when the randomization was performed.

To present all participants and provide a way of comparing their personal histories, we envisioned another visualization where users select a number of variables, and participants are plotted according to them using a dimensionality reduction (DR) technique, such as PCA. We presented this interface as well as the improved questionnaire status visualization in another meeting, where they approved the visualizations and suggested that filtering options could be added to our DR techniques. They were interested in filtering out participants according to their field center, randomization group, and the number of days since they last interacted with the trial.

After developing all the suggestions, we studied new ideas to improve the DR technique, by providing more information on the participants and enabling a better understanding on the distribution of each data collected during the trial. To achieve this, we proposed visualizations for filtering, selecting variables and many small views for a number of temporal variables from the trial (which were also added to the dashboard of each participant). We also developed an overview of the whole set of participants, also showing the control and intervention groups, for keeping track of all participants during the selection or filtering operations performed on the interface.

After implementing all these features, an informal meeting was conducted to show the resulting tool and obtain feedback, as well as a preliminary formal evaluation where a specialist was asked to answer usability questions and make suggestions for improving the interactive visualizations (questionnaires and summarized results from this evaluation can be found in the Appendix Sections B.1 and B.2, respectively). Developers of the tool were not present during the formal evaluation, and the specialist was asked to use the tutorials provided by the tool for guidance.

During the in-person meeting, epidemiologists stated that they were very satisfied with how easier it was to check the progression of certain variables for each participant and were very eager to start using the tool in their work. However, during the formal evaluation, the specialist found the Participant Information Analysis view not so easy to understand, especially the visualization created using PCA. The specialist also noted that it would be interesting to apply the same filters used in the Participant Information Analysis to the questionnaire status visualization, and that it could be embedded in the same interface as the PCA, to provide the same filtering tools. This would also allow interaction with other features available in the interface, including the visualization of specific temporal variables relevant to the study.

As mentioned before, an important fact to be detected and informed to the researchers is a participant that has not answered calls or missed visits (loss of contact). The number of days since the participant was last seen by the trial should also be calculated taking into consideration when the patient is to return, only counting as "loss of contact" after the expected return date has passed. This information should also be used in the questionnaire status visualization, only indicating that the questionnaire is incomplete when its expected completion date has passed. An alternative version of a survey should also not be marked as incomplete if its other version has been answered.

They also suggested modifications and alternative versions to certain variable graphs and other small details. A number of small improvements on the temporal graphs for secondary outcomes were suggested, including the ability to present weight without calculating the participant's BMI, and changing the information on the Y-axis of some graphs to show more relevant variables.

In previous meetings, specialists noted that while BMI is very relevant when comparing multiple participants (since it tries to compensate differences in height between subjects), weight fluctuations are better demonstrated using the raw value. Since there were reasons for using both versions of the graph, instead of removing one version in favour of another, a button was added on the right of the variable's title, letting users choose their preferred method of visualization. This method was then used in other variables with the same purpose.

All the suggestions were implemented and usability issues collected during the preliminary formal evaluation were analyzed.

Finally, we recorded a number of videos and tips that were added to the interface, usually regarding small features that facilitate the interaction with the system. We focused on creating hints for tasks that users reported not being able to perform on their own and certain features that would be hard to explain textually.

The tool was then again presented for evaluation in an informal meeting, where some extra features were discussed, such as the addition of a new variable for visualization and a printing feature for exporting the graphs of a participant.

In the next chapter, we describe the resulting visualization-based interface for the LINDA-Brasil study.

5 VISUALIZATION TECHNIQUES FOR MONITORING THE DEVELOPMENT OF LINDA-BRASIL STUDY

Taking into consideration the framework for visualization analysis and design proposed by Munzner (MUNZNER, 2014), we have already described the "What", i.e., the data collected during the trial (Section 2.3.1) and the "Why", i.e., the tasks performed by LINDA's research team (Section 4.1.1).

In this chapter, we describe the "How", i.e., the interactive visualization techniques implemented as tools that were integrated as a single interface for the LINDA-Brasil dataset. The interface also contains pages for video tutorials, hints, and a home screen for accessing each tool, but these are not described herein. An overview of all features described in this chapter can be seen in an introductory video[1].

Three main interactive visualization tools were designed, each one providing a view of the dataset:

- The Participants' Information Analysis view (Section 5.1) provides a set of tools to filter out subjects and select variables to analyze the progression of patients and their similarities.
- The Questionnaire Status visualization, described in Subsection 5.1.5, was created to show an overview of the trial's progress, and was incorporated as a plug-in to the Participants' Information Analysis view.
- The Participant's Dashboard focuses on viewing data of a single participant, showing dossier information necessary for performing follow-up calls and plots from important variables of the study and is further discussed in Section 5.2.

5.1 Participants' Information Analysis View

Healthcare-related systems usually either support tasks for the analysis of single or multiple patients separately. Tasks that involve the comparison of a single patient with multiple patients of similar histories, as well as transitioning between single to multiple patient analyses, are still not widely studied (RIND, 2013). In the Participant Information Analysis view (Figure A.1), we focused on providing ways of comparing cohorts of participants by representing their similarities while still providing a detailed view of im-

[1]<https://vimeo.com/406916544>

portant variables for a single or a group of participants. The comparison between patient histories is supported by the display of a scatterplot built using PCA by Singular Value Decomposition (SVD) (GOLUB; REINSCH, 1970) or t-SNE (MAATEN; HINTON, 2008) on user-selected variables for a group of participants. The filtering out of participants by their field center, randomization group, and days since the loss of contact was also an important feature added according to the needs of clinical trial researchers.

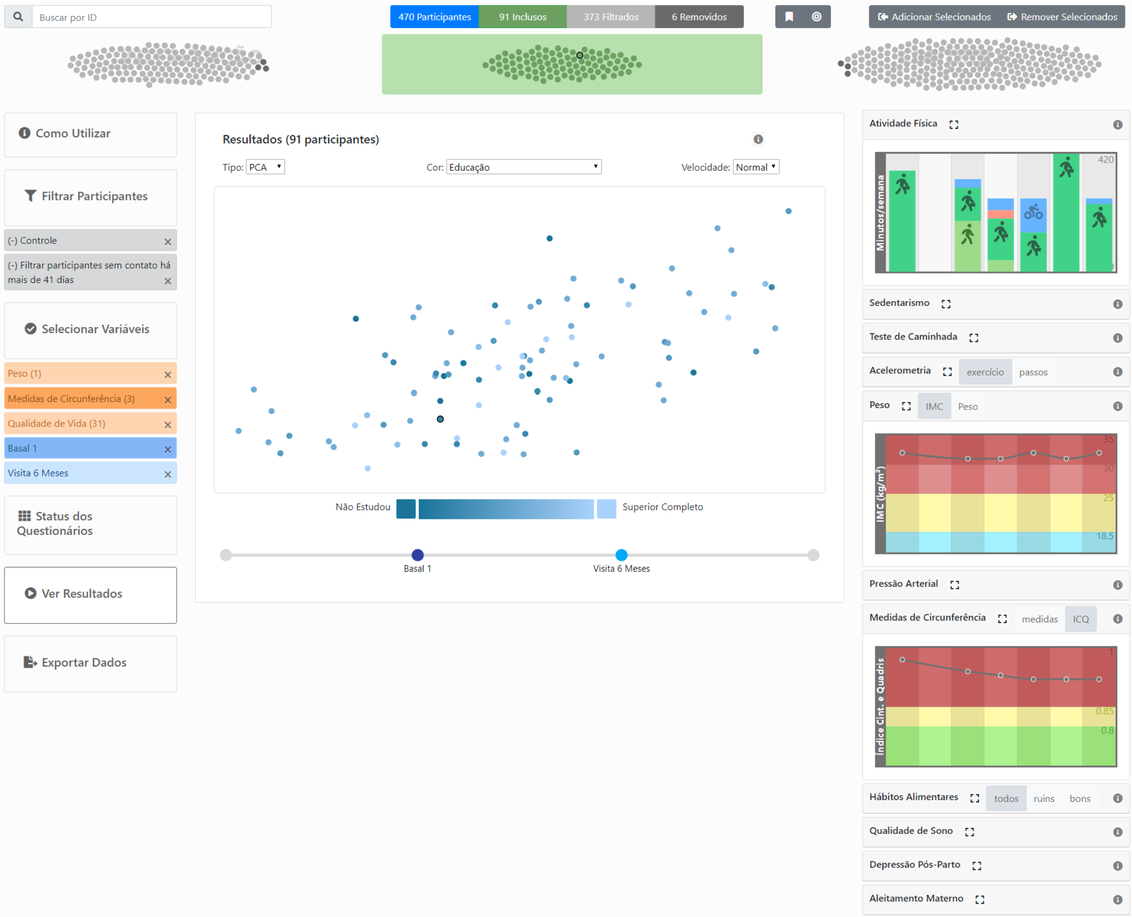
Visualizations provided in this view are coordinated based on user interaction. Highlights made in one visualization are made visible in others, allowing a better contextualization of the participant. Participants represented in the views can be highlighted in two different ways: a mouse-over provides all visual representations of the participant to be highlighted, including where the subject stands within histograms (described in Subsection 5.1.3), and a click marks the participant in all views and shows compact visualizations of her data (described in Subsection 5.3). The latter can be applied to a number of participants simultaneously, allowing a comparison between them.

5.1.1 Overview Visualization

When creating a visualization primarily based on the filtering out and selection of variables, it is important to provide an intuitive way to keep track of modifications brought by each interaction. With Shneiderman's Visual Information-Seeking Mantra (SHNEIDERMAN, 1996) in mind, we created an overview visualization of the selection of participants. In this view, all selected participants are displayed inside a green area on the center of the screen (Figure 5.2 shows some possible states of the visualization). As the subjects are filtered out, circles representing the participants are moved outside of the green area to the left of the screen if they are randomized to the intervention group and to the right if they belong to the control group. This movement of elements was created to help users visualize the results of their actions when altering the selection, as opposed to only presenting these changes by altering a counter on the screen. Such a solution also allows users to individually track whether specific participants are being excluded and enables the visualization of temporal variables for both filtered out and non-filtered patients.

The visualization was developed by creating three points of gravity: one for included participants, other for filtered out Intervention participants and another for filtered out Control participants. Subjects can be dragged with the mouse and moved outside the

Figure 5.1: Participant Information Analysis view, showing PCA results for a group of 91 subjects in phase Basal 1, considering BMI and Body measures variables. Dot colors map education level of the corresponding participant. The upper portion shows an overview of all study participants. On the left side of the view, a menu is available for defining filters, selection of variables, results, and more. A breadcrumbs approach shows all selections below their respective menu options. The right side of the view allows visualizing graphs of temporal variables on demand, showing data about a single or multiple participants.



Source: Author

inclusion zone, causing their representations to be removed from the other visualizations, and their gravity pull altered to match their new group. Other useful interactions are also available in the view, including:

- Search and selection of participants by their ID.
- Total number of subjects included, filtered out and manually removed. This information can be clicked to select all participant from each category and work as a legend to the colors used on the visualization.
- Manual removal of participants, which can also be accomplished by the use of auxiliary buttons on the top right of the screen.
- Selection of participants to be marked in other views and show their temporal vari-

ables graphs, described in Section 5.3.

- Bookmarking a group of selected participants that can be re-selected when necessary.
- Hovering of subjects for checking their ID, and highlight them in other visualizations.

Figure 5.2: Overview visualization where each circle is a participant, with included participants colored green on the center. A search bar is available on the top left to find subjects by their ID. On the center, the total number of participants, subjects included, filtered out and removed from the visualizations are shown. Various states are depicted: (A) initial state of the view. (B) view after filters are applied, moving filtered out subjects to the sides. (C) selection of a group of participants (black stroke). When a selection is made, new buttons for adding/removing and bookmarking the selection are available. (D) Bookmarking of the selection. A button for loading the selection appears. (E) Removing participants moves them outside the center and changes their color to a stronger tone of grey. (F) Returning to a bookmarked selection. (G) Hovering over a subject, showing its ID on a tool-tip, and its other representations are highlighted in other views.

Source: Author

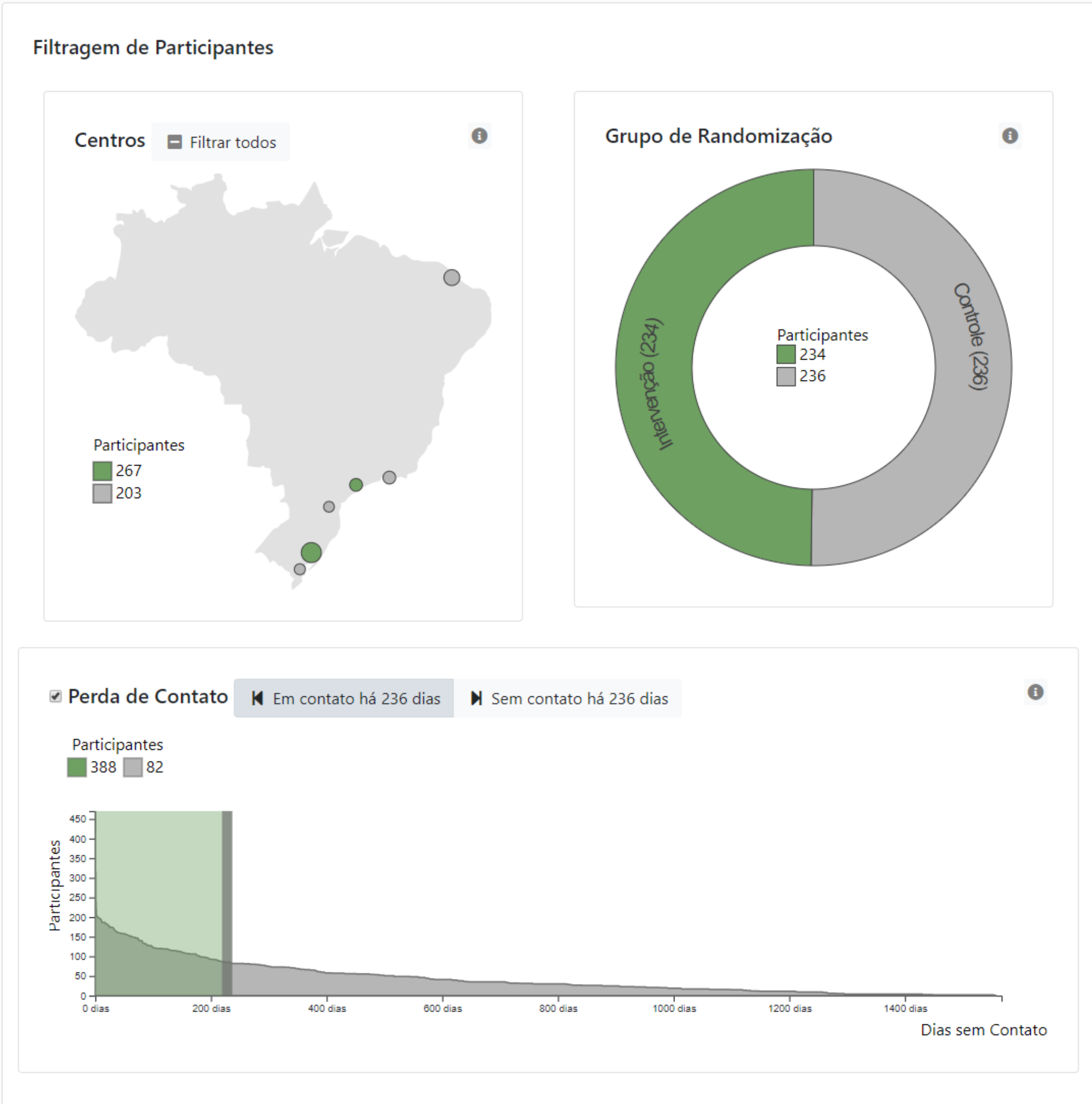
5.1.2 Filtering Out Participants

Removing certain participants depending on their data is a very common strategy when analyzing clinical information and creating a cohort of patients. Three main characteristics were selected by specialists to be filtered out: the city of the field center where the participant is enrolled, the randomization group of the patient, and the time since participants are late for their appointments.

Each of these filters can be applied by interacting with a different visualization that shows an overview of the data being filtered out. A legend is available for each, showing the number of included and excluded participants affected by the filter. This allows the user to better understand what is being filtered out while providing information about the dataset. After a filter is applied, a tag representing it is added below the filtering menu option, allowing for quick assessment of what is affecting the selection as well as its removal without returning to the filtering screen.

Usually, most systems that we analyzed allow selecting features for visualization instead of filtering out information before analysis. We chose this method of filtering out attributes since users can choose to skip this process, and visualize the entire dataset, which normally is not possible in other tools since they work with much larger clinical trials. Skipping this step simplifies the process of generating results, while also allowing the same customization of the selection as other systems provide.

Figure 5.3: Filtering options available on the tool and their visualizations. Artifacts colored green indicate that the corresponding subset is being included in the visualization and items colored grey are being filtered out from the selection. A legend accompanies each graph, describing the number of participants being filtered out by each filter. On the top left, a map shows all field centers participating in the trial where the size of each point represents the number of enrolled subjects from that field center. On the top right, a donut chart shows the percentage of participants in each randomization group. On the bottom, an area chart indicates how many subjects have not had any contact with the trial for a number of days, where any participants with more than 236 days without contact are being filtered.



Source: Author

5.1.2.1 Field Centers

When choosing a visualization for enabling the filtering of participants by their field centers, it is important to facilitate the researchers' quick assessment on what is being filtered out and the distribution of subjects between each center. Since each participant belongs to a different city, it was considered as an intuitive visualization choice to utilize a map. Each field center's location is plotted on a map of Brazil as a circle (top left of Figure 5.3). The circle's color represents whether the center is being included (green) or filtered out (grey). The size of each circle shows the number of participants that belong to the center, facilitating the visualization of the distribution of patients between centers. When hovering each city, it is also possible to check its name and the exact number of participants from that field center.

5.1.2.2 Randomization Group

Subjects are separated into two different groups for the trial: Control and Intervention. Intervention patients receive a more intensive program for the prevention of diabetes, while the control receive only basic health instructions. Therefore, it is very important for researchers to be able to be informed which subject belongs to which group when visualizing data.

A 'donut' chart was chosen to show each group, as seen on the top right of Figure 5.3. The circle's color shows whether the group is being shown (green) or being filtered out (grey). The number of participants of each group is written inside or can be seen in a tooltip when hovering the slice. Although 'donut' charts and pie charts are not the most effective tool to show the difference in numbers when analyzing very similar values, we concluded that it was more relevant to show that the sum of these two groups represent the entirety of the dataset and removing one would essentially remove half of the information being visualized.

5.1.2.3 Number of Days Since Loss of Contact

There is a major concern of LINDA's researchers on participants that abandon the study, therefore it is considered important for them that such participants could be discovered and filtered out from the visualizations as soon as they reach a threshold. There is also a need to select these subjects in order to regain contact, especially in the final years of the trial. Since there is no information saved on the database to indicate whether a subject has left the trial, we calculate its expected return date based on the study's definition of when the participant would reach each phase and its previous return dates. Subjects are only considered as a lost contact when they have surpassed their expected return date with no new data recorded in the database.

An area chart is generated (bottom of Figure 5.3) to show the distribution of the number of participants that lost contact for each number of days (subjects that are on schedule are shown as having zero days of lost contact). The graph's x-axis starts at zero days inactive and goes to the maximum number of inactive days registered for a participant. The y-axis shows the cumulative number of participants that have been inactive for each number of days. A slider can be dragged to select a range of inactive days, and only participants active within that range are not filtered out. A button is also available to enable the filtering of participants that are active in the study to allow selecting subjects that lost contact to be contacted and returned to the trial. This changes the area of selection to the right side of the visualization. Additionally, the filter is only applied when its checkbox is marked.

5.1.3 Variable Selection

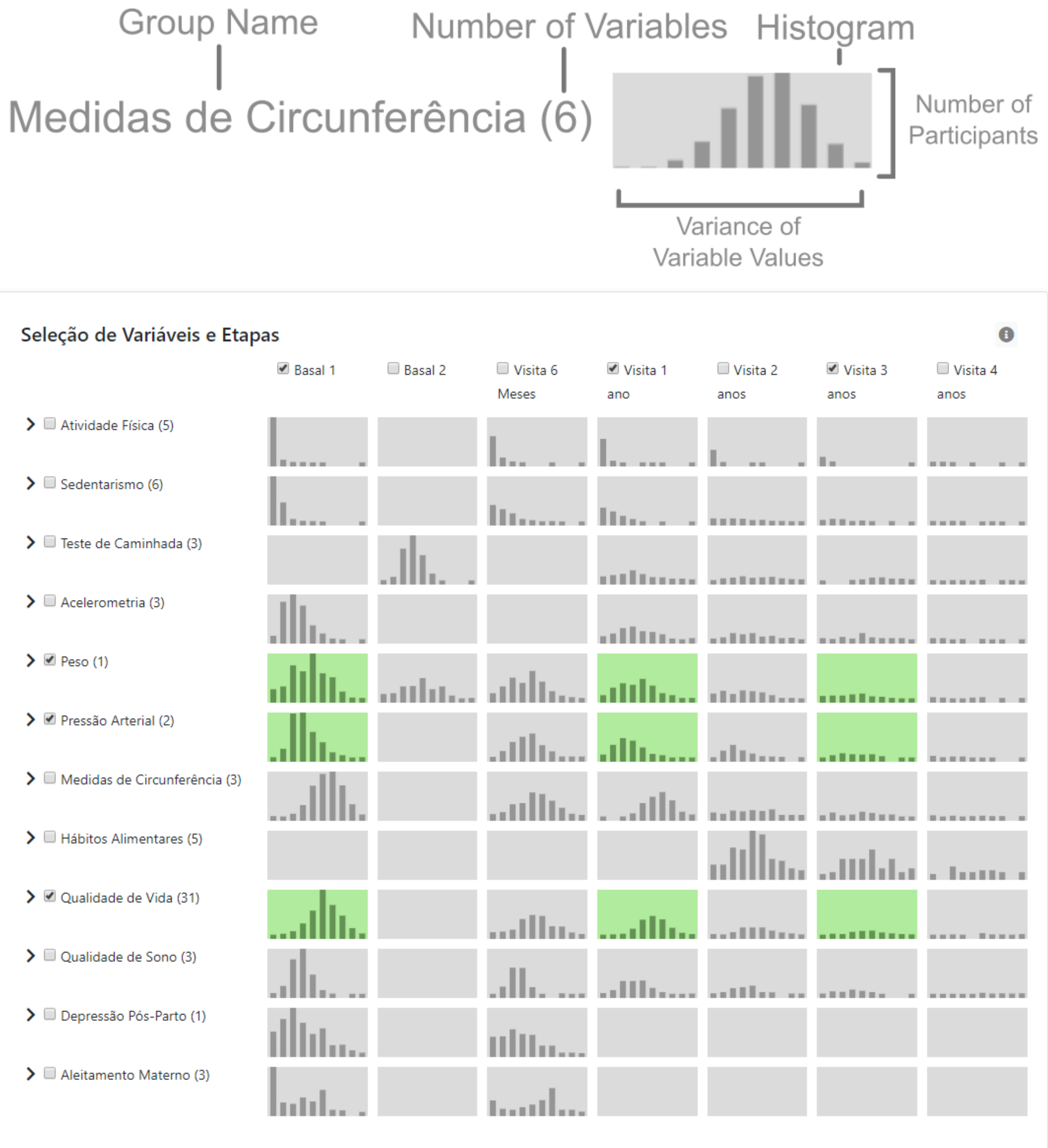
To create the scatterplot of a participants cohort, users must select variables and phases to be used as a multidimensional vector to describe each participant. In each phase, a variable set of questionnaires is applied to participants. So, researchers are required to have a comprehensive understanding of the minutia of each phase as well as the overall trial protocol to know which variables are available to be used as a descriptor of each participant. Also, information gathered for the trial greatly varies in range, distribution, and amount of data available for each visit.

With this in mind, we envisioned a visualization (Figure 5.4) to help researchers more easily understand the distribution of each variable, and to better clarify which part of the dataset is being selected. To achieve this goal, we created a matrix of histograms, where each column corresponds to a phase, and each line contains histograms for a variable. Thus, along the same line, we have histograms showing the distribution of values of a specific variable in each phase of the study. Information from filtered out participants is not used for creating this view so that histograms have data from the participants included in the current selection. In order to show the difference between the amount of participants data for each phase, the same scale is used for all histograms created for the same variable. When users mark variables and phases, the histograms of the chosen (variable, phase) pairs are colored green to show what data are currently selected. This features helps preventing the user from selecting a phase with no information on the variable. After each selection, a tag representing it is created below the variable selection menu option. This way, the user can keep track of all selected information when in other views and deselect them without the need to go back to the variable selection interface. The selection of variables and phases triggers the creation of the matrix used for DR techniques, further described in Subsection 5.1.4. Participants with not enough information on the selection made are immediately filtered out, allowing users to analyze the group of subjects left in the result and change the selection accordingly.

Each variable holds a varying number of sub-variables, which can also be viewed individually in their own histogram and deselected from their groups (Figure 5.5). Sub-variables can be seen by clicking on the arrow to the left of each variable's name, showing their own histogram with slightly lighter color tones. The histogram of a variable is created by calculating the average of all selected sub-variables. There must be at least one phase and two sub-variables selected in order to enable the visualization of the cohort scatterplot.

Some other small interactions with the view were implemented to coordinate the histograms with the overview visualization. Histogram bars can be clicked, causing all participants with values within that range to be selected. This is useful for analyzing participants within that range and removing outliers from the visualization. Furthermore, when participants are highlighted in other views, the bars representing the range of their variables are also highlighted. This coordination feature allows for rapid visual analysis of subsets of participants.

Figure 5.4: **Top**: Histogram of variable for one phase of the trial, generated from participants' data; the height indicates the number of participants in each bin. **Bottom:** Matrix of variables per phase, where histograms show the distribution of values for each phase. Check-boxes are used to select variables and phases, the resulting selection of cells being painted green, and used for generating the DR scatterplot.



Source: Author

Figure 5.5: Matrix of variables per phase, where blood pressure and circumference measures were expanded to show their sub-variables, their histograms presented in lighter colors.

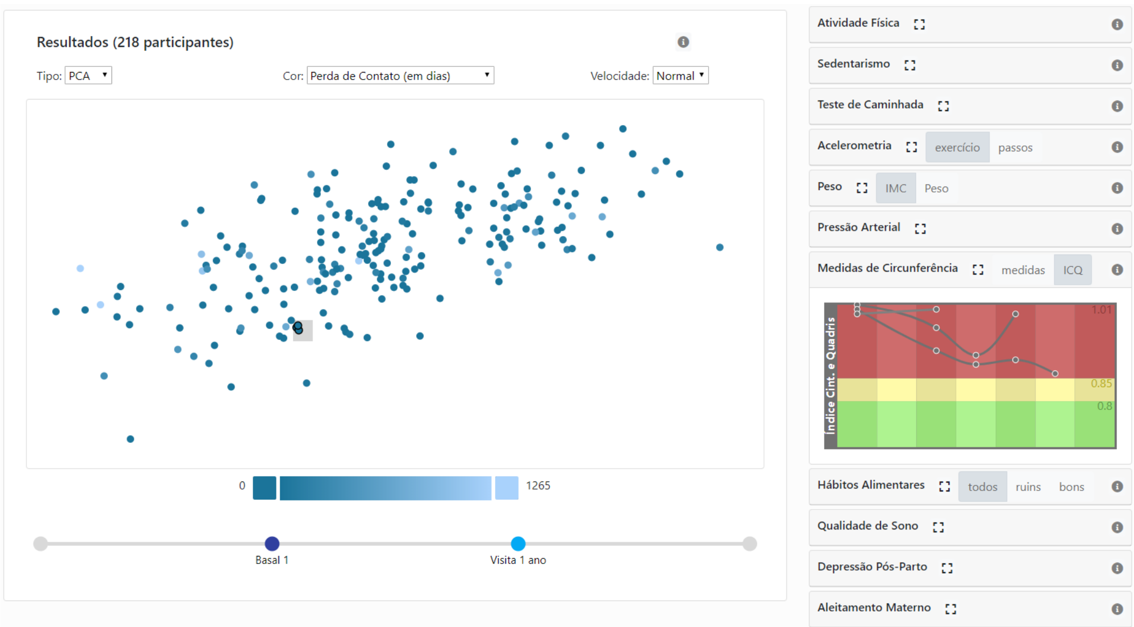
Source: Author

5.1.4 Cohort Scatterplot

The exploration of cohorts using multiple variables is often benefited from dimension reduction techniques (PREIM et al., 2016). DR techniques reduce the number of dimensions while maintaining or emphasizing some characteristics of the dataset, which can be useful for comparing participants based on a large amount of information from their personal histories and aid in the prediction of diabetes (ROOPA; ASHA, 2019). This comparison can be useful for the discovery of patterns between similar patients, allowing specialists to more easily discriminate which factors influenced more positive and negative results in a participant's health.

Variables and phases selected on the Variable Selection view are used to generate DR scatterplots using PCA (Figure 5.6) by Singular Value Decomposition (SVD) or t-SNE (Figure 5.7), ignoring patients filtered out or removed by the user. Each selected phase generates a different scatterplot. If more than one phase is chosen, the DR of a phase includes data from the previous phase. The reason behind this approach is to avoid temporal incoherence, an impairment in the visualization of temporal trends due to the independent application of DR techniques for each time step (RAUBER; FALCÃO; TELEA, 2016).

Figure 5.6: Results generated using PCA for variables of circumference measures and quality of life for phases 'Basal 1' and '1 Year Visit'. Color shows days since lost contact. A cluster is selected, showing that participants within it show very similar values of measurements during the 'Basal 1' phase.



Source: Author

Each phase scatterplot to be displayed can be chosen from a timeline below the visualization. When transitioning between phases, an animation is played to show how participants' positions change from one to another. There are a number of customization options available, including selecting a variable to be assigned to the color of each participant marker (further described in Subsection 5.1.4.3), as well as modifying the colors used for the scale, changing the speed of the animation between subsequent phases, and altering the type of DR (PCA or t-SNE) being used and its parameters.

To perform the dimensionality reduction, a matrix is created for each selected phase, where lines represent participants and columns represent selected variables. If a participant is missing values for more than half of the variables, she is excluded from the visualization. Since categorical data are saved as numbers in the database, they are used in the same manner as numerical variables.

After the matrix is populated, remaining participants that still have some missing information have their missing values replaced by the mean of the variables of the other participants, one of the simplest methods available to minimize the impact of missing data (DRAY; JOSSE, 2015). This solution allows for the missing variable do not influence the position of the participants while allowing the ones with small amounts of incomplete information to be displayed. It is only used to fill the matrix used for DR and does not influence the data stored or other visualizations. After the matrix is completely filled, data are then normalized and ready for DR.

5.1.4.1 Principal Component Analysis (PCA)

Principal Component Analysis is a linear dimensionality reduction method that finds a linear combination of features of the dataset. Data are transformed in scores that represent the similarity of items within the dataset. Thus, only the distance between points convey meaning, leaving y and x-axis with no formal definition. At the same time that it is useful for obtaining important insights from a dataset with a large number of dimensions that would be difficult to visualize, such an abstraction and the loss of information during the dimensionality reduction process can be considered a drawback of the technique.

In this work, the PCA scatterplot from the selected variables is created using Singular Value Decomposition (SVD), which provides the same results as PCA but is a much faster algorithm. SVD takes a matrix M as input and decomposes it into 3 matrices: M = U * S * V*, where U and V are orthonormal bases composed by eigenvectors and S is composed of the singular values of combinations of MM* and M*M. From these components we generate two matrices. The first matrix is obtained by multiplying the two largest singular values of S by the left singular vectors of U. This matrix is the one plotted in the visualization, plotting each unfiltered participant according to the distribution of selected traits given the dimensionality reduction. The second matrix is obtained by multiplying the two largest singular values of S by the right singular vectors of V. We estimate the most influential variable within the decomposition vector of PCA by evaluating this second matrix, which represents the contribution of each variable to the principal components (WOLD; ESBENSEN; GELADI, 1987). This variable and its phase are emphasized in the interface by a stronger color in its breadcrumb: when hovered, it shows the sub-variable it corresponds to.

5.1.4.2 t-Distributed Stochastic Neighbor Embedding (t-SNE)

t-Distributed Stochastic Neighbor Embedding (MAATEN; HINTON, 2008) is a non-linear DR technique that, as with PCA, creates clusters of similar data in two or three dimensions. Although t-SNE can perform well for non-linear data, it is very inefficient for large amounts of information and can take some time to generate results. It also requires some amount of experimentation with its parameters to generate a relevant visualization, which can be a tiresome experience when combined with its response time. Figure 5.7 shows a plot we created with t-SNE.

Figure 5.7: Results using t-SNE for physical activity and quality of life for phase '6 Months Visit'. A cluster is selected, showing that participants within it show very similar values for physical activity during the phase.

Source: Author

5.1.4.3 Use of Color

It is well known that, when used correctly, color can be a powerful tool in information visualization techniques for adding a new dimension to a plot without further cluttering the interface (MUNZNER, 2014). Variables assigned to color were mainly selected by their possible influence in the outcome of the general lack of periodic collection throughout the duration of the trial. The definition of each variable is summarized below:

1. *Randomization:* whether the participant belongs to the Control or Randomization group
2. *Loss of Contact:* number of days since the participant's expected return date, described in Subsection 5.1.2.3
3. *Postnatal Depression:* score of postnatal depression on the participant, same measure and value described in Chapter 2
4. *Number of children:* number of children the participant has at the moment
5. *LINDA's Goal:* weight loss goal advised by the study
6. *Contraception:* if the participant is using any kind of contraceptive measures
7. *Binge Eating:* the frequency the subject eats without self-control

8. *Food Cravings:* the frequency the subject craves certain types of food
9. *DM's Family History:* if there are any cases of Diabetes Mellitus in the subject's family
10. *Education:* participant's current education, ranging from no formal education and a post-doctoral degree

When users select a variable to be assigned to color, participants plotted in the cohort scatterplot are painted according to their respective values for the data. The lowest and highest values for the selection are calculated and assigned to two colors that are interpolated to form a gradient, which in turn defines the color for every value inside the range. Colors and gradient are depicted on the bottom of the plot, as well as the minimum and maximum values for the variable. Colors for lower and higher values are presented as squares that can be clicked so that users can select different colors to better depict the meaning of a domain. Variables linked to categories, *i.e.* education level and randomization group have labels instead of values for their lower and higher bounds. Additionally, besides relying on color-coding, users can also check the precise value of color-assigned variables by hovering over-plotted participants.

5.1.5 Questionnaire Status

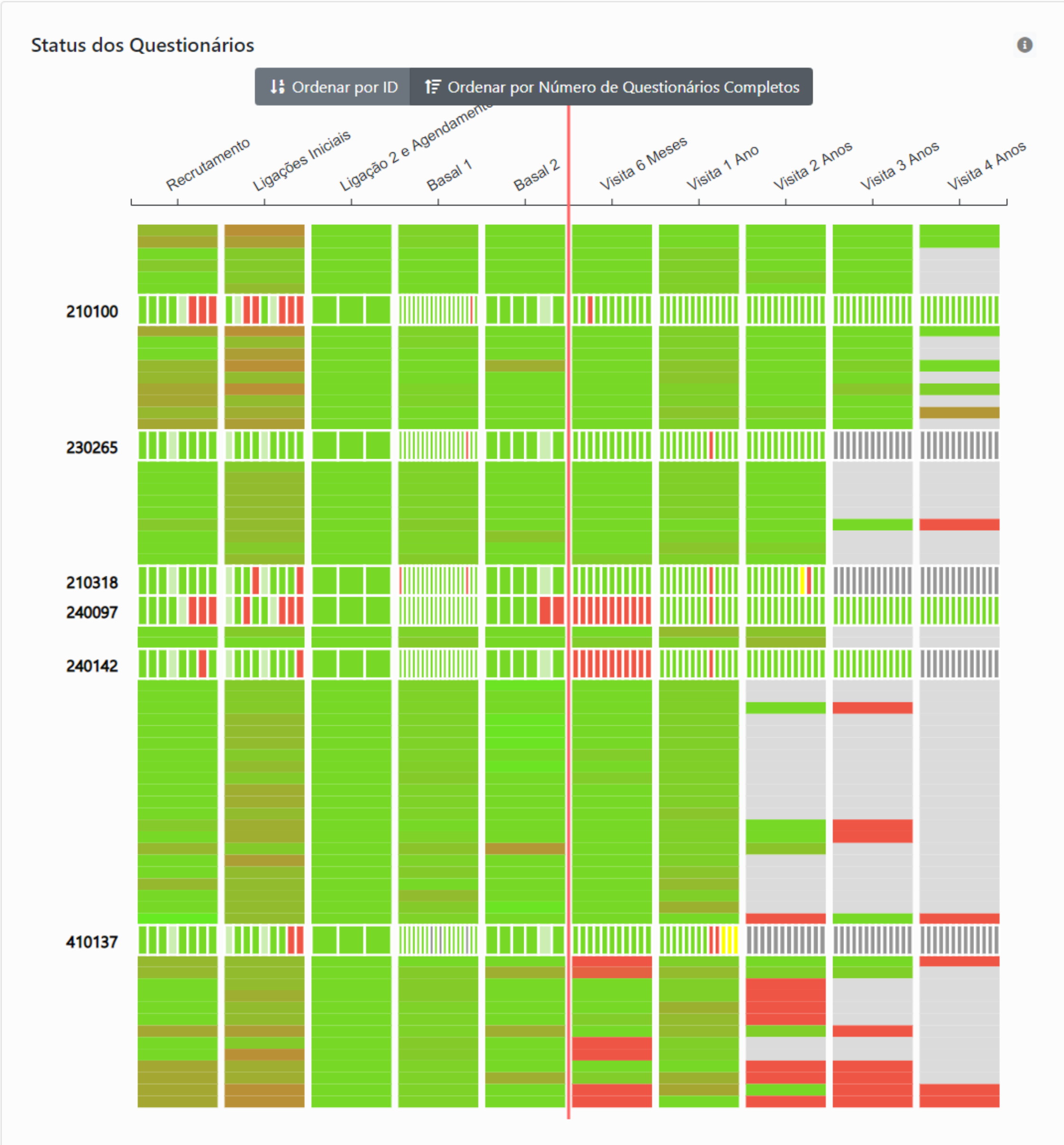
With the Questionnaire Status view, researchers can have an overview of the questionnaire completion for all participants, being able to check how far in the study each one has come, as well as if questionnaires were neglected in previous phases.

The Questionnaire Status view (Figure 5.8) was inspired by Table Lens (RAO; CARD, 1994), and allows to explore large amounts of tabular data dynamically. Each row represents a different subject, while each column shows a phase of the clinical trial. Rows are ordered from patients that completed the most questionnaires to patients with the lowest amount of data collected. Users can also choose to order them by their ID number. A rectangle is created for each item in the table, and its color is defined by the number of questionnaires completed for the phase, ranging from red (low) to green (high).

Questionnaires and Phases that are still not expected to be completed by participants are painted grey. This information is not available on the database and is calculated using the expected return date, as described by the trial's specialists. These calculations take into consideration the patient's enrollment, labour, and randomization dates. For example, the "6-Months Visit" phase should happen six months after the randomization date of the participant.

A participant's line can be clicked to expand the phases, creating a rectangle for each questionnaire where its color is defined by its current status of completion. This also causes the participant to be selected in other visualizations shown at the moment, *i.e.* temporal variables plots and the cohort scatterplot. The expanded line enables new interaction options, such as a tool-tip in each questionnaire to check its name and shows the ID of the selected participant, which can be clicked to trigger the display of her dashboard, described in Section 5.2.

Figure 5.8: Questionnaire status visualization. Each column shows a phase and each line a participant. Participants can be clicked to present the status of all questionnaires from each phase and select them in other visualizations.

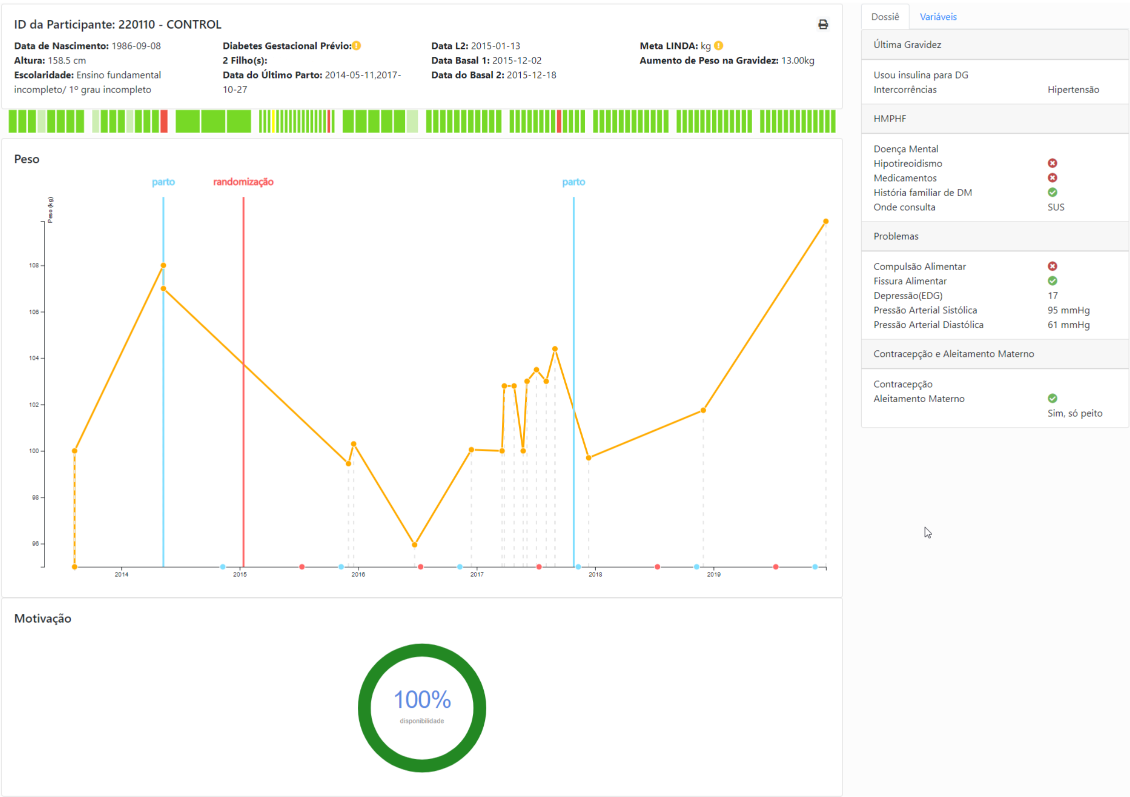


Source: Author

5.2 Participant's Dashboard

Phone sessions are the main method for delivering the clinical trial's intervention, and to perform these calls, specialists need access to all relevant information about the participant in hand, especially its weight progression and other important milestones of the study. Nowadays, such information is held as a dossier. The Participant's Dashboard show all information needed for performing the call to a single participant as well as additional graphs and data (Figure A.2 and 5.10).

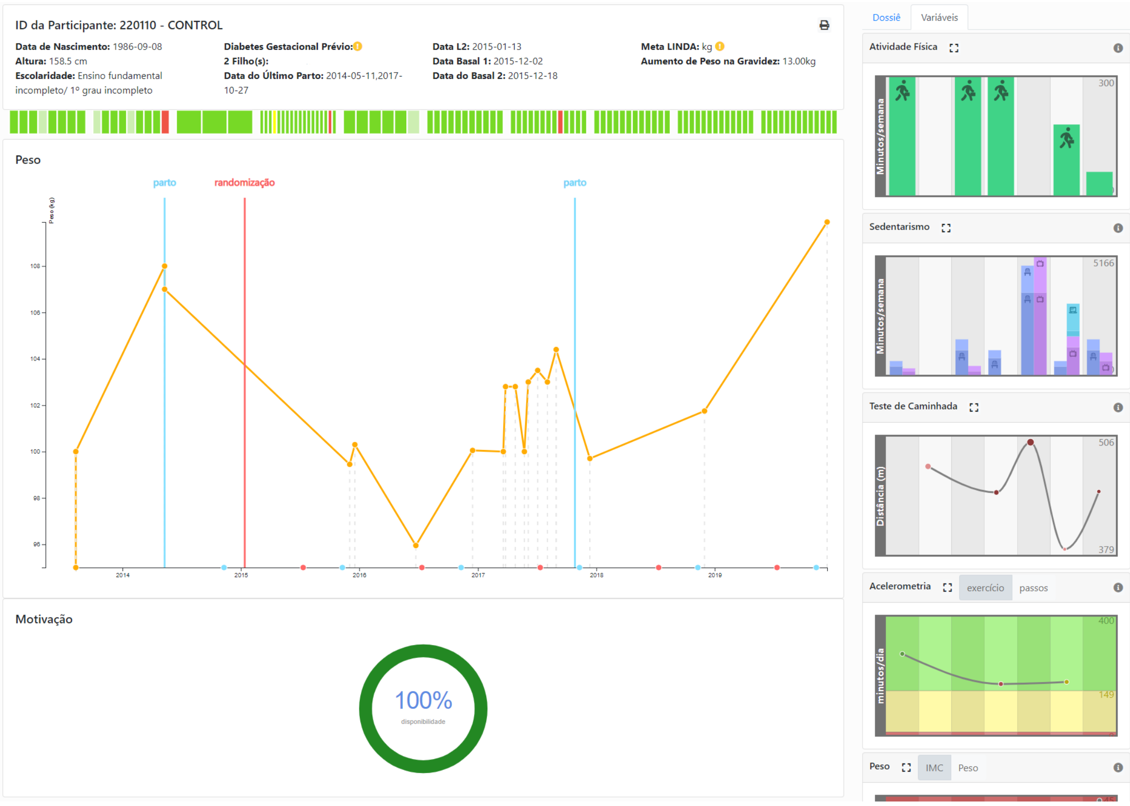
Figure 5.9: Participant’s Dashboard interface, showing dossier data.



Source: Author

The most important information that needs to be visualized by researchers in our target clinical trial is the progression of weight changes, the weight goal defined for the participant, and certain events’ dates. To visualize this information more easily, a line chart with the weight plotted through time is drawn in the center of the screen. In this same plot, lines are used to mark the date of important events to the study, such as the subject’s randomization (red) and the pregnancy’s labour date (blue). Then, a dot with the corresponding color is used to mark six months, and then the number of years after these dates. Furthermore, the interface contains all information available on the previously extracted dossier, while also providing additional visualizations of temporal data, as described in Section 5.3 and 2.3.1. It also provides the line of the status of questionnaires of the subject, described in Section 5.1.5.

Figure 5.10: Participant's Dashboard interface, showing temporal variable's visualization.



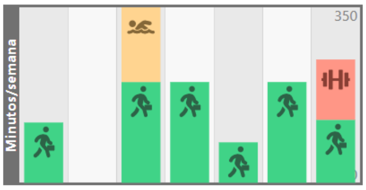
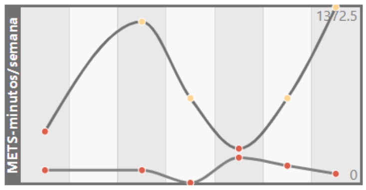
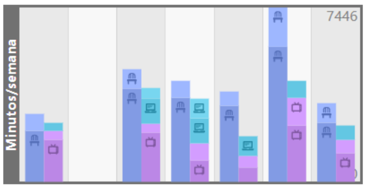
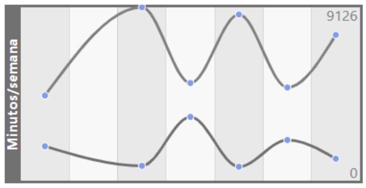
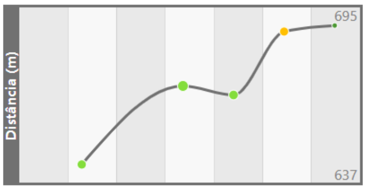
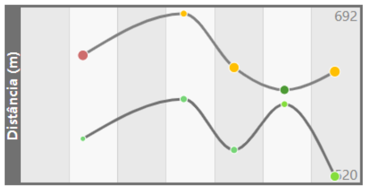
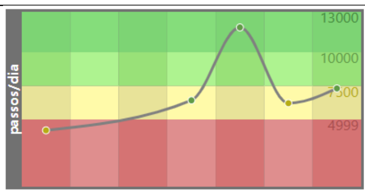
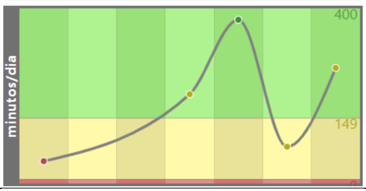
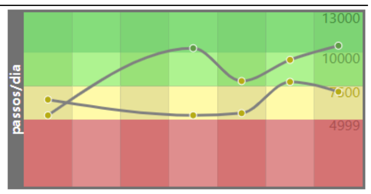
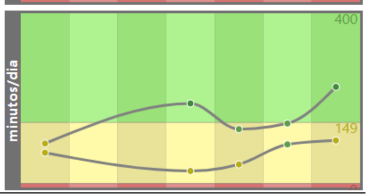
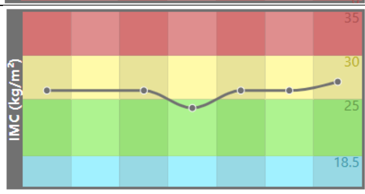
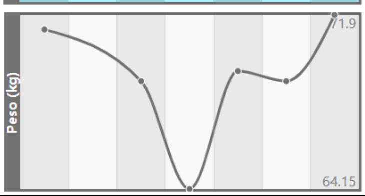
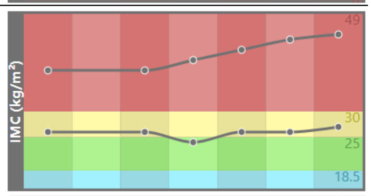
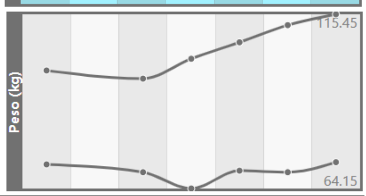
Source: Author

5.3 Temporal Variables

Many variables collected along time help indicate changes in lifestyle and quality of life of participants, which is part of the intervention proposed by the clinical trial. We designed a series of compact visualizations to allow quick analysis of the progress of a single or several participants concerning important temporal variables. These visualizations, which are shown on the right in the Participants' Information Analysis view (Figure A.1), can be accessed by clicking on participants on this view (refer to Section 5.1), or on each participant's dashboard (Section 5.2). They can all be maximized for better visualization, and some of them provide alternative versions that can be toggled by buttons on their cards.

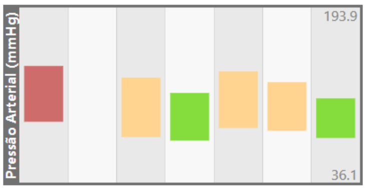
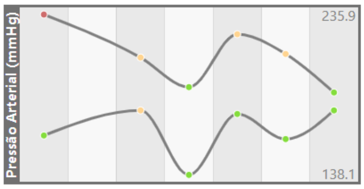
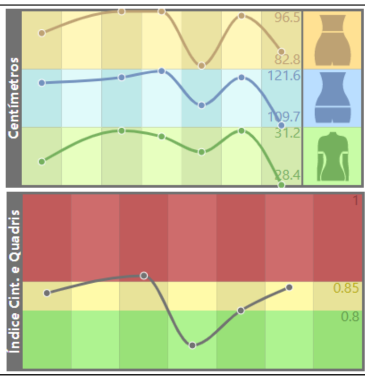
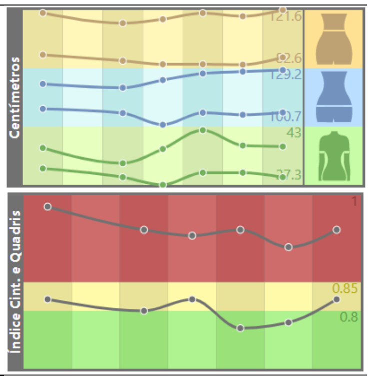
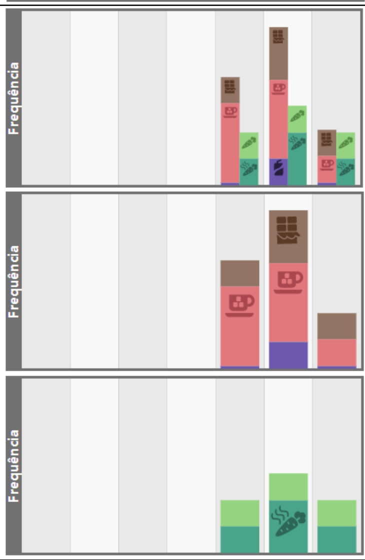
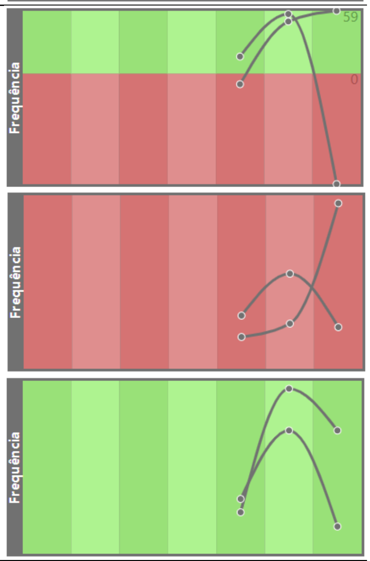
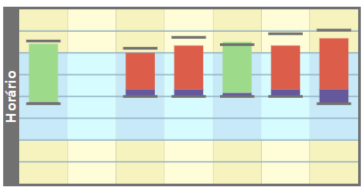
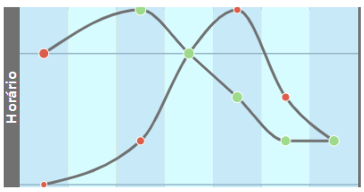
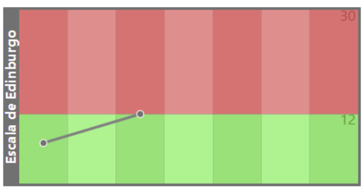
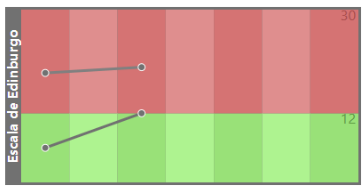
Table 5.1 summarizes the visualizations specifically designed to quickly show positive or negative results related to the variables collected during the intervention progress. More information about each variable was provided in Chapter 2, and the next subsections discusses each visualization.

Table 5.1: Study's temporal variables, available for DR, and their specific visualizations. Some variables have alternative versions, shown in a new line.

	Sub-variables	Single Participant	Multiple Participants
Physical Activity	Walking Walking to work Medium activity Intense activity Cycling to work		
Sedentarism	Time sitting down Time watching TV/screens Time studying/working in front of screen		
Threadmill Test	• Distance covered • Final heart rate • Final Borg Scale		
Accelerometer	• Average number of steps per day • Time doing physical activity • Time sitting down		
Weight	• BMI		

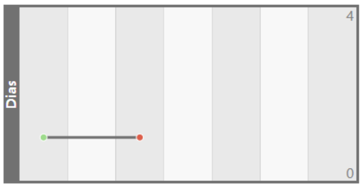
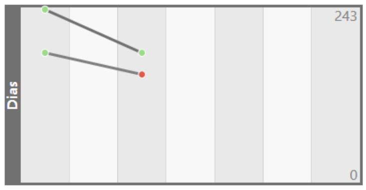
Continued on next page

Table 5.1 – *Continued from previous page*

	Sub-variables	Single Participant	Multiple Participants
Blood Pressure	• Systolic blood pressure • Diastolic blood pressure		
Body Measures	Waist circumference Hip circumference Arm circumference		
Eating Habits	Soda Sugared coffee/tea Chocolate Vegetables Steamed Vegetables		
Sleep Quality	• Time until sleeping • Total sleep time • Time went to bed • Time got up		
Postnatal Depression	• Edinburgh Scale		

Continued on next page

Table 5.1 – *Continued from previous page*

	Sub-variables	Single Participant	Multiple Participants
Breastfeeding	• Baby is breastfeeding • Baby is only breastfeeding • Age baby started taking other liquids		

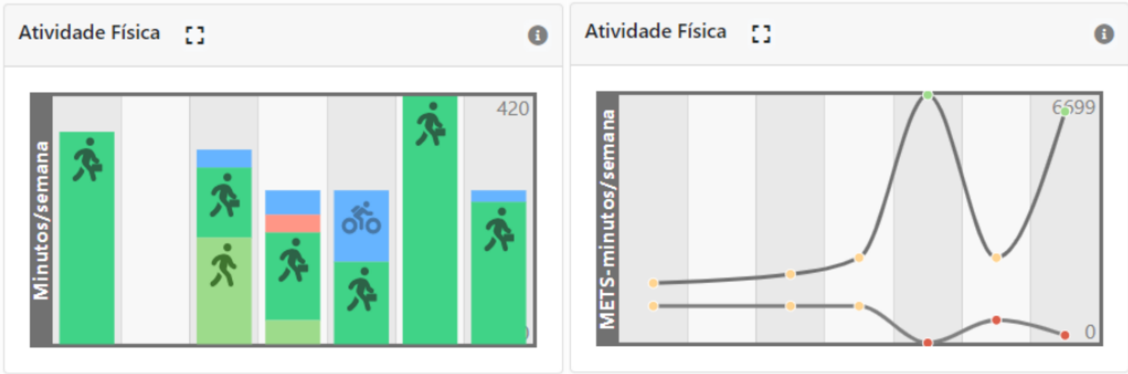
5.3.1 Physical Activity

To show all different activities and their duration for one participant, a stacked bar chart was created, as illustrated on the left of Figure 5.11. Each bar represents a different type of physical activity, and its height represents the minutes per week the participant performed during each phase. The bars are stacked for each phase and discriminated using color and icon. A different visualization was envisioned for multiple participants, shown on the right of Figure 5.11. Instead of clearly showing what types of physical activities were performed by each participant, the total number of MET-minutes/week was calculated for each phase, for each participant, and presented using a line chart where the y-axis shows the number of MET-minutes per week, each line corresponding to a participant. The score is calculated using the following equations:

1. *Walking MET levels:* 3.3 * minutes of activity/ day * days per week
2. *Moderate Intensity MET levels:* 4.0 * minutes of medium physical activity/ day * days per week
3. *Vigorous Intensity MET levels:* 8.0 * minutes of strong physical activity/ day * days per week
4. *Cycling for Transportation MET levels:* 6.0 * minutes of activity/ day * days per week

The color of each point shows the categorical classification of the resulting score according to IPAQ's scoring protocol, varying from inactive (red) to active (green).

Figure 5.11: Physical activity visualization for single and multiple patients. On the left, a single patient's activity is shown as a bar chart. On the right, multiple participants are shown as lines, plotted by the calculated MET-minutes/week and its categorical classification according to IPAQ's scoring protocol.

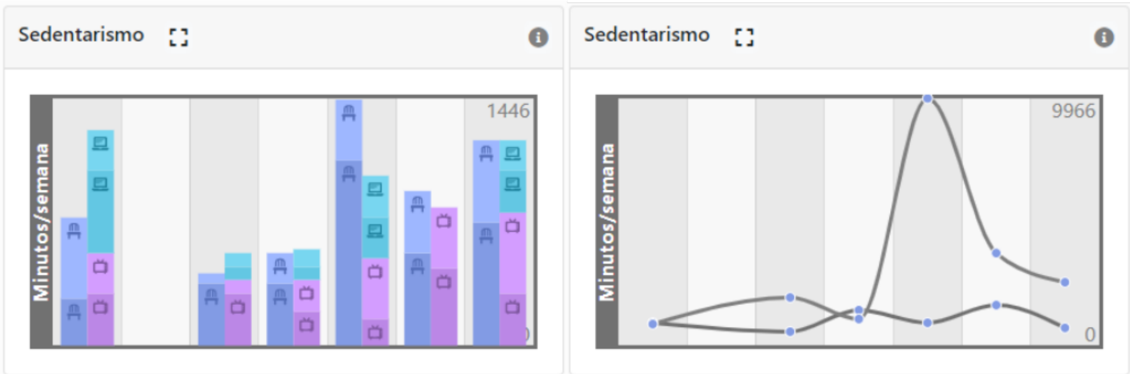


Source: Author

5.3.2 Sedentary Behavior

Two different visualizations were created to show sedentary results for single and multiple participants (Figure 5.12). Single patient's sedentary records are shown by means of two stacked bar columns for each phase between Basal 1 and the 4-Year Visit: the first bar depicts time sitting down during the week and the weekend, and a second column represents time watching TV during the week and weekend, and working or studying during the week and weekend. It was decided to separate the activities in these two different groups since it is likely that time watching TV and working are also being represented inside the time sitting down. This way it is possible to visualize what percentage of the sitting time is attributed to these activities. Each activity is represented by its own icon and color. Bars representing the same activity but at different times of the week are represented with the same color but in different lightness (for activities performed during the week a darker color is shown compared to the color attributed to the same activity during the weekend). The resulting visualization is shown on the left of Figure 5.12. A different visualization was chosen for multiple participants. The total minutes per week of all activities are presented on the y-axis of the visualization, and each participant is represented by a different line (right of Figure 5.12).

Figure 5.12: Sedentary behavior visualization for a single (left) and multiple (right) patients. On the left, two columns are plotted for complementary types of activity. Weekend values are shown in a lighter color compared to week values. On the right, the total minutes per week of inactivity is shown.

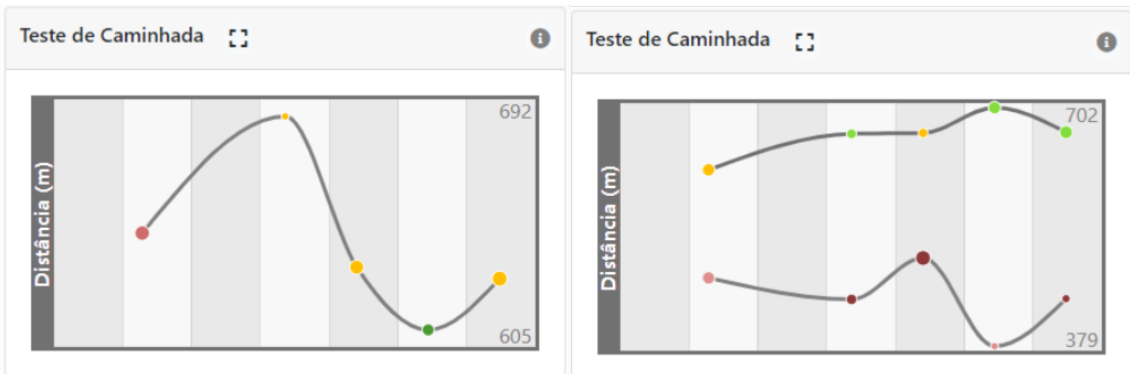


Source: Author

5.3.3 Thread mill

A visualization was created in order to view results from thread mill exams performed during visits (Figure 5.13). The distance reached during the test is plotted on the y-axis, while the circle's size represents the patient's heart rate during the exercise. The circle's color shows the level of activity according to the Borg Scale (BORG, 1982). The heart-rate zone was also calculated and presented in the tooltip for each point. The Karvonen formula (KARVONEN E. KENTALA, 1957) was used to calculate each range. The resting heart rate used in the equation was gathered from the heart rate measurement collected using the ANT questionnaires.

Figure 5.13: Thread-mill data visualization for a single (left) and multiple (right) participants. Each line shows a different participant where the y-axis shows distance in meters, the size of the circle represents heart rate and its color shows the level of activity according to the Borg Scale.



Source: Author

5.3.4 Accelerometer

A visualization was created to show the number of steps performed by participants and in which fitness category they belong to (bottom of Figure 5.14) as a result. A line is drawn for each participant selected, its height representing the number of steps taken. The background is painted according to the different categorical ranges defined by the study, from red (less than 5000 steps per day) to strong green (more than 10000 steps per day). Each point is also colored by the category of physical activity calculated using the trial's guidelines of recommended minutes of activity per week.

As recommended during one of the formal evaluations (described in Chapter 7), a different method of visualizing these values was also created, shown in the upper section of Figure 5.14. Instead of showing the number of steps per day in the y-axis, the second method shows the minutes per day of physical activity, painting on the background each range's category as defined by the trial's specialists. The color of points show the category for the number of steps taken. Users can choose between the two visualizations using the buttons located on the top.

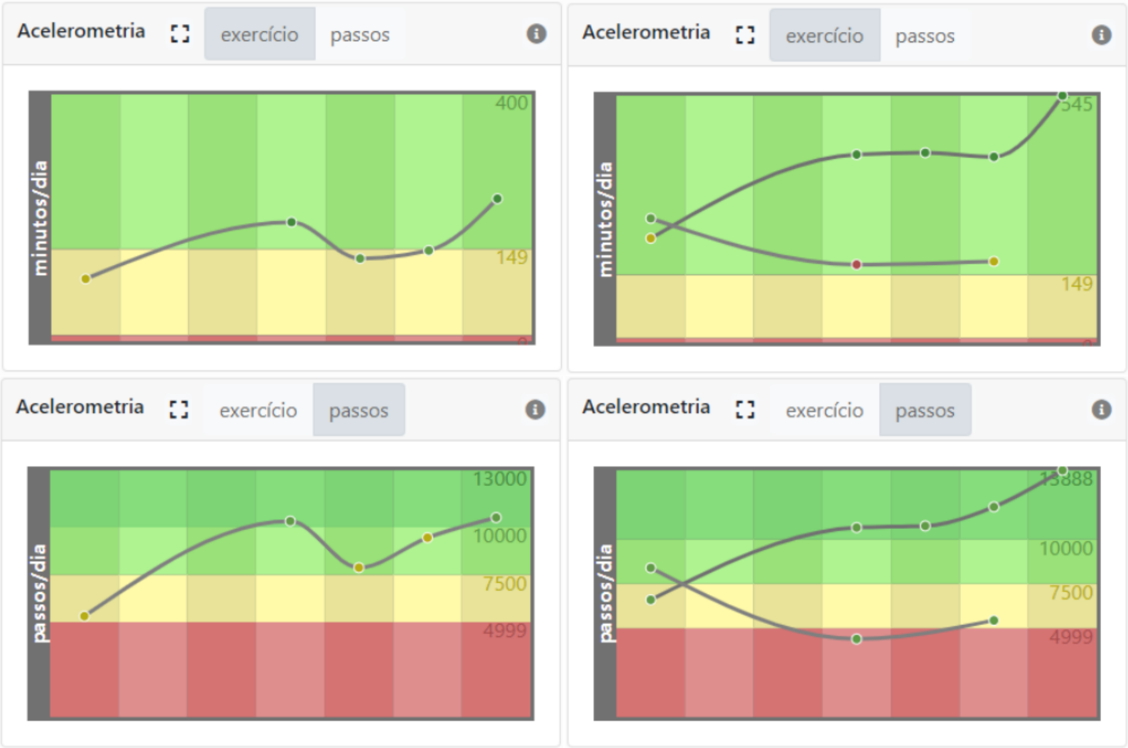
5.3.5 Weight

Two types of visualizations were created for viewing weight measurements: one showing BMI and another showing the raw weight. The calculated BMI is plotted in a graph where each participant is represented by a line (top of Figure 5.15). The graph's y-scale ranges from the lowest to the highest BMI score. The commonly accepted ranges by the World Health Organization (WHO)[2] are color-coded on the background of the visualization, showing underweight (under 18.5 kg/m^2), normal weight (18.5 kg/m^2 to 25 kg/m^2), overweight (25 kg/m^2 to 30 kg/m^2), and obesity (above 30 kg/m^2). A line shows the selected participants' BMI for every phase presented.

As recommended during one of the formal evaluations (described in Chapter 7), a second method of visualizing these values was created, shown on the left of Figure 5.15. In this version, the raw weight is plotted on the y-axis of the graph.

[2]WHO | Mean Body Mass Index <https://www.who.int/gho/ncd/risk_factors/bmi_text/en/>

Figure 5.14: Accelerometer data visualization for single (left) and multiple (right) participants. Two versions are available, one primarily showing average minutes of physical activity as the y-axis and another showing the average number of steps per day. Categorical classifications for each variable are represented as background color. The visualizations on the left show the same participant, and the visualizations on the right show another two participants.



Source: Author

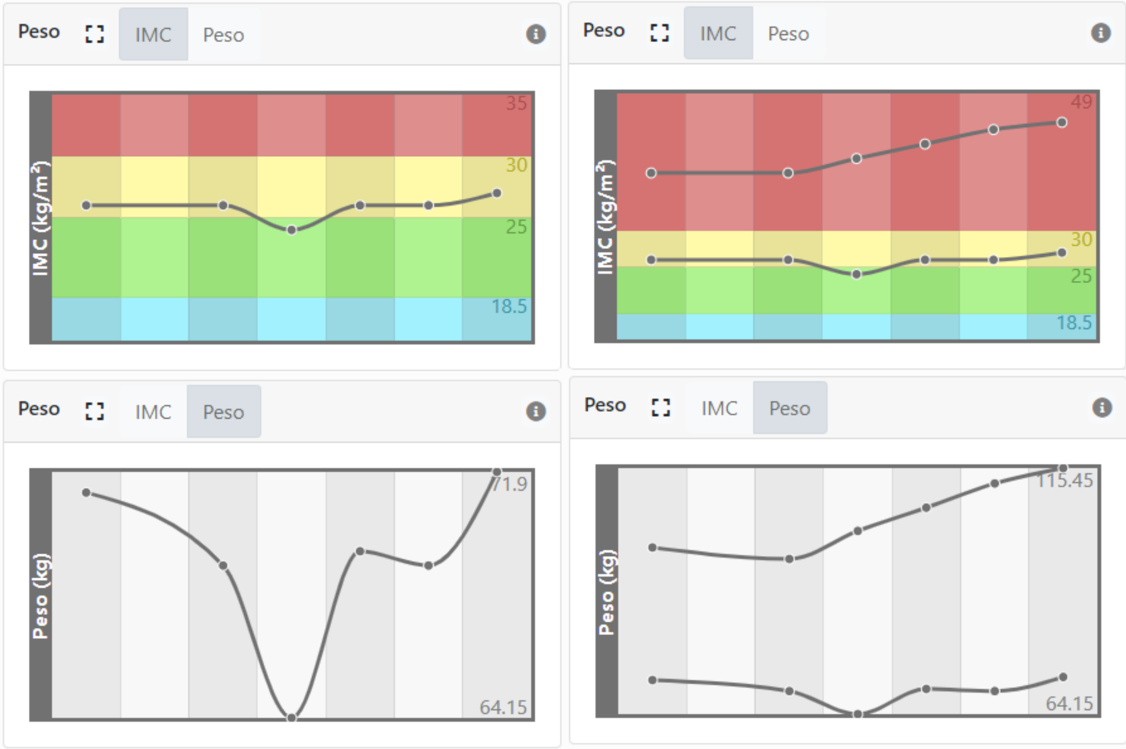
5.3.6 Blood Pressure

Two different visualizations were created for viewing the blood pressure of a single and multiple patients (Figure 5.16). When viewing information from a single participant, a rectangle is drawn where the top is located on the Systolic blood pressure value on a blood pressure scale, and the bottom ends on the Diastolic value of the patient. A color is assigned to the rectangle depending on metrics defined by the United Kingdom's Blood Pressure Association[3] , ranging from blue (low blood pressure) to red (high blood pressure).

Another visualization is generated when multiple participants are selected. In this case, the values on the y-axis correspond to the sum of both Systolic and Diastolic blood pressures, allowing for an overview of the patient's overall blood pressure. Each patient is represented by a line, and the points are color-coded using the blood pressure metrics

[3]Blood Pressure : Blood Pressure Chart <http://www.bloodpressureuk.org/BloodPressureandyou/Thebasics/Bloodpressurechart>

Figure 5.15: Weight data visualization for single (left) and multiple (right) participants. Two versions are available, one showing patients' BMI, and another showing their raw weight. In the BMI version, categories of weight are color-coded on the background of the graph. The visualizations on the left show the same participant, and the visualizations on the right show another two participants.



Source: Author

as well.

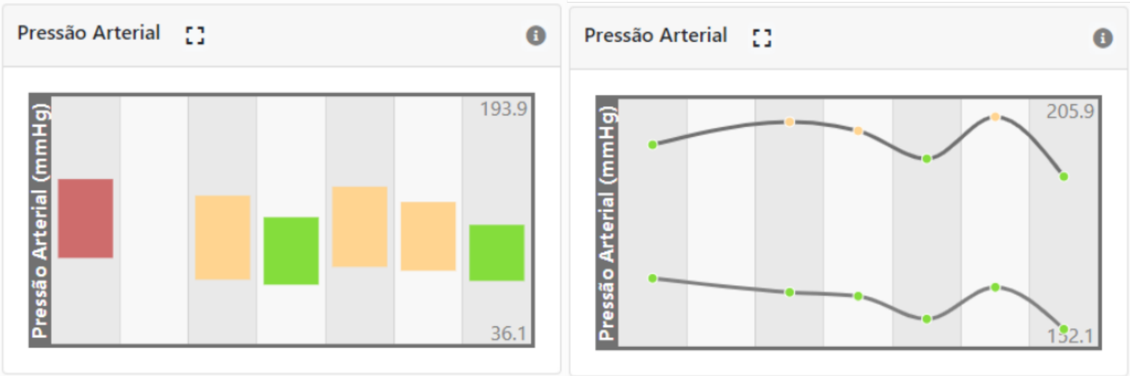
5.3.7 Body Measures

Body measurements can be viewed in two different visualizations. In the first one, circumference measurements are plotted (top of Figure 5.17), and the y-axis is segmented in three parts, one for each measure. Each of these stacked parts contains its own scale and an icon depicting which measurement they belong to.

While the view can be useful to analyze these three measurements from a couple of participants, it does not provide much analytical information nor facilitate the comparison between larger groups of participants. With this in mind, a second visualization was created, showing the waist to hip ratio of the subject. This ratio can be used to indicate obesity by comparing it to guidelines provided by organizations such as the World Health Organization (WHO)[4] or the Deutsche Gesellschaft für Sportmedizin und Präven-

[4]WHO | Waist circumference and waist-hip ratio <https://www.who.int/nutrition/publications/obesity/

Figure 5.16: Blood pressure data visualization for a single (left) and multiple (right) participants. On the left, Systolic and Diastolic blood pressures define the rectangles, which are color-coded following the United Kingdom's Blood Pressure Association metrics. On the right, lines represent multiple participants, with points also representing blood pressures and the same color-coding scheme.



Source: Author

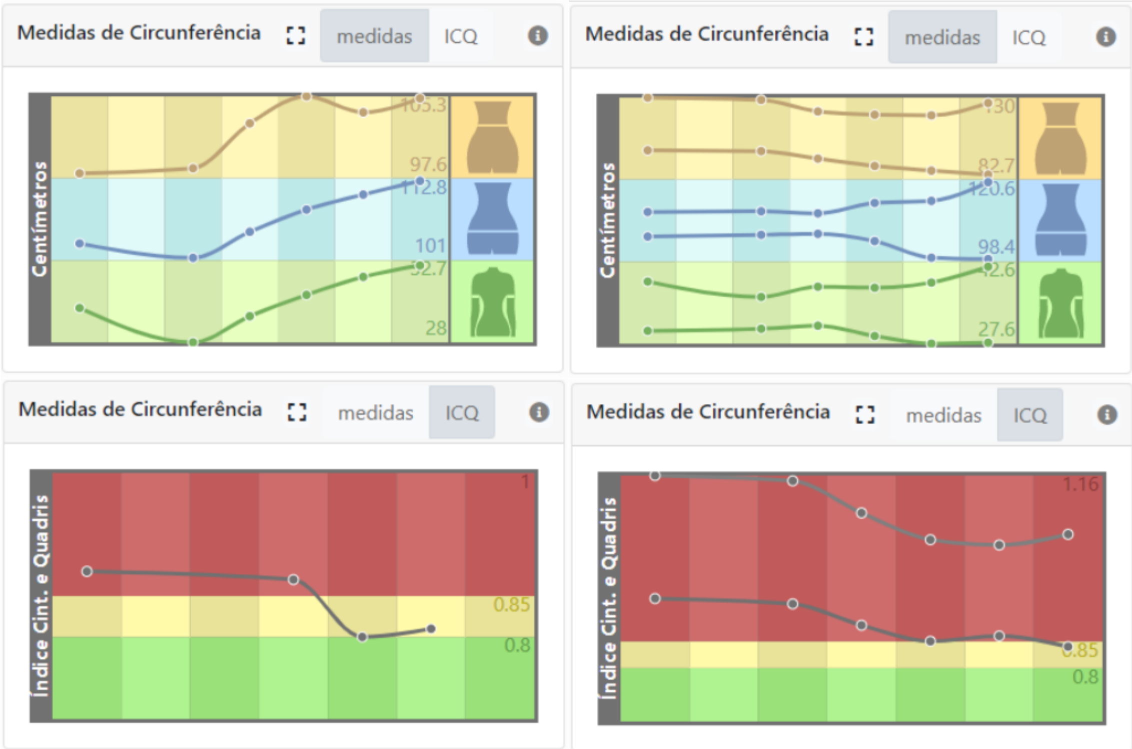
tion (DGSP)[5] , which establishes that values below 0.8 indicate normal weight, values between 0.8 and 0.85 indicate overweight, and any values above that are signs of obesity.

Figure 5.17 (bottom) shows the waist to hip ratio in the y-axis and each phase on the x-axis. The background of the graph represents the metrics mentioned before. A button is available on the top to change between the two visualizations available.

WHO_report_waistcircumference_and_waisthip_ratio/en/>

[5]DGSP | Deutsche Gesellschaft für Sportmedizin und Prävention <https://www.dgsp.de/texte/seite.php?id=278046:>, Appendix 3 to the S 1 guideline - preventive medical check-up

Figure 5.17: Body measures visualization for a single (left) and multiple (right) participants. This graph has two versions available. On the top, the plot is separated in three parts, one for each measurement of waist, hip and arm. On the bottom, the waist/hip ratio is calculated and plotted while the background shows guidelines for the measurement. Each visualization is showing different subjects.



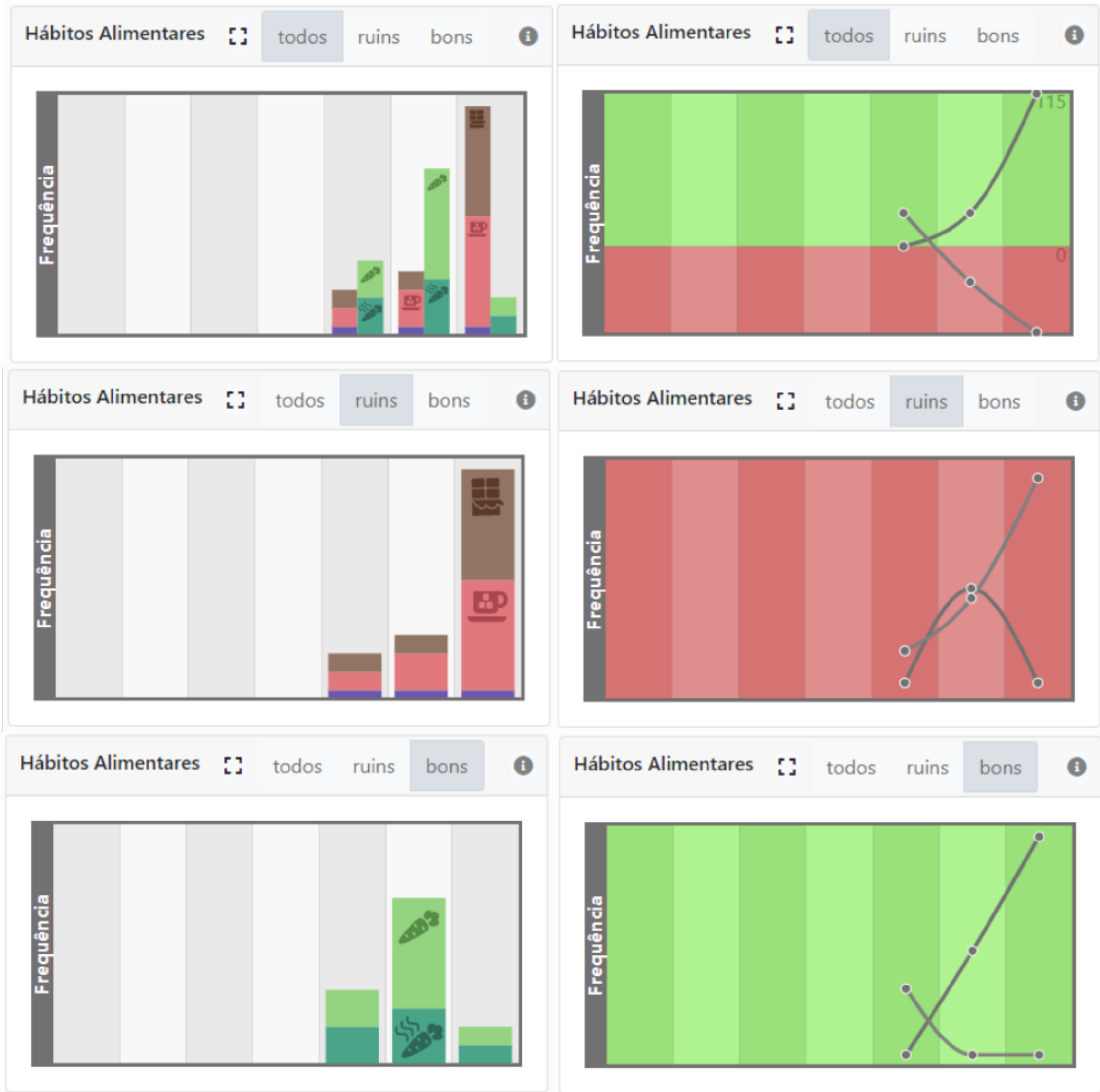
Source: Author

5.3.8 Eating Habits

A visualization was created to show single and multiple patients' eating habits (Figure 5.18). Three versions are provided to help users visualize data more easily, whether a single or multiple participants are selected. The versions can be selected using the buttons on the top of the view. For a single participant, two columns of stacked bar charts are shown, similar to the one described in Section 5.3.2. On the left bar, bad eating habits are stacked and shown by their frequency while, on the right bar, good eating habits are plotted. Such a separation helps researchers to analyze if participants are switching to more healthy eating habits or not. Alternative versions of the graph show only the bad habits bars, or the good habits ones.

For more than one participant, a different set of visualizations is created. For representing all eating habits, we calculate the sum of all positive habits minus the sum of all negative eating habits. If the resulting value is positive, it shows that the participant has more good eating habits than bad ones. A line is then plotted for each participant with the resulting value for each phase. The background of the plot is painted red for all values below 0, and green, for all values above it. Such a visualization can be useful when analyzing nutritional changes in participants. The other versions of the eating habits visualization show only the good or bad eating habits: a line is plotted or each participant showing the sum of the frequency of habits of the selected category. The background is also painted accordingly to reinforce which version of the visualization is being shown.

Figure 5.18: Eating habits visualizations for single (left) and multiple (right) participants. There are three different versions available for each, showing all eating habits, only bad eating habits or only good eating habits. The visualizations on the left show the same participant, and the visualizations on the right show another two participants.



Source: Author

5.3.9 Quality of Sleep

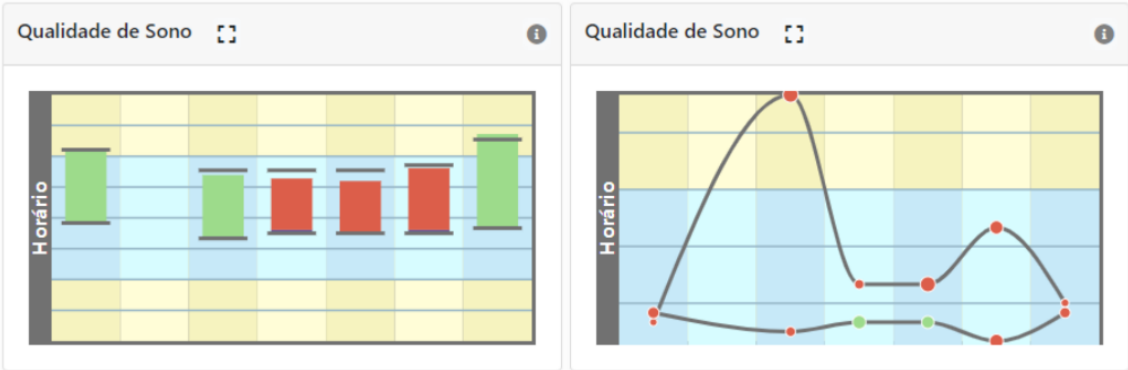
The sleep information of a single or multiple participants is also represented in a specific visualization (Figure 5.19). On the left, data from a single participant is depicted in a plot where the y-axis represents the hours in a day, centered on night-time. Two horizontal marks indicate the time when the participant went to bed, and the time she got up. The height of a purple bar, which is located at the time she went to bed, represents the amount of time the participant spent trying to sleep. A larger rectangle indicates the amount of sleep she had, and its color is defined by the Pittsburgh Sleep Quality Index (BUYSSE CHARLES F. REYNOLDS; KUPFER, 1989) (green for good sleep quality, and red for bad). In theory, the mark indicating the time the patient got up should align with the end of the duration of sleep rectangle, but this is not always the case. This redundancy of information can help discover inconsistencies in data.

Shown on the right of the Figure, a different visualization is rendered when there are multiple participants selected. A line is created for each one, where the position of points in the y-axis shows the time the participant went to bed, while their size represents the amount of sleep, and color shows the PSQI result. While the single-participant visualization shows all hours of the day, this graph only shows hours between the minimum and maximum time being plotted. This approach allows for a better separation between participants since most people tend to sleep at the same time range, causing a cluttered visualization in certain areas of the graph while others would remain empty.

5.3.10 Postnatal Depression

The visualization of the levels of postnatal depression for one or multiple participants is based on the depression score from the Edinburgh Postnatal Depression Scale (EPDS) (COX; HOLDEN; SAGOVSKY, 1987) (Figure 5.20). The background of the graph is painted according to the meaning of the score, coloring green the area representing values between 0 and 10 (no signs of depression), and red for values between 11 and 30 (signs of depression). Even though there are only 2 phases with information on this variable, all the phases are depicted in the x-axis of the graph to maintain the same scale used in the other visualizations.

Figure 5.19: Sleep data visualization for a single (left) and multiple (right) participants. The background shows different hours of the day. On the left, horizontal marks show the time the participant went to bed and got up. A purple bar shows the amount of time spent trying to sleep, and the large rectangle shows the duration of sleep, its color defined by the PSQI. On the right, multiple participants are shown, each represented by a line. The y-axis shows the time the participant went to bed. The size of the point represents the number of hours slept, its color the resulting PSQI.



Source: Author

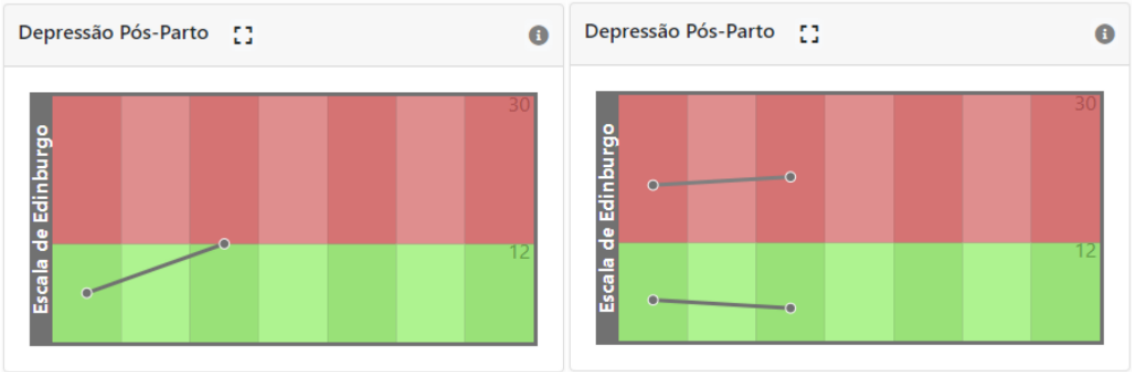
5.3.11 Breastfeeding

A simple visualization was created to show some of the variables important for keeping track of the baby's breastfeeding (Figure 5.21). Each line shows a different participant, where its y position represents the number of days since her baby started taking other liquids besides breast milk. The color of each point shows whether the baby is still breastfeeding (green) or not (red). A participant should have a horizontal line if she remains consistent in reporting the number of days since her baby started taking other liquids, which is usually not the case. As with the Postnatal Depression visualization, even though there are only 2 phases with information on these variables, all phases between Basal 1 and 4-Year Visit are being plotted in order to maintain the same scale as the other graphs.

5.4 Final Comments

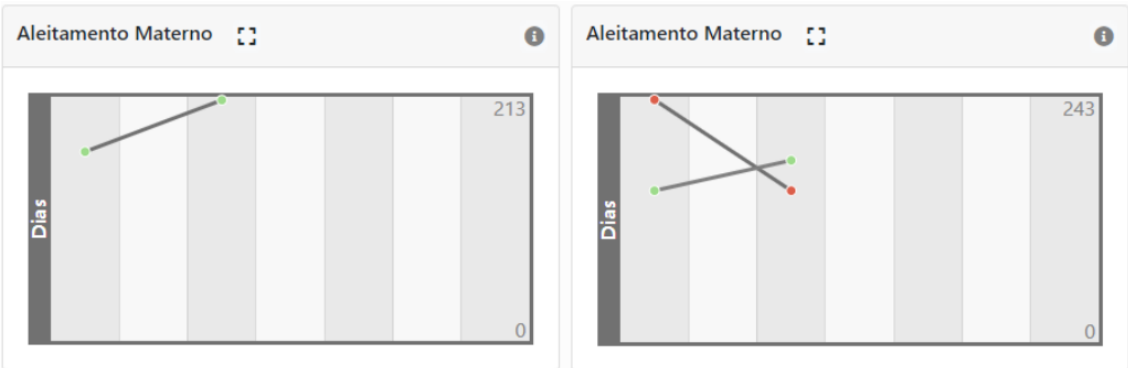
In this chapter, we described in detail all the features of the interactive visualization techniques we have developed for supporting visual insights derived from the exploration of a complex, although not large dataset. Each visual representation or interactive feature was designed to investigate the power of a visualization-based interface in the process of monitoring a long-term clinical trial as well as a tool for discovering patterns and

Figure 5.20: Postnatal depression visualization for a single (left) and multiple (right) participants. Each line shows a participant's score according to the EPDS. The background is painted according to the meaning of the score: red for signs of depression, and green where there are no such signs.



Source: Author

Figure 5.21: Breastfeeding visualization for a single (left) and multiple (right) patients. The position of each line on the y-axis depicts the number of days since the participant's baby started taking other liquids. The color of each point represents whether the baby is still breastfeeding.



Source: Author

trends.

We justify our design choices based on the requirements and feedback we gathered from the trial's researchers. Moreover, we also envisioned visualizations they have not thought about since we foresaw other usage scenarios after having acquired a better knowledge of the clinical trial domain.

As for implementation aspects, the front-end of the system was developed using JavaScript with Angular, Bootstrap and D3 (BOSTOCK; OGIEVETSKY; HEER, 2011) for creating the visualizations. Some auxiliary libraries were also used to generate the dimensionality reduction-based visualizations (numeric and tsnejs), and some other small features such as color pickers (Pickr), tutorials (Intro.js) and interface icons (Font Awesome). Icons embedded in the visualizations were individually created in Inkscape.

As for the back-end, PHP was used to access the PostgreSQL database of LINDA-Brasil. Two data retrievals are performed for the tool, one for collecting the information on the completion of questionnaires for each participant, and another for collecting information about the participant from the surveys. The retrieval regarding questionnaire completion consists of retrieving information, for each participant, of whether each questionnaire has been completed or not. All participants' data are collected in a separate request, where data are then organized and structured by type. Basic information about the participant is primarily stored, such as their IDs, level of education and income, field center, and randomization group. Temporal variables gathered throughout the trial are also collected, grouped by type, and classified by the phase to which they belong.

Since each performed query merged a large number of views from the database, each triggering its own query, the performance of such retrievals was greatly affected. Such a delay resulted in the user waiting nearly half a minute for the application to be ready to use. To tackle this issue, two materialized views were created for each query performed. A materialized view is useful for providing static data since the query is performed, and its results are stored without updating the information every time data is requested. As a drawback of this feature, the data being visualized may not be the most recent one stored in the database. We circumvent this problem by providing an option for the user to update the view manually when necessary, also showing the date of the last update.

6 USAGE SCENARIO

In this chapter, we describe a typical usage scenario, assuming A is a *coach*, i.e., a team member responsible for making phone calls to participants and also tracking their progression during the trial. Although it is a single usage scenario, we separated the description in sections for better organization.

6.1 Retrieving data about a set of participants

Coach A needs to check on the progress of a number of participants that are under her care. She lists the ID numbers of the participants she needs to contact soon: 230424, 260109, 220513, 260107, 220469. Then, she accesses the Participant's Analysis interface, and enters her appointed participants' IDs on the search bar at the upper left corner of the interface, one at a time (Figure 6.1). Their corresponding dots are outlined in black in the overview visualization, and subsequently, the graphs on the right side of the view show the values of their temporal variables over time. This visualization allows coach A to check their progression and compare the evolution of the participants as a group. She can obtain more detailed data about each one by hovering an entry on any of the graphs, which also causes highlighting the participant in all other views. She clicks on the "bookmark" button at the top of the interface, thus saving the outlined group of participants. Such an action allows her to retrieve this group, if she alters the selection.

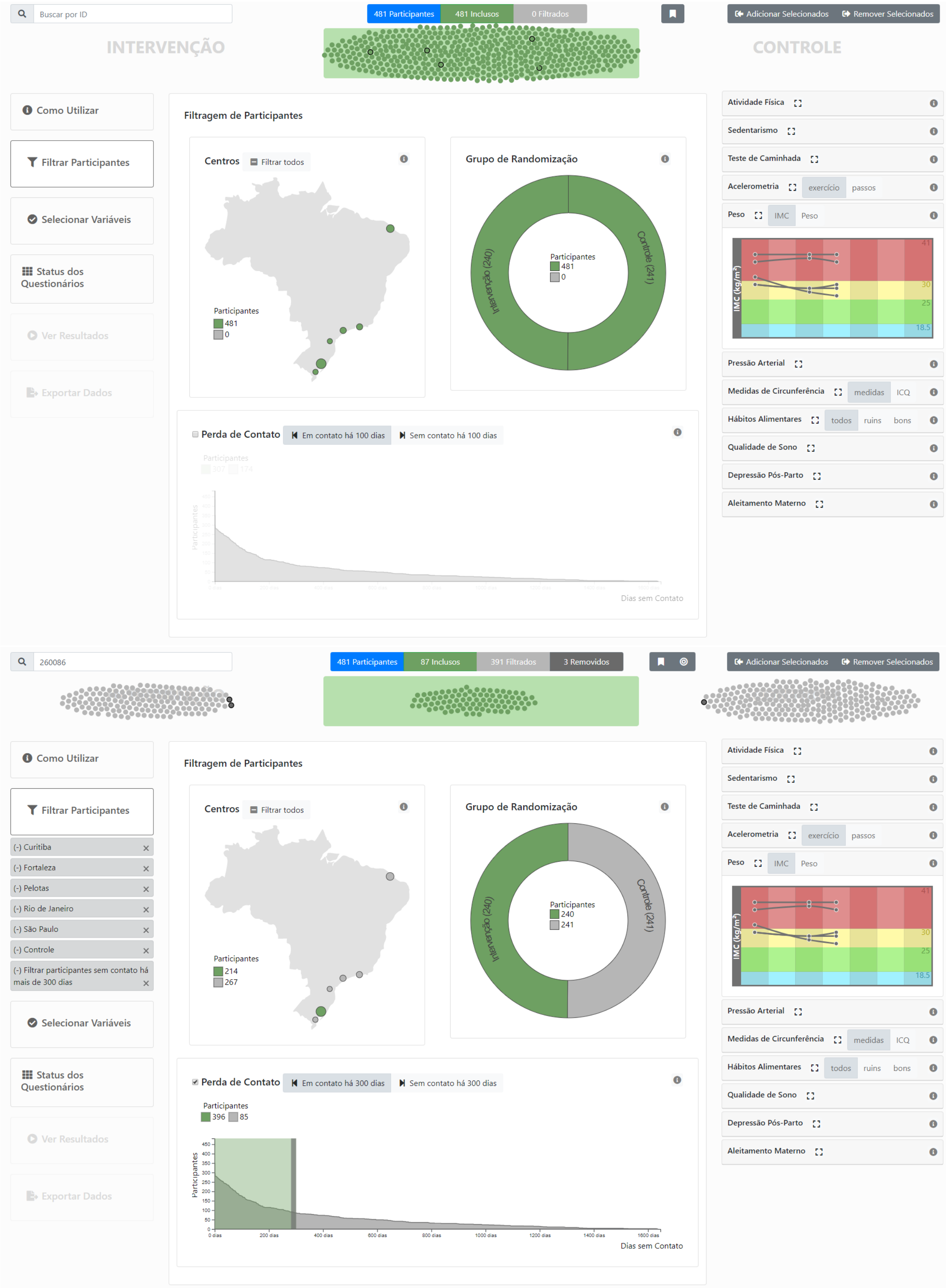
Figure 6.1: Participant’s Analysis interface after team member A enters all the participants’ IDs under her coaching and compares their weight using the BMI visualization, while highlighting participant 260109. Her selected participants are marked with a black outline in the overview, and other temporal variables graphs can be visualized with a simple click on their identification tab.

Source: Author

6.2 Filtering Out Participants

Coach A would like to compare the selected participants to others from the same field center. She enters the menu option "Filter Participants" and checks the available visualizations. They show that every field center and randomization group are currently selected. Coach A then clicks on the button at the top of the field center visualization to deselect all research centers. All subjects are deselected, and she observes the movement of participants in the overview visualization. Since A is only interested in viewing participants from Porto Alegre, she selects that city on the map. This will cause all participants from Porto Alegre to reenter the center of the overview. She is also only interested in comparing participants belonging to the Intervention group, so she deselects the portion of the chart representing the Control group of participants. Now, participants that are from Porto Alegre but belong to the Control group are moved out, to the right side of the overview visualization. A would also like to exclude from the included participants anyone that lost contact with the trial for more than 300 days. To achieve this, she enables the ’Lost Contact’ filter and moves the area selected until it reaches 300 days. This action filters out a number of participants to the left side of the overview visualization (since they all belong to the Intervention group as an effect of other filters already applied). The filters applied can be seen in Figure 6.2).

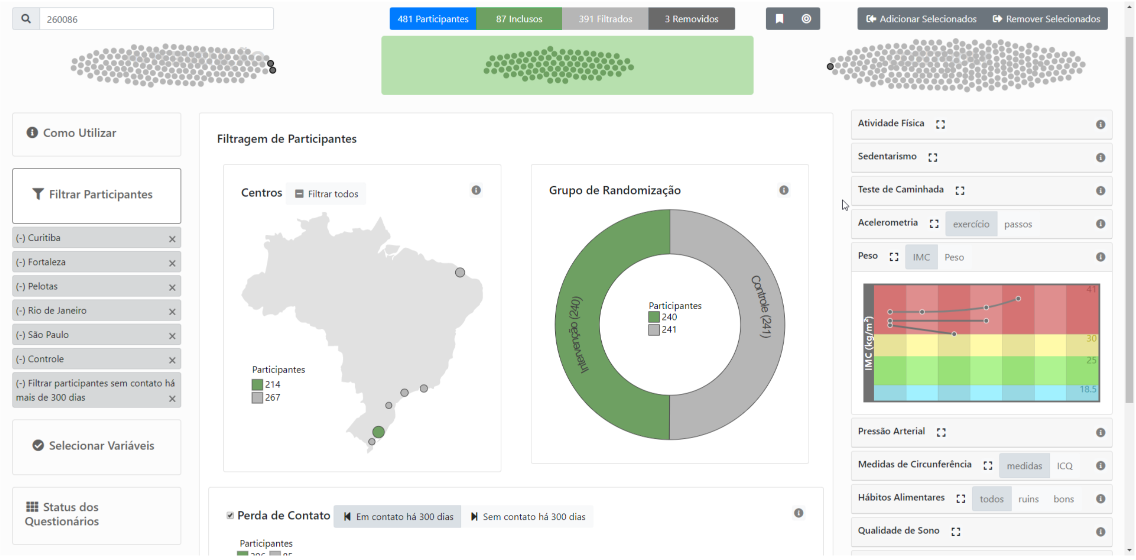
Figure 6.2: On the top, the filtering menu before any filters were applied. On the bottom, filters applied by A, with their respective breadcrumbs appearing on the left.



Source: Author

There are a few participants that have been wrongly randomized and should be excluded from any analysis performed. She has a list of these participants' IDs and enters them on the search bar at the upper left corner of the screen. The subjects are outlined in black in the overview visualization, and new buttons appear on the top right of the page. A clicks on the button that allows excluding outlined participants from the selection, and they move to the set of filtered out participants, painted with a stronger shade of grey (Figure 6.3).

Figure 6.3: Participant's Analysis interface showing removed subjects on the left and right side of the screen in a darker shade of grey. The counter for removed participants also appears on the top of the view.

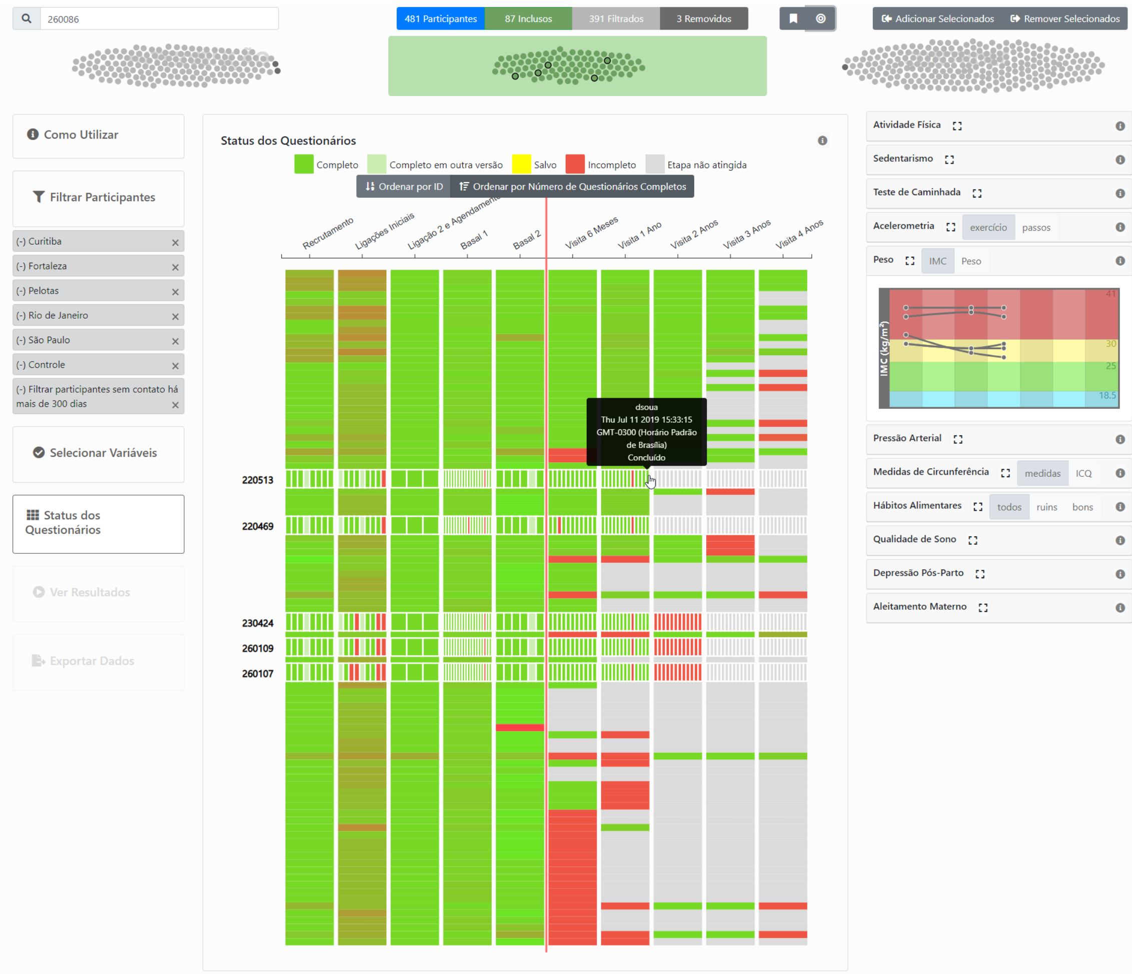


Source: Author

6.3 Inspecting questionnaire status for a set of participants

Now coach A would like to check what questionnaires were already completed for her participants. Then, A clicks on the 'Questionnaire Status' menu option, and the corresponding visualization is displayed with her participants highlighted and shown in more detail (Figure 6.4). In the detailed view, she examines if there is any survey left incomplete from previous phases, or if the patient is late for the next phase.

Figure 6.4: Questionnaire Status visualization showing A's participants in detail. The questionnaire 'DOSUA' of participant 220513 is being hovered, showing information on its completion date.



Source: Author

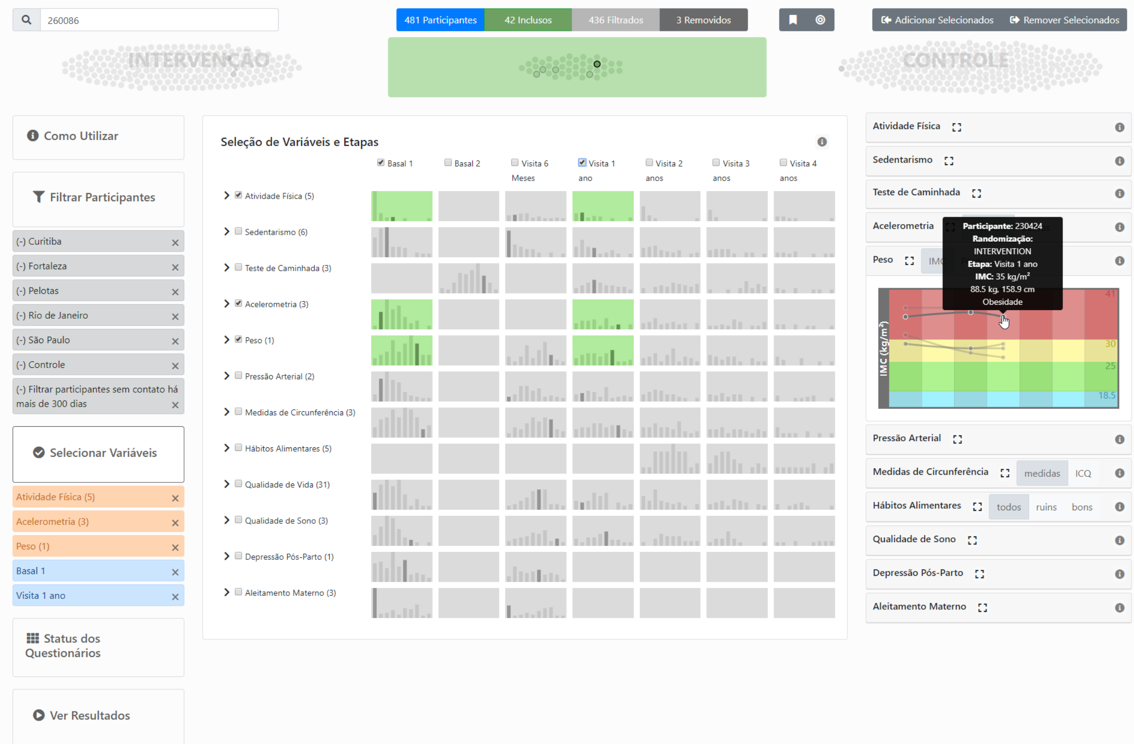
6.4 Inspecting the evolution of participants

Next, coach A selects the menu option 'Select Variables' for indicating which variables from which phase she wants to inspect and use for comparison. By checking the histogram matrix visualization, she can see a normalized distribution of the participants' traits for each combination of variables and phase. She can observe the number of participants who have that combination available. Furthermore, by hovering a specific participant in the overview visualization, the matrix highlights the bins of the histograms the hovered participant belongs to, showing which phases she has already completed and which variables are recorded for her (Figure 6.5).

She decides to inspect the evolution of specific aspects and selects variables of physical activity, weight, and accelerometer measured in phases Basal 1 and 1-Year Visit.

This action highlights all histograms of the selected variables and phases in the matrix, while also filtering out participants in the overview visualization to remove those that do not have enough information to be displayed. Next, she can check whether her participants (those from her first list) were filtered out by such actions. Since they weren't, she can proceed to the 'See Results' menu option.

Figure 6.5: Histogram Matrix visualization with variables and phases selected by A. She highlights participant 230424 in the weight visualization, which also highlights its respective bins in the histograms.

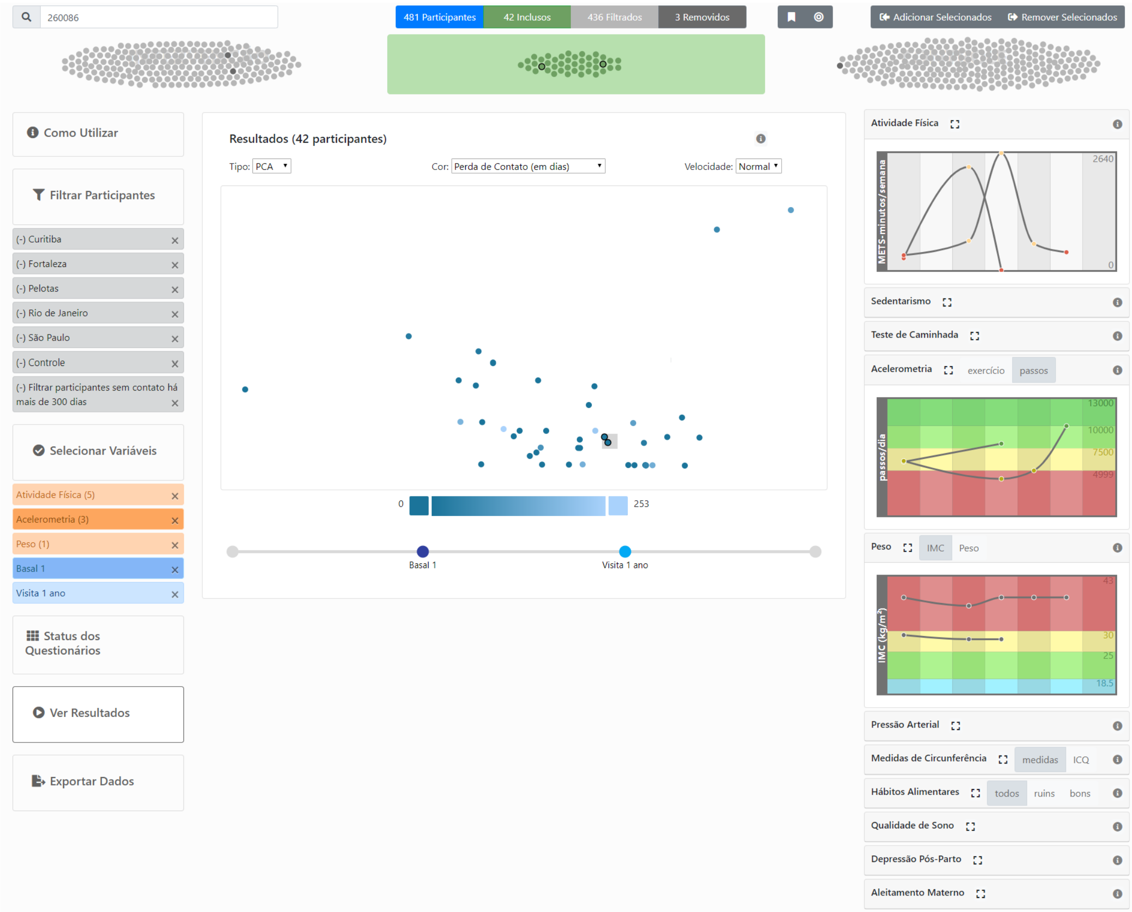


Source: Author

In the 'See Results' option, the PCA-based sactterplot is generated for the Basal 1 phase with all unfiltered participants. A timeline at the bottom of the PCA graph shows all the chosen phases, Basal 1 and 1-Year Visit, each displaying a different visualization when selected. Her participants are also marked with a black outline in this plot, which can help her to find others that are close to them, meaning they show similarities regarding at least some of the previously chosen variables. She assigns loss of contact as the color of each participant in the scatterplot.

Coach A now selects two of her participants directly on the scatterplot to check their temporal progress, differences and similarities (Figure 6.6). In PCA, typically, some of the variables have more considerable influence in the position of points, which can be seen clearly by analyzing the graphs showing the selected variables. She can interpret how their personal histories evolved along with the phases of the study and what other aspects could have influenced this outcome. After comparing these close subjects, she can return the selection to all her participants by loading the previously bookmarked selection and repeat the analyses until she finds any interesting facts.

Figure 6.6: Cohort scatterplot visualization created using PCA. Two participants that are drawn close in the plot are selected, with their graphs for physical activity and accelerometry shown on the right. In these graphs it is clear that both participants had very similar values for these variables during the first phase.



Source: Author

6.5 Final comments

Other possible usage scenarios could have been described herein. For example, the statistics group can use the interface for exploring the data about different subsets of participants to design hypotheses to be tested. They could perform preliminary comparisons between Control and Intervention groups in the same center or across different centers. Coaches can use the plots for a single participant to produce a report about her progress, which could be used to impact her commitment with good habits positively. Researchers can also use the plots to illustrate their reports and papers. We restrained ourselves to the coach usage scenario since we learned from the meetings that it is the one likely to be used more often.

7 USER EVALUATION

The first formal evaluation was performed by one of the trial researchers so that we could collect feedback regarding features as well as usability issues. Then, the final version of the interface underwent two formal evaluations, one with clinical trial researchers, and another with people who had no epidemiology background. These two formal evaluations are described in this chapter.

7.1 Expert Evaluation

The first formal evaluation was conducted to assess the usability of the tool and know what tasks would be hard to perform without assistance. This evaluation was performed by experts on the field of epidemiology, preferably by specialists with connections with the trial.

7.1.1 Method

Systems should be tested by the target audience doing their own work, instead of being based on abstract operations defined by developers (MUNZNER, 2009). Based on this, we asked researchers to use the tool freely and collected answers using standardized usability questionnaires (BROOKE, 1996; LAUGWITZ; HELD; SCHREPP, 2008) and other more specific questions about each presented visualization. Specific questions were generally regarding the usefulness of each view for tasks performed in their workflow, whether they understood certain aspects of the visualizations, if they used the tutorials available and if these tutorials were necessary for their understanding of the tool. We also asked if they were able to perform specific tasks for each view, which we expected they could execute without assistance. There was also a variety of textual input fields that could be used to leave comments, suggestions and problems for each part of the interface.

They were invited by e-mail to interact with the system and fill the questionnaires, which are included in the Appendix, Section B.3. Participants from outside of the study were presented to the interface in person since it was their first time accessing the system.

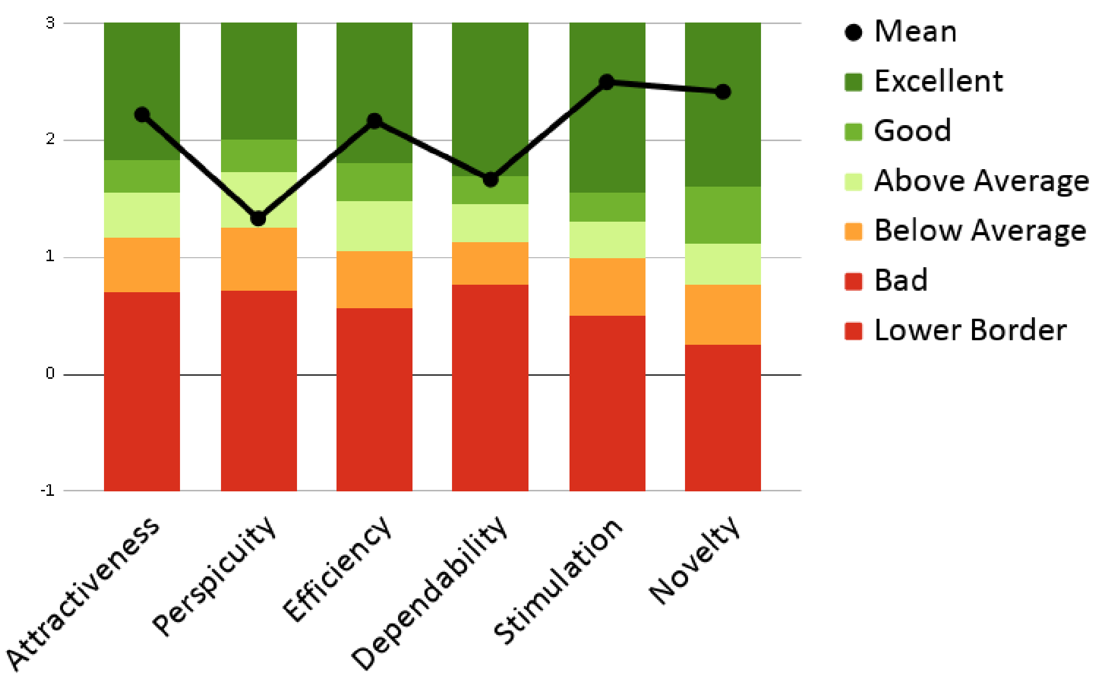
7.1.2 Demographics

This evaluation was conducted with two members of the LINDA study and a third external researcher with experience in other software for the management of clinical trials, all females. The first member is 34 years old, has a Ph.D. Physical Education, and has been working in the LINDA study for nine years. The second member is also 34 years old, has an MSc degree in Nutrition, and six years of working in the LINDA study. The external specialist evaluator is a 32-year old post-doctoral researcher with a Ph.D. in Nutrition.

7.1.3 Results

Since we had only three specialists, the results will be presented and discussed qualitatively. Nevertheless, results from User Experience Questionnaire (UEQ) (LAUGWITZ; HELD; SCHREPP, 2008) (Figure 7.1) and System Usability Scale (SUS) (SUS. . . , 1996) (average score of 78.3) were positively increased compared to the preliminary evaluation, performed during the design process.

Figure 7.1: UEQ benchmark results from the specialists' final evaluation (3 users).



Source: Author

7.1.3.1 Participants' Information Analysis and Overview Visualizations

Regarding the Participants' Information Analysis, all specialists agreed or strongly agreed that they understood how to use each feature of the interface (such as filtering out, selections of variables, and results). Two out of three agreed that the breadcrumbs items generated after each filter, variable, or phase is selected was useful for understanding what was being enabled. Two also agreed that the tool helped them discover information that would be hard to achieve otherwise.

As for the Participants Overview visualization, one participant was neutral, and the others agreed that the visualization helped them understand how their actions affected the selection of participants. The neutral user (a specialist from LINDA research team) also commented that she found the visualization and selection possibilities interesting, although the selection (especially including variables) was not intuitive and required more familiarization.

7.1.3.2 Filtering Out

All three specialists strongly agreed that the movement of participants from inside to outside in the Participants Overview was useful feedback when applying filters, helping them comprehend how many subjects were affected by them. When asked about the number of filtering options, one found that there were few options available, while the other two disagreed with that. Only the external specialist had problems in understanding what was being filtered out by the randomization group.

We asked specialists whether the visualizations helped them understand how the filters worked. For the field centers, two specialists agreed or strongly agreed that it helped while the first trial member disagreed. In the randomization group and lost contact visualizations, a similar pattern could be seen, although the second trial member was neutral regarding the lost contact visualization. This specialist also had trouble distinguishing between the two modes of filtering available in the lost contact visualization, which did not happen with the two others.

The first trial member commented that she had not watched tutorials because she felt instructed on the usage during the meetings. Otherwise, she would use them. The second trial member said that she liked the filtering method, especially by field center and randomization group. She noted that the more serious difficulty was understanding the lost contact filter. The external researcher commented that she would like to select what she would like to include during filtering, and not exclude.

7.1.3.3 Variable Selection and DR scatterplots

In the variable selection interface, both trial members agreed that the histograms helped them understand what was being selected. The external specialist stated that the histograms were not easy to understand but was neutral regarding if she understood their meaning.

As for the DRs scatterplots, only one specialist agreed that she understood the meaning behind the positioning of points. The second trial member and the external specialist both stated that they were not familiar with PCA or t-SNE and did not understand very well the logic behind it. The trial member that understood the visualization was the only one to agree that the graph helped her gather insights into trial's progress.

7.1.3.4 Questionnaire Status

All specialists agreed or strongly agreed that they understood the meaning of each line and column of the visualization and understood how selections and filters influenced the view. They also agreed that it was useful as an overview of LINDA's progress regarding questionnaire completion. As an additional comment, the second trial member found it useful, mainly for noticing unanswered questionnaires.

7.1.3.5 Temporal Variables Visualizations

Regarding the graphs generated for the temporal variables of the trial, two specialists agreed or strongly agreed that the visualizations is useful for the comparison of participants, while the other was neutral. They also agreed that the visualizations allow for tracking the participants' progression and disagreed when asked if the colors indicating metrics and categories were unnecessary. When asking about their comprehension for each graph, all participants agreed or strongly agreed that they could understand them. Only visualizations showing eating habits, sleep quality, and breastfeeding had only one specialist agreeing with the statement. The first specialist on the trial commented that they missed numerical labels for each point or on the y-axis. The external researcher commented she wished some basic statistics presented for the variables.

7.1.3.6 Final comments from the specialists

In the final comments section of our evaluation form, the first trial member suggested that in the physical activity visualization a line should be traced in the 150 minute mark, since they use the value as a cutoff point. She also summarized how the tool could be used during their work: "The system allows us to evaluate typos, visualize contact losses with participants, help us prepare for phone sessions with subjects focusing on their needs, while also providing graphs that we can use as a way of delivering results". The second member noted: "I found it to be a good system. Some adjustments could make it even better".

7.2 Non-Expert Users Evaluation

Although expert evaluation is essential for validating a specific visualization system as the one developed in this work, we wanted to verify how our interface would perform when used by people new to the domain. The feedback from non-experts would give us information about basic ergonomic principles of interfaces such as consistency, robustness, guidance and others.

Then, we designed a second experiment where we could gather feedback from more users and check if people new to the system could perform essential tasks. With this second evaluation we also aimed at discovering general usability problems of the tool.

7.2.1 Method

The evaluation was performed in person, one at a time, and the user was observed while interacting with the system. We first presented a text briefly describing LINDA-Brasil and the goals of our work. Then, the user was asked to fill a form with their basic information such as age, education level, and professional area. After having filled in this form, we guide the user through the interface showing its most relevant features, and how they could be used by specialists working on the trial. Then, the user was asked to interact with the interface for as long as needed and, if necessary, check hints and tutorial videos available on the tool. After feeling confident about the tool, the user was presented with tasks based on the usage scenario (described in Chapter 6). Each task was timed, and the user was asked about his/her perceived difficulty for each one, using the Single

Ease Question (SEQ), which ranges from 1 (very hard) and 7 (very easy). Then, UEQ (LAUGWITZ; HELD; SCHREPP, 2008) and SUS (BROOKE, 1996) questionnaires were applied, also leaving a comments section for any additional feedback. Questionnaires used in this evaluation are included in Appendix, Section B.4.

7.2.2 Demographics

Sixteen non-expert users participated in this experiment, ranging from 21 to 59 years old, 75% male and 25% female. Only 18% had some previous knowledge about LINDA. 87% of participants had graduated university, and 50% had an MSc degree. 81.2% graduated in Computer Science and are MSc or Ph.D. students of varying topics inside the field, *i.e.* computer networks, visualization and deep learning. 18.7% of participants were graduated in other areas, such as design and social studies.

7.2.3 Results

During the exploration phase of the evaluation, most users asked questions and seemed interested in using the interface. 18.7% of the users tried dragging multiple participants into the Participants Overview visualization to select them (a feature that is available in the Cohort Scatterplot). 31.2% of users looked into greater detail in each temporal visualization. 12.5% of participants tried clicking on each questionnaire inside the Questionnaire Status visualization to select it (a feature that was not implemented in the system).

Table 7.1 shows the tasks presented to users, their average success in completing them, their perceived difficulty based on the Single Ease Question (SEQ) and average duration of each. The description of the task is a simplified version of the text, and complete descriptions can be found in the Appendix, Section B.4.

In task 1.1, users were asked to annotate five IDs in a piece of paper and then select them on the interface. All users entered the IDs using the search bar, but 12.5% of them clicked on the "bookmark selection" button after each ID, and 6.2% of them clicked on the 'Add selection' button after entering each ID. These actions are unnecessary for the task but do not hinder it in any way. 12.5% of users stated that it would be easier if a list of IDs could be entered on the search box instead of entering them one by one. The task had one of the longest average duration since it demanded manually entering each ID instead of copying and pasting the numbers. This allows us to consider the result as the longest possible duration for the task.

Task 1.2 was considered easy among users, since it was only necessary to remember which button saved the currently selected participants, which was explained during the presentation of the interface.

Table 7.1: Results from the formal evaluation tasks performed by 16 non-expert users. Difficulty was self-reported by users and measured by the Single Ease Question (SEQ), ranging from 1 (very hard) to 7 (very easy).

	Task	Avg. Success Rate	Avg. Difficulty	Avg. Time
1.1	Select participants 230424, 260109, 220513, 260107, 220469	100%	6.3	47.2s
1.2	Save group of participants	100%	6.9	2.5s
2.1	Filter out all field centers except Porto Alegre	75%	6.6	11s
2.2	Filter out randomization group Control	100%	6.5	8.25s
2.3	Filter out participants with more than 300 days since they lost contact with the study	87.5%	6.1	28s
2.4	Check the total number of participants filtered out	93.7%		
3.1	Remove participants 240327, 240287, 260086	93.7%	6.3	41s
3.2	Load group of participants	81.2%	6.6	5.3s
4	Check number of incomplete questionnaires from 230424	87.5%	6.3	25.2s
5.1	Hover participant to check its histogram bins	100%		18s
5.2	Select variables Physical Activity, Weight, Accelerometry, and phases Basal 1, 1 Year Visit	100%	6.5	12.6s
6.1	Change color variable on PCA to Lost Contact	100%	6.8	8.3s
6.2	Find similar participant(s) to one of the selected subjects on PCA	100%	5.5	56.6s

The filtering of data proved to be one of the most confusing parts of the experiment. In particular, in task 2.1, users had a considerably lower success rate (75%). There were two different ways the task could be accomplished: deselecting all cities except Porto Alegre (done by half of the users successful in the task) or clicking on the "Filter

All" button and then selecting Porto Alegre (done by the other half of successful users). Users that chose the second option were considerably quicker than the others, taking on average 8.5 seconds to complete it compared to the average of 14 seconds. Users that failed the task reported that the difficulty was not in executing it on the interface, but understanding exactly what was being asked. The main problem was that, when asked to filter something, some users were unsure if it meant to filter out from the selection or only select it. Similarly, 12.5% also understood the task 2.3 backwards, changing the selection rectangle and doing the opposite of the intended interaction.

In task 2.4, only 6.2% of users answered the question incorrectly, saying the number of subjects included in the selection instead of filtered out. This problem seems to be the same as with previous tasks, showing that a small percentage of users were confused in the nomenclature used but understood how to use the system. The decreasing number of users providing wrong answers in tasks 2.2, 2.3, and 2.4 are compatible with the fact that users who answered incorrectly had the correct answer explained in order to keep future answers consistent.

Before task 3.1, users were asked to deselect the current selection (the initial 5 IDs that they entered on task 1.1). While 6.2% misunderstood this request and thought that they were asked to remove these subjects from the selection, 18.7% made mistakes in this task.

After deselecting them, users were asked to select participants 240327, 240287, and 260086 and remove them from the selection. The removal of participants could be performed in two different ways: dragging and dropping them outside the selection (done by 31.2% of users) or using the buttons on the top left of the page to remove them automatically (done by 62.5% of participants). The average time and difficulties reported by users using the techniques were very similar, although slightly higher for participants using the drag and drop technique (40.4 seconds and 6.2 difficulty on average for dragging and 37.2 seconds and 6.4 difficulties for using the buttons).

During task 3.2, 18.7% of users, instead of loading the previously saved selection, overrode its saved participants by bookmarking the removed participants' selection. This led to reentering all 5 IDs again since they were needed to complete future tasks. One user, in particular, was rather frustrated and suggested that a confirmation popup be added when overwriting a saved selection.

As for task 4, 87.5% of users were able to quickly understand the question and provide the correct answer. 6.2% of users were confused if they should also count questionnaires marked grey or only the ones marked red. 12.5% of users altered the selection to only visualize the participant asked, although it was not strictly necessary since this user was already selected in task 3.2. 12.5% of users missed a questionnaire when counting.

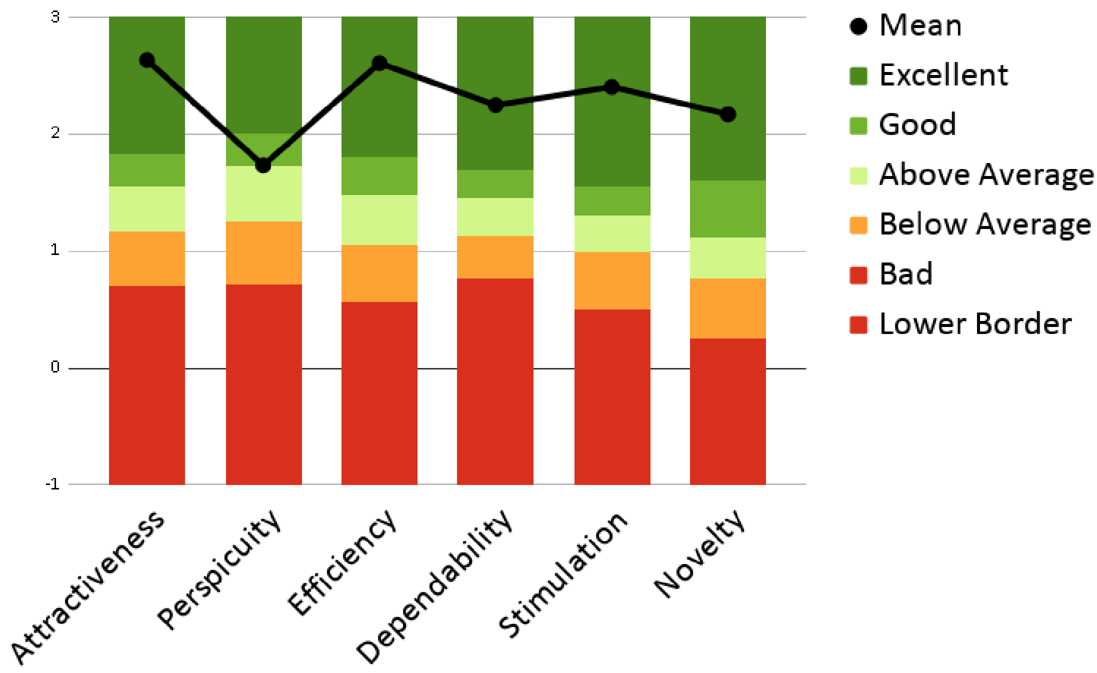
In task 5.1, all users could hover one of the selected participants in order to check its histogram bins. While 81.2% provided a complete and correct answer on the meaning of the highlight, 18.7% were vague in their answers. All users were able to select variables and phases as requested.

All users were able to perform tasks 6.1 and 6.2 successfully. As for task 6.2 (select participants and compare them using the temporal variables' graphs), 12.5% found the task more difficult to perform than others, rating it a 2 and a 3 in difficulty

Since the users were free to provide any similarity between the trial's participants, we did not consider any answer wrong as long as the user was able to provide some comparison. 43.7% of the users compared values for a single phase of the study, while 40% compared them in all phases available. 28.5% found similarities between subjects in the categories defined (*e.g.* overweight, high blood pressure), and 33.3% analyzed their increase, decrease, or consistency of certain variables.

After the tasks were performed, users filled UEQ and SUS questionnaires. Benchmark results from UEQ (Figure 7.2) show excellent results in all categories and a good score for Perspicuity, which indicates how easy it if to get familiar with the tool.

Figure 7.2: UEQ benchmark results from the non-expert users evaluation (16 users).

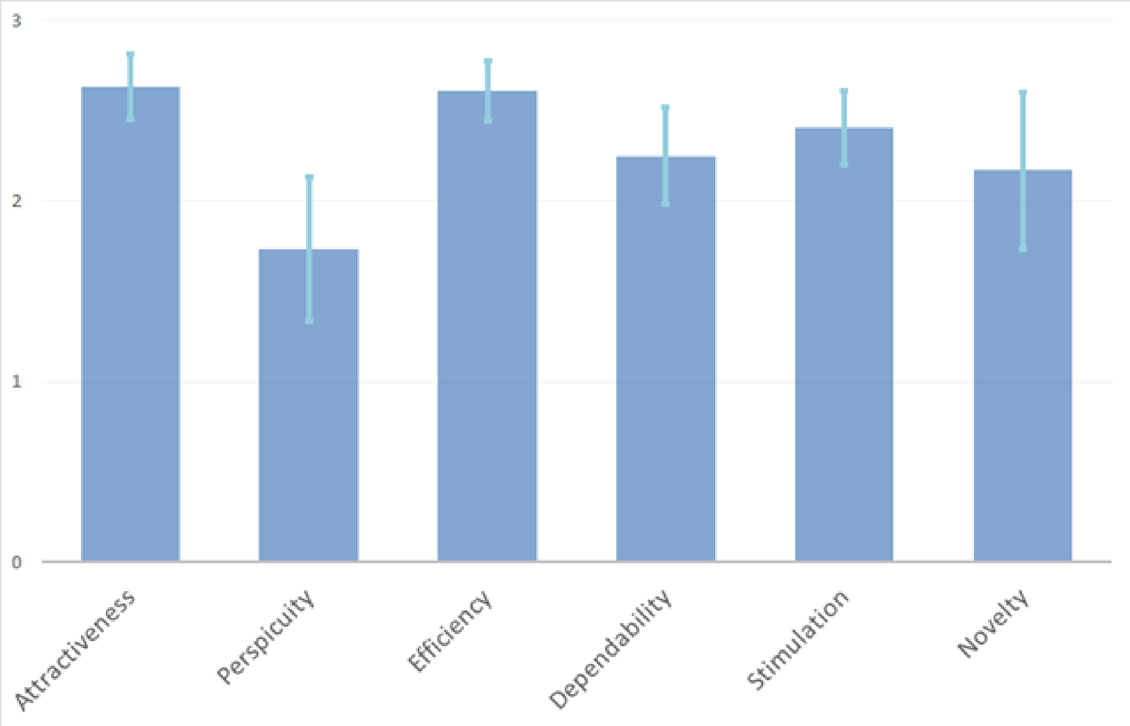


Source: Author

SUS results achieved an average score of 86.2, which can be considered as excellent and above average when compared to mean scores from SUS results for web applications (68.05 points) (BANGOR; KORTUM; MILLER, 2008). Figure 7.4 shows SUS results for even-numbered questions and odd-numbered questions, separately. Although results from individual questions should not be analyzed, most questions have positive answers, with the exception of questions 4 (I think that I would need the support of a technical person to be able to use this system) and 10 (I needed to learn a lot of things before I could get going with this system).

As users finished the test, many pointed out that the system was intuitive and easy to learn. Some also added suggestions in the final comments section of the evaluation form, all related to small changes to some aspects of the tool. Moreover, all non-expert users who left suggestions also said the tool seems to be very useful to the field of study, and it is easy to use, attractive, and well-integrated.

Figure 7.3: Distribution of UEQ answers in each of its categories for the non-expert users evaluation (16 users).



Source: Author

7.3 Final Comments

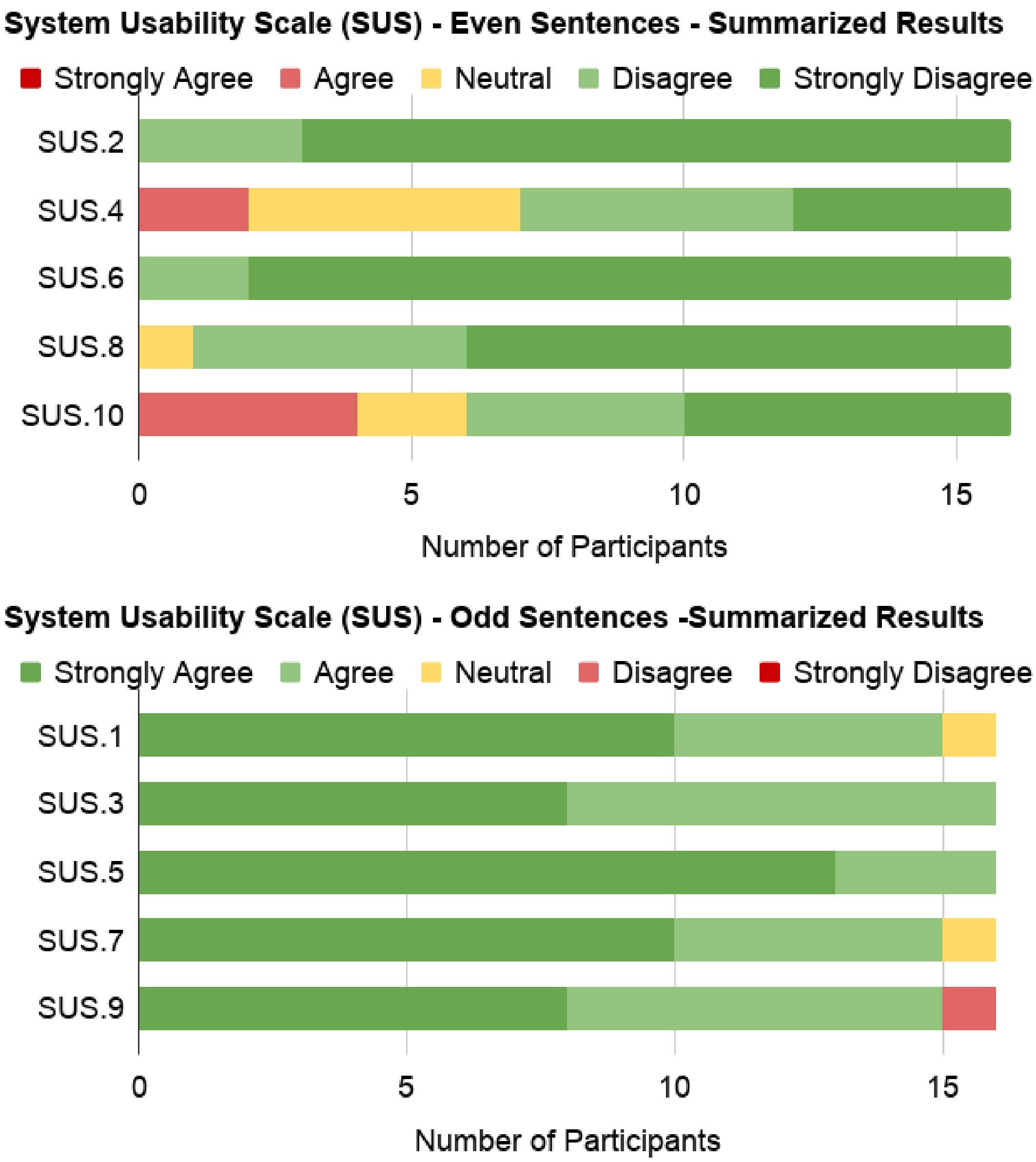
There are several challenges in performing formal evaluations with expert users. First of all, they are in a small number and usually have a tight schedule. The completion rate becomes a more significant problem than in evaluations with non-experts since the process needs to be fitted into their tight schedule. In our case, trying to fit in this situation, we proposed to perform the evaluation remotely, but that seemed to have worsened the problem because there was no commitment to a scheduled date for the test. The experts tended to forget to fill the form and postpone the evaluation several times. Remote evaluations also provide an uncertainty in the way users performed it and harbor outside influence on the answers. Nevertheless, the comments provided by the few who answered were very useful in pointing out problems with the tool and improvements that were not brought up during the informal meetings.

The majority of specialists had trouble understanding dimensionality-reduction based visualizations. Most non-expert users were also unfamiliar with PCA or t-SNE and received a similar explanation as we did with LINDA researchers during informal meetings. Nevertheless, a much smaller percentage had trouble performing the tasks or complained about not understanding the scatterplot. This could be related to the large percentage of computer science majors that answered the survey.

The lack of understanding of more elaborated visualizations by specialists brings the discussion of whether it is worth using such methods instead of more straightforward, universally understood options. We believe that systems directed to a specific audience that will be continuously used can take advantage of more complex interfaces as users have time to get used to more unusual visualizations. Tools focused on occasional use by a large number of users of different backgrounds, on the other hand, would greatly benefit from simpler interfaces.

When comparing results from specialists and non-expert users, we can see that the SUS average score was considerably higher for non-experts (86.2 compared to 78.3 for experts). Also, although such comparison can be biased by the small number of responses from experts, UEQ results for non-experts showed overall better scores, so they seemed to understand how the tools work better. On the other hand, specialists had slightly higher scores for stimulation and novelty parameters, possibly for not being exposed to innovative systems so often, as was common for the majority of non-experts who performed the experiment.

Figure 7.4: SUS results for even-numbered sentences and odd-numbered sentences from the non-expert users evaluation (16 users).



Source: Author

8 CONCLUSION

This work presented a visualization-based interface designed for monitoring the development of a randomized clinical trial focused on the effects of lifestyle intervention in the development of Type 2 Diabetes for patients with Gestational Diabetes Mellitus (GDM). A list of requirements gathered from epidemiologists directly working within LINDA-Brasil was analyzed, and we designed an intuitive interface for easier assessment of the information stored while also allowing for a deeper analysis of similarities between subjects. Visualization techniques were created to allow following a participant's progress and compare it to others. The resulting tool integrates a number of features inspired in previous works in a single interface, creating a hybrid approach for the discovery of similarities and trends between groups of participants and detailed visualizations of individuals.

As for our general research question ("to what extent a set of interactive visualization techniques assists epidemiologists in a longitudinal study?"), the design process we adopted, in tight collaboration with the researchers, which included a preliminary formal evaluation, and the two evaluations we performed with the final interface, provided us with evidence that we have developed a tool which can assist researchers in extracting insights from data collected in longitudinal studies. The results from the formal evaluation by specialists showed us that the interface was well-received among them. One of the specialists stated that "The system allows us to evaluate typos, visualize contact losses with participants, help us prepare for phone sessions with subjects focusing on their needs, while also providing graphs that we can use as a way of delivering results".

Regarding the use of our tool for other clinical trials, many of the concepts and solutions we adopted could be used on studies focused on longitudinal data collection, although the current input of data is tailored to fit LINDA-Brasil study. We add some comments on that in Section 8.2.

8.1 Lessons Learned

After reflecting on the development of this work and its outcome, we arrived at a list of lessons that could be learned from the process of designing the tool. These lessons can be useful when developing systems and especially when a specific group of users is taken into consideration during the design process.

8.1.1 Users are Hardly Prepared for Providing User Requirements

When we first began designing the tool, interviewed specialists seemed to be interested in small features that, while very useful for performing their work, were very far from the potential benefits that could be achieved with a set of visualization techniques. We found out that asking specialists what functionalities they desire, at first, will hardly lead to the optimal design since most users are not aware of the possibilities of analysis and interaction and are mostly unfamiliar with more complex visualization techniques. We filled this gap by creating prototypes and implementing features that were not directly demanded from specialists, but allowed us to show their potential usefulness.

8.1.2 Usability and Innovation need to be Balanced

The unfamiliarity with less common visualization techniques may reveal usability problems otherwise not detected when users are accustomed to the interface. When we demonstrated the use of our tool, in many of our meetings, the specialists spent a considerable amount of time observing some of the graphs to understand their meaning. This brings the discussion of when visualizations should be based on common graphs such as line plots or bar charts, or more complex designs that can bring innovation to an interface. We found out that common graphic designs should be used whenever possible. But, different visualizations can be appreciated by users even when requiring some explanation on the design, as long as they are intuitive in their representation of the data and grounded on widely used visual paradigms.

8.1.3 Formal Evaluations were Essential for Solving Usability Problems

Most of our design process consisted of informal meetings with target users to assess the usefulness and usability of the interface. Although this method provided quick feedback, we found that some potential problems were not brought up by users until a formal evaluation was performed. While new features and ideas were commonly presented during the meetings, experts rarely commented on any negative aspects. However, when a formal evaluation was conducted, users reported issues they found in a less confrontational manner.

8.2 Future Work

There are a number of interesting future works that can be developed to improve the tool and the techniques adopted herein. Regarding the LINDA-Brasil trial, it would be interesting to add the ability to compare multiple cohorts of patients, for improving the analysis of the effects of the intervention in different subjects. Also, we could add the possibility of calculating some basic statistics for subsets of participants.

Although the tool was developed for a specific clinical trial, its concepts and many visualizations can be easily converted to other clinical trials, with some extra-coding for importing data in a standardized way.

Finally, it would be interesting to provide adaptive visualizations, *i.e.*, those that can be modified by the user to better fit with the intended analysis.

REFERENCES

ALONSO; MCCORMICK. Epipoi: A user-friendly analytical tool for the extraction and visualization of temporal parameters from epidemiological time series. **BMC Public Health**, BMC Public Health, v. 12, n. 982, 2012.

BADE, R.; SCHLECHTWEG, S.; MIKSCH, S. Connecting time-oriented data and information to a coherent interactive visualization. **Conference on Human Factors in Computing Systems - Proceedings**, v. 6, n. 1, p. 105–112, 2004.

BANGOR, A.; KORTUM, P. T.; MILLER, J. T. An empirical evaluation of the system usability scale. **International Journal of Human–Computer Interaction**, Taylor and Francis, v. 24, n. 6, p. 574–594, 2008. Available from Internet: <https://doi.org/10.1080/10447310802205776>. Accessed 1 Jun. 2020.

BEAGLEY, J. et al. Global estimates of undiagnosed diabetes in adults. **Diabetes Research and Clinical Practice**, Elsevier Ireland Ltd, v. 103, n. 2, p. 150–160, 2014. ISSN 18728227. Available from Internet: <http://dx.doi.org/10.1016/j.diabres.2013.11.001>. Accessed 1 Jun. 2020.

BERNARD, J. et al. Using dashboard networks to visualize multiple patient histories: A design study on post-operative prostate cancer. **IEEE Transactions on Visualization and Computer Graphics**, v. 25, n. 3, p. 1615–1628, 2019.

BOOTH, M. Assessment of physical activity: An international perspective. **Research Quarterly for Exercise and Sport**, Routledge, v. 71, p. 114–120, 2000.

BORG, G. A. V. Psychophysical bases of perceived exertion. **Medicine Science in Sports Exercise**, Routledge, v. 14, p. 377–381, 1982.

BOSTOCK, M.; OGIEVETSKY, V.; HEER, J. D3 data-driven documents. **IEEE transactions on visualization and computer graphics**, v. 17, n. 12, p. 2301–2309, 2011. ISSN 1077-2626.

BRODBECK, D.; GASSER, R.; DEGEN, M. Enabling large-scale telemedical disease management through interactive visualization. **European Notes in Medical Informatics**, v. 1, n. 1, p. 1172–1177, 2005.

BROOKE, J. SUS: A quick and dirty usability scale. **Usability evaluation in industry**, London: Taylor and Francis, v. 189, n. 194, p. 4–7, 1996.

BUYSSE CHARLES F. REYNOLDS, T. H. M. S. R. B. D. J.; KUPFER, D. J. The pittsburgh sleep quality index: A new instrument for psychiatric practice and research. **Psychiatry Research**, v. 28, n. 2, p. 193 – 213, 1989.

CHO, N. H. et al. IDF Diabetes Atlas: Global estimates of diabetes prevalence for 2017 and projections for 2045. **Diabetes Research and Clinical Practice**, Elsevier B.V., v. 138, p. 271–281, 2018. ISSN 18728227. Available from Internet: <https://doi.org/10.1016/j.diabres.2018.02.023>. Accessed 1 Jun. 2020.

COGGON, D.; ROSE, G.; BARKER, D. G. P. **Epidemiology for the uninitiated**. 5. ed. London: BMJ Books, 2003. ISBN 30727916041.

COX, J. L.; HOLDEN, J. M.; SAGOVSKY, R. Detection of postnatal depression: Development of the 10-item edinburgh postnatal depression scale. **British Journal of Psychiatry**, Cambridge University Press, v. 150, n. 6, p. 782–786, 1987.

CUNNINGHAM, J. P.; GHAHRAMANI, Z. Linear dimensionality reduction: Survey, insights, and generalizations. **J. Mach. Learn. Res.**, JMLR.org, v. 16, n. 1, p. 2859–2900, jan. 2015. ISSN 1532-4435.

DRAY, S.; JOSSE, J. Principal component analysis with missing values: a comparative survey of methods. **Plant Ecology**, v. 216, n. 5, p. 657–667, 2015. ISSN 15735052.

FAIOLA, A. et al. Managing patient health across diverse spaces: Using activity theory to model pervasive decision support. **Proceedings of the CHI2012 Workshop "Bridging Clinical and Non-Clinical Health Practice: Opportunities and Challenges"**, 2012.

FAIOLA, A.; NEWLON, C. Advancing critical care in the icu: A human-centered biomedical data visualization systems. **Ergonomics and Health Aspects, Proceedings of the International Conference on Human-Computer Interaction (HCII 2011), (M. M. Robertson, ed.)**, Springer, Berlin, Heidelberg, v. 6779, p. 119–128, 2011.

FLOR, L. S.; CAMPOS, M. R. Prevalência de diabetes mellitus e fatores associados na população adulta brasileira: evidências de um inquérito de base populacional. **Revista Brasileira de Epidemiologia**, v. 20, n. 1, p. 16–29, 2017. ISSN 1415-790X. Available from Internet: <http://www.scielo.br/scielo.php?script=sci{_}arttext{&}pid=S1415-790X2017000100016{&}lng=p>. Accessed 1 Jun. 2020.

GLICKSBERG, B. S. et al. Patientexplorer: an extensible application for dynamic visualization of patient clinical history from electronic health records in the omop common data model. **Bioinformatics**, v. 35, n. 21, p. 4515–4518, 2019.

GOLUB, G. H.; REINSCH, C. Singular value decomposition and least squares solutions. **Numerische Mathematik**, v. 14, n. 5, p. 403–420, 1970.

HINUM, K. et al. Gravi++: Interactive information visualization to explore highly structured temporal data. **Journal of Universal Computer Science**, v. 11, n. 11, p. 1792–1805, 2005.

HOTELLING, H. Analysis of a complex of statistical variables into principal components. **Journal of Educational Psychology**, v. 24, n. 6, p. 417–441, 1933.

KARVONEN E. KENTALA, O. M. M. The effects of training on heart rate: a longitudinal study. **Ann Med Exp Biol Fenn**, v. 35, n. 3, p. 307–15, 1957.

LAUGWITZ, B.; HELD, T.; SCHREPP, M. Construction and evaluation of a user experience questionnaire. In: . [S.l.: s.n.], 2008. v. 5298, p. 63–76.

MAATEN, L. van der; HINTON, G. Visualizing high-dimensional data using t-sne. **Journal of Machine Learning Research**, v. 9, p. 2579–2605, 2008.

MAGLIANO, D. J.; ZIMMET, P.; SHAW, J. E. Classification of diabetes mellitus and other categories of glucose intolerance. In: ____. **International Textbook of Diabetes Mellitus**. John Wiley and Sons, Ltd, 2015. chp. 1, p. 1–16. ISBN 9781118387658. Available from Internet: <https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118387658.ch1>. Accessed 1 Jun. 2020.

MALIK, S. et al. An evaluation of visual analytics approaches to comparing cohorts of event sequences. **Proc. of IEEE VIS 2014 Workshop on Visualization of Electronic Health Records**, p. 1–6, 2014.

MAY, T. et al. A Visual-Interactive System for Prostate Cancer Cohort Analysis. **IEEE Computer Graphics and Applications**, v. 35, n. 3, p. 44–55, 2015. ISSN 0272-1716.

MUNZNER, T. A nested model for visualization design and validation. **IEEE Transactions on Visualization and Computer Graphics**, v. 15, n. 6, p. 921–928, Nov 2009.

MUNZNER, T. **Visualization Analysis and Design**. [S.l.]: A K Peters/CRC Press, 2014. ISBN 9781466508910.

NIGHTINGALE, F. Notes on matters affecting the health, efficiency, and hospital administration of the british army. founded chiefly on the experience of the late war. **Presented by Request to the Secretary of State for War. Privately printed for Miss Nightingale, Harrison and Sons**, 1858.

NOBRE, C. et al. Lineage: Visualizing multivariate clinical data in genealogy graphs. **IEEE Transactions on Visualization and Computer Graphics**, v. 25, n. 3, p. 1543–1558, 2019. ISSN 19410506.

PEARCE, N. Classification of epidemiological study designs. **International Journal of Epidemiology**, v. 41, n. 2, p. 393–397, 04 2012. ISSN 0300-5771. Available from Internet: <https://doi.org/10.1093/ije/dys049>. Accessed 1 Jun. 2020.

PLAISANT, C. et al. Lifelines: Visualizing personal histories. **SIGCHI Conference on Human Factors in Computing Systems Proceedings**, v. 1, p. 221–227, 1996.

PREIM, B. et al. Visual analytics of image-centric cohort studies in epidemiology. **Mathematics and Visualization**, n. January, p. 221–248, 2016.

RAO, R.; CARD, S. K. Table lens: merging graphical and symbolic representations in an interactive focus + context visualization for tabular information. **Conference on Human Factors in Computing Systems - Proceedings**, p. 318–322, 1994.

RAUBER, P. E.; FALCÃO, A. X.; TELEA, A. C. Visualizing time-dependent data using dynamic t-sne. **Eurographics Conference on Visualization (EuroVis)**, 2016.

RIND, A. Interactive information visualization to explore and query electronic health records. **Foundations and Trends® in Human-Computer Interaction**, v. 5, p. 207–298, 01 2013.

RIND, A. et al. Visual exploration of time-oriented patient data for chronic diseases: Design study and evaluation. **Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)**, v. 7058 LNCS, p. 301–320, 2011.

RIND, A. et al. Visually exploring multivariate trends in patient cohorts using animated scatter plots. **Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)**, v. 6779 LNCS, p. 139–148, 2011. ISSN 03029743.

ROOPA, H.; ASHA, T. A linear model based on principal component analysis for disease prediction. **IEEE Access**, v. 7, p. 105314–105318, 2019.

SCHMIDT, M. et al. Prevalence of diabetes and hypertension based on self-reported morbidity survey, brazil, 2006. **Revista de saúde pública**, v. 43 Suppl 2, p. 74–82, 11 2009.

SCHMIDT, M. I. et al. Lifestyle intervention for diabetes prevention after pregnancy (linda-brasil): Study protocol for a multicenter randomized controlled trial. **BMC Pregnancy and Childbirth**, BMC Pregnancy and Childbirth, v. 16, n. 1, p. 1–12, 2016. ISSN 14712393.

SHNEIDERMAN, B. The eyes have it: a task by data type taxonomy for information visualizations. **Proceedings 1996 IEEE Symposium on Visual Languages**, p. 336–343, 1996.

SHNEIDERMAN, B.; PLAISANT, C. Strategies for evaluating information visualization tools: Multi-dimensional in-depth long-term case studies. In: **Proceedings of the 2006 AVI Workshop on BEyond Time and Errors: Novel Evaluation Methods for Information Visualization**. New York, NY, USA: ACM, 2006. (BELIV '06), p. 1–7. ISBN 1-59593-562-2. Available from Internet: <http://doi.acm.org/10.1145/1168149.1168158>. Accessed 1 Jun. 2020.

SHNEIDERMAN, B.; PLAISANT, C.; HESSE, B. W. Improving healthcare with interactive visualization. **Computer**, v. 46, n. 5, p. 58–66, May 2013.

SUS - A quick and dirty usability scale. **Usability evaluation in industry**, v. 189, n. 194, p. 4–7, 1996. ISSN 1097-0193. Available from Internet: <http://hell.meiert.org/core/pdf/sus.pdf>. Accessed 1 Jun. 2020.

THIESE, M. S. Observational and interventional study design types; an overview. **Biochemia Medica**, v. 24, n. 2, p. 199–210, 2014.

WANG, T. D. et al. Aligning temporal data by sentinel events: Discovering patterns in electronic health records. In: **Proceedings of the SIGCHI Conference on Human Factors in Computing Systems**. New York, NY, USA: ACM, 2008. (CHI '08), p. 457–466. ISBN 978-1-60558-011-1. Available from Internet: <http://doi.acm.org/10.1145/1357054.1357129>. Accessed 1 Jun. 2020.

WEST, V.; BORLAND, D.; HAMMOND, W. E. Visualization of EHR and Health Related Data for Information Discovery. n. November, 2013.

WEST, V. L.; BORLAND, D.; HAMMOND, W. E. Innovative information visualization of electronic health record data: a systematic review. **Journal of the American Medical Informatics Association**, p. 330–339, 2015.

WOLD, S.; ESBENSEN, K.; GELADI, P. Principal component analysis. **Chemometrics and Intelligent Laboratory Systems**, v. 2, n. 1, p. 37 – 52, 1987. ISSN 0169-7439. Proceedings of the Multivariate Statistical Workshop for Geologists and Geochemists. Available from Internet: <http://www.sciencedirect.com/science/article/pii/0169743987800849>. Accessed 1 Jun. 2020.

WU, D. T. et al. Evaluating visual analytics for health informatics applications: A systematic review from the american medical informatics association visual analytics working group task force on evaluation. **Journal of the American Medical Informatics Association**, v. 26, n. 4, p. 314–323, 2019.

ZHANG, Y.; CHANANA, K.; DUNNE, C. IDMVis: Temporal Event Sequence Visualization for Type 1 Diabetes Treatment Decision Support. **IEEE Transactions on Visualization and Computer Graphics**, v. 25, n. 1, p. 512–522, 2019. ISSN 19410506.

ZHANG, Z.; GOTZ, D.; PERER, A. Iterative cohort analysis and exploration. **Information Visualization**, v. 14, n. 4, p. 289–307, 2015.

APPENDIX A — RESUMO ESTENDIDO

A.1 Introdução

Um dos mais prevalentes tópicos de pesquisa atualmente é o estudo de doenças crônicas, que requerem testes e observações periódicas durante um longo período de tempo. Esse tipo de estudo é conhecido como estudo epidemiológico. Eles são baseados em acompanhar uma parte da população por um período de tempo (PEARCE, 2012). Correlações entre esses dados longitudinais são importantes para a tomada de decisão de epidemiologistas (PLAISANT et al., 1996). Esse trabalho emergiu de uma colaboração entre pesquisadores do estudo epidemiológico LINDA-Brasil, um ensaio clínico randomizado focado em investigar os efeitos de uma intervenção no estilo de vida no desenvolvimento da diabetes de tipo 2 após gravidez com diabetes gestacional (SCHMIDT et al., 2016). Essas mulheres são recrutadas e acompanhadas através de ligações telefônicas regulares e visitas clínicas para detectar o desenvolvimento da diabetes e coletar dados antropométricos e de estilo de vida. O estudo ainda está sendo realizado e seu término está previsto para 2021.

O principal objetivo deste trabalho é investigar os benefícios de técnicas de visualização interativas no fluxo de trabalho de epidemiologistas. Nós focamos em utilizar essas técnicas para criar uma interface que auxiliasse especialistas do LINDA-Brasil em acompanhar o progresso de participantes além de descobrir similaridades entre seus históricos. Nossa hipótese é de que, ao auxiliar pesquisadores a descobrir padrões nos dados, poderíamos habilitar a descoberta de participantes com potencial de abandonarem o estudo e, assim, prevenir o total abandono e o desenvolvimento da diabetes. Nós podemos definir nossa pergunta de pesquisa como: "até que ponto técnicas de visualização interativas auxiliam epidemiologistas em um estudo longitudinal?". Para responder essa pergunta, nós criamos três visões de interação, cada uma contribuindo de maneira diferente para o fluxo de trabalho dos pesquisadores.

A.2 Metodologia

Três ferramentas de visualização interativas foram criadas, cada uma provendo uma visão dos dados:

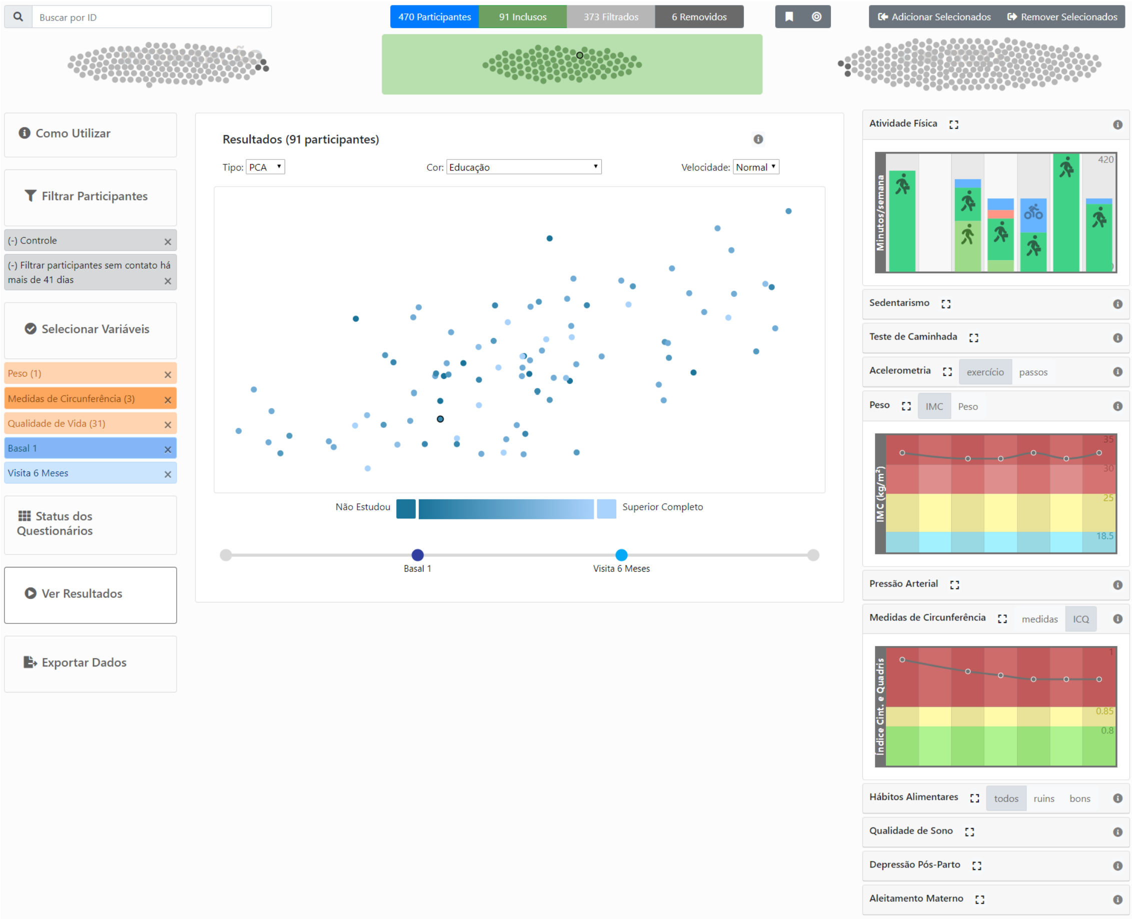
- O painel da Análise das Informações das Participantes (Figura A.1), que fornece um conjunto de ferramentas de filtragem e seleção de variáveis para a análise do progresso de pacientes e suas similaridades.
- O Status dos Questionários, criado para mostrar uma visão geral do progresso do ensaio clínico, e que foi incorporado dentro do painel da Análise das Informações das Participantes.
- O Dashboard da Participante, focado em visualizar os dados de uma única participante, mostrando as informações do dossier necessárias para realizar ligações de acompanhamento e gráficos de variáveis importantes para o estudo.

A.2.1 Painel da Análise das Informações das Participantes

No Painel da Análise das Informações das Participantes (Figura A.1), nós focamos em prover métodos de análise de coortes de participantes ao representar suas similaridades além de disponibilizar uma visão detalhada de variáveis para uma ou múltiplas participantes. A comparação de histórias de participantes é realizada através de um scatterplot construído com PCA por Singular Value Decomposition (SVD) (GOLUB; REINSCH, 1970) ou t-SNE (MAATEN; HINTON, 2008) a partir de variáveis selecionadas pelo usuário para um grupo de participantes. A filtragem de participantes pelo seu centro do estudo, grupo de randomização e dias desde a perda de contato, segundo às necessidades dos pesquisadores, também é uma funcionalidade importante adicionada ao painel.

As visualizações disponíveis desse painel são coordenadas através da interação com o usuário. Realces feitos em uma visualização são replicados em outras, permitindo uma melhor contextualização da participante realçada. Participantes representadas nas visualizações podem ser realçadas de duas maneiras: passar o mouse por cima realça todas as representações da participante que estão visíveis, e clicar marca a participante em outras visualizações e mostra seus gráficos temporais na direita da tela. O último pode ser aplicado em múltiplas participantes simultaneamente, permitindo a análise entre eles.

Figure A.1: Painel da Análise das Informações das Participantes, mostrando resultados do PCA para um grupo de 91 participantes na etapa Basal 1, considerando variáveis de IMC e medidas corporais. A cor dos pontos mostra o nível de escolaridade de cada participante. A parte superior mostra uma visão geral de todas as participantes do estudo. No lado esquerdo do painel, há um menu para filtragem, seleção de variáveis, visualização de resultados, etc. À direita, visualizações de variáveis temporais estão disponíveis sob demanda.



Source: Author

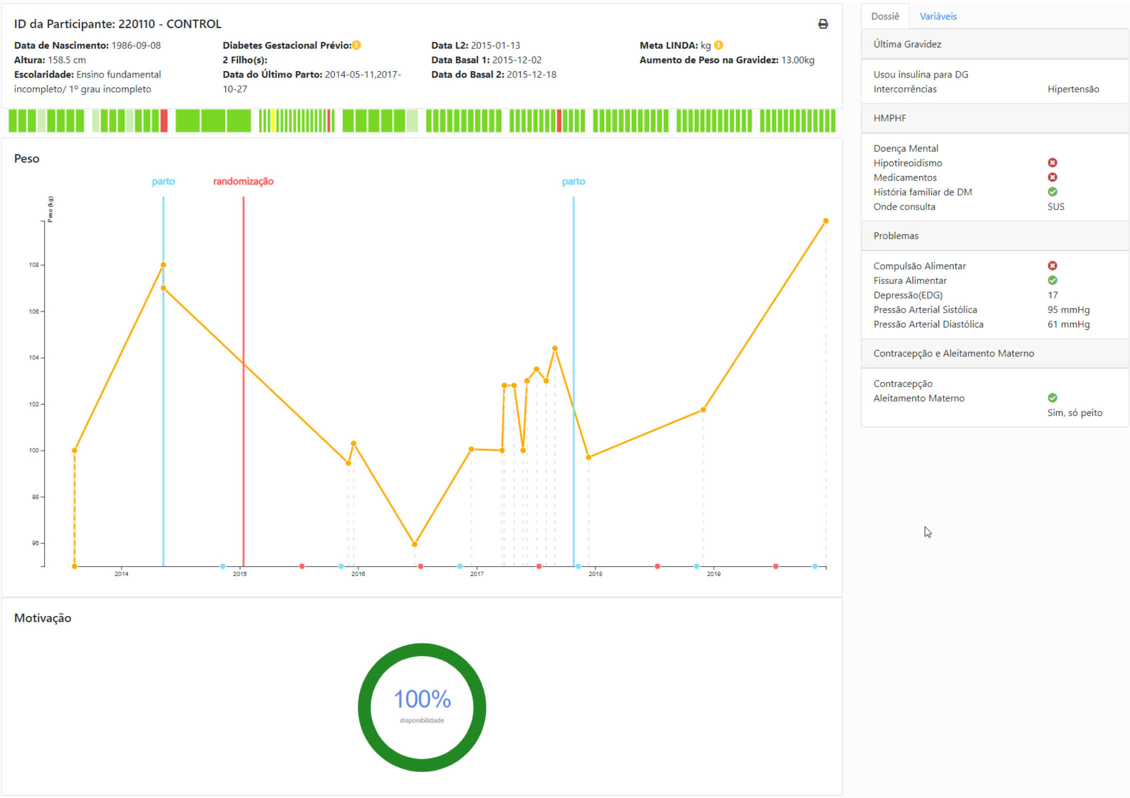
A.2.2 Dashboard da Participante

Ligações telefônicas são o principal método de aplicação da intervenção do estudo e, para realizar essas ligações, especialistas precisam ter acesso a todas as informações relevantes da participante em mãos, especialmente a progressão do seu peso e data importantes para o estudo. Atualmente, essas informações são obtidas através de um dossier.

O Dashboard da Participante mostra todas as informações necessárias para realizar as ligações de acompanhamento de uma participante além de gráficos e dados adicionais, como o status dos questionários da participante (Figura A.2).

A informação mais importante que precisa ser visualizada pelos pesquisadores do

Figure A.2: Interface do Dashboard da Participante, mostrando dados do dossier.



Source: Author

LINDA são a progressão de alterações no peso da participante, a meta de peso definida e certas datas relevantes ao estudo. Para melhor visualizar essas informações, um gráfico de linha com o peso pelo tempo é mostrado ao centro da tela. Nesse mesmo gráfico, linhas são usadas para marcar a data de eventos importantes, como a data de randomização (vermelho) e a data do parto (azul). Círculos são utilizados para marcar seis meses, e o número de anos depois da data depois da randomização.

A.3 Avaliação

A versão final da interface foi submetida a duas avaliações formais: a primeira com experts em ensaios clínicos, para coletar opiniões sobre a utilidade da ferramenta, e a segunda com não-experts, para observar a sua usabilidade.

A avaliação com experts foi realizada remotamente, para que as especialistas utilizassem a interface para conduzir o seu próprio trabalho, em vez de tarefas definidas pelos desenvolvedores (MUNZNER, 2009). Após especialistas utilizarem o sistema, eram apresentadas perguntas sobre a utilidade de partes da interface além de questionários de usabilidade padronizados (BROOKE, 1996; LAUGWITZ; HELD; SCHREPP, 2008). A avaliação foi conduzida com 3 usuários, dois membros do LINDA e uma terceira pesquisadora com experiência em software de gerenciamento de ensaios clínicos. Resultados do User Experience Questionnaire (UEQ) (LAUGWITZ; HELD; SCHREPP, 2008) e System Usability Scale (SUS) (SUS..., 1996) (score médio de 78,3) mostraram uma melhora significativa comparado com resultados da avaliação preliminar, realizada durante o processo de design. Em relação a perguntas sobre funcionalidades e partes específicas da interface, o scatterplot da coorte foi considerada a parte mais confusa do sistema, com duas especialistas não compreendendo o significado do posicionamento dos pontos, provavelmente por não ter conhecimento prévio de técnicas de redução de dimensionalidade.

Embora a avaliação com experts seja essencial para validar um sistema como o desenvolvido neste trabalho, nós buscamos verificar se a interface poderia ser utilizada por pessoas sem conhecimento prévio sobre o domínio. Para isso, desenvolvemos um segundo experimento, verificando se pessoas sem experiência no sistema poderiam realizar tarefas essenciais após uma breve explicação sobre a interface e uma fase de exploração. Essa avaliação foi realizada presencialmente e os usuários foram observados ao interagir com o sistema. Participaram 16 usuários, entre 21 e 59 anos e 81,2% com formação em ciência da computação. Durante a fase de exploração, a maioria dos usuários fizeram perguntas e pareciam interessados em utilizar a interface. O resultado médio do SUS foi 86,2, que pode ser considerado excelente e acima da média para sistemas web. Tanto o resultado do SUS quanto do UEQ foram consideravelmente mais altos na avaliação com não-experts.

A.4 Conclusão

Esse trabalho apresentou uma interface baseada em visualização para monitorar o desenvolvimento de um ensaio clínico randomizado focado nos efeitos de uma intervenção no estilo de vida no desenvolvimento da diabetes de tipo 2 para pacientes com histórico de diabetes gestacional. Uma lista de requisitos foi coletada de epidemiologistas que trabalham no LINDA-Brasil e analisada, para então desenvolvermos uma interface intuitiva para facilitar a avaliação das informações coletadas além de proporcionar uma análise mais profunda da similaridade entre participantes. Sobre a nossa pergunta de pesquisa ("até que ponto técnicas de visualização interativas auxiliam epidemiologistas em um estudo longitudinal?"), o processo de design adotado, a colaboração com pesquisadores e avaliações aplicadas nos disponibilizaram evidências do desenvolvimento de uma ferramenta que pode auxiliar pesquisadores em extrair conclusões dos dados coletados. Segundo uma das pesquisadoras, o sistema consegue ajudá-las a avaliar problemas de digitação, visualizar perdas de contato com participantes, se preparar para ligações de acompanhamento além de disponibilizar gráficos que podem gerar resultados para o estudo. Também, durante as reuniões, as especialistas comentaram sobre como as visualizações temporais facilitam na checagem e comparação dos dados com as guidelines que elas utilizam.

Existem vários trabalhos futuros interessantes para melhorar a ferramenta e as técnicas utilizadas. Em relação ao LINDA-Brasil, seria interessante a possibilidade de comparação entre duas coortes de participantes, para melhorar a análise dos efeitos da intervenção. Também, poderia ser adicionado cálculos de certos dados estatísticos para um grupo de participantes. Finalmente, seria interessante disponibilizar visualizações adaptativas, que podem ser modificadas pelo usuário para melhor auxiliar a análise do dado.

APPENDIX B — FORMAL EVALUATION QUESTIONNAIRES

B.1 Preliminary Evaluation with Specialists

Table B.1: Personal information questions (Preliminary Evaluation with Specialists)

P1	Age	
P2	Gender	☐ Male ☐ Female ☐ Other
P3	Education	☐ High School Student ☐ Graduated School ☐ Graduation Student ☐ MSc Degree ☐ PhD Degree
P4	Field of work	
P5	Do you have any experience with interactive systems? (check all applicable options)	☐ I have experience with usual web systems (shopping, social networks, banking) ☐ I have experience with systems necessary for my professional activities ☐ I have experience with computer games ☐ I navigate and make search on the web
P6	Do you have any experience with systems used for the visualization of clinical trials? (check all applicable options)	☐ No Experience ☐ Professional Experience ☐ Other ☐ Unprofessional Experience
P7	How familiar are you with LINDA?	☐ Unfamiliar ☐ A little familiar ☐ Familiar ☐ Very familiar ☐ Extremely familiar
P8	How long have you been involved with LINDA?	

Table B.2: User Experience Questionnaire (Preliminary Evaluation with Specialists)

annoying	☐	☐	☐	☐	☐	enjoyable
not understandable	☐	☐	☐	☐	☐	understandable
creative	☐	☐	☐	☐	☐	dull
easy to learn	☐	☐	☐	☐	☐	difficult to learn
valuable	☐	☐	☐	☐	☐	inferior
boring	☐	☐	☐	☐	☐	exciting
not interesting	☐	☐	☐	☐	☐	interesting
unpredictable	☐	☐	☐	☐	☐	predictable
fast	☐	☐	☐	☐	☐	slow
inventive	☐	☐	☐	☐	☐	conventional
obstructive	☐	☐	☐	☐	☐	supportive
good	☐	☐	☐	☐	☐	bad
complicated	☐	☐	☐	☐	☐	easy
unlikable	☐	☐	☐	☐	☐	pleasing
usual	☐	☐	☐	☐	☐	leading edge
unpleasant	☐	☐	☐	☐	☐	pleasant
secure	☐	☐	☐	☐	☐	not secure
motivating	☐	☐	☐	☐	☐	demotivating
meets expectations	☐	☐	☐	☐	☐	does not meet expectations
inefficient	☐	☐	☐	☐	☐	efficient
clear	☐	☐	☐	☐	☐	confusing
impractical	☐	☐	☐	☐	☐	practical
organized	☐	☐	☐	☐	☐	cluttered
attractive	☐	☐	☐	☐	☐	unattractive
friendly	☐	☐	☐	☐	☐	unfriendly
conservative	☐	☐	☐	☐	☐	innovative

Table B.3: SUS questions from the survey (Preliminary Evaluation with Specialists)

SUS1	I think that I would like to use this system frequently	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS2	I found the system unnecessarily complex	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS3	I thought the system was easy to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS4	I think that I would need the support of a technical person to be able to use this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS5	I found the various functions in this system were well integrated	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS6	I thought there was too much inconsistency in this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS7	I would imagine that most people would learn to use this system very quickly	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS8	I found the system very cumbersome to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS9	I felt very confident using the system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS10	I needed to learn a lot of things before I could get going with this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

Table B.4: Specific questions for the Questionnaire Status visualization (Preliminary Evaluation with Specialists)

QS1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
QS2	I understood the meaning of each line in the visualization	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS3	I understood how to interact with the visualization, clicking on participants to open a detailed view of each	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS4	I found the visualization useful as an overview of LINDA's progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS5	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.5: Overview questions for the Participants Information Analysis View (Preliminary Evaluation with Specialists)

PV1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
PV2	I understood the meaning of every functionality (filtering, selection of variables, results)	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV3	The item generated on the left side of the screen for each filter, variable and phase selected helped me to understand what was being selected without needing to return to their menus	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV4	The tool helped me discover information that would be hard to obtain otherwise	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV5	I could use the following features:	☐ Filter participants ☐ Select variables and phases ☐ Check results from DR ☐ Export data ☐ Select groups of participants ☐ Check a participant's graphs from variables such as physical activity, weight and accelerometry
PV6	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.6: Specific questions for the Participants Overview visualization inside the Participants Information Analysis View (Preliminary Evaluation with Specialists)

PO1	The participants visualization helped me understand how my actions influenced the participants selected	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PO2	I could use the following features:	☐ Selection of a participant by its ID ☐ Selection of participants by their groups (included, filtered, removed) ☐ Removal or re-addition of participants by the buttons on the upper right of the screen ☐ Removal or re-addition of participants by dragging them outside or inside the central area
PO3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.7: Specific questions for the filtering of participants inside the Participants Information Analysis View (Preliminary Evaluation with Specialists)

F1	I thought there were few filtering options available	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.1	It was not clear to me what was being filtered [Field Centers]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.2	It was not clear to me what was being filtered [Randomization Group]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.3	It was not clear to me what was being filtered [Lost Contact]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.1	The visualizations helped in my comprehension of how the filter worked [Field Centers]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.2	The visualizations helped in my comprehension of how the filter worked [Randomization Group]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.3	The visualizations helped in my comprehension of how the filter worked [Lost Contact]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F4	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.8: Specific questions for the selection of variables and phases inside the Participants Information Analysis View (Preliminary Evaluation with Specialists)

SV1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
SV2	The histograms helped me understand what was being selected	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SV3	I understood the meaning of the variable's histograms	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SV4	I could use the following features:	☐ Selection of variables ☐ Selection of phases ☐ Open variables, showing histograms and selection options for their sub-variables ☐ Selection of a group of participants by clicking on a bar inside a histogram
SV3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.9: Specific questions for the dimensionality reduction results inside the Participants Information Analysis View (Preliminary Evaluation with Specialists)

DR1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
DR2	I understood the meaning behing the positioning of points	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
DR3	The visualization helped me gather insights on LINDA's progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
DR4	I could use the following features:	☐ Selection of participants ☐ Selection of a variable in order to define it as the color of each point ☐ Change the currently selected phase for visualization in the timeline ☐ Change the colors used in the color scale ☐ Alter the technique of dimensionality reduction used (from PCA to t-SNE)
DR3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.10: Specific questions for the Dashboard interface (Preliminary Evaluation with Specialists)

D1	I could use the following features:	☐ Check a participant's information ☐ Check, on the weight graph, markers for labor and randomization dates ☐ Check variable's graphs from the participant, such as physical activity, weight and accelerometry
D2	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.11: Specific questions for the visualizations created for temporal variables of the study (Preliminary Evaluation with Specialists)

V1	I thought the visualizations were important for tracking the participants' progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V2	I found the colors indicating metrics and categories unnecessary	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V3	I found the graphs useful for comparison between participants	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.1	I needed to check the tutorial in order to understand the visualization [Physical Activity]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.2	I needed to check the tutorial in order to understand the visualization [Sedentary Behavior]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.3	I needed to check the tutorial in order to understand the visualization [Thread mill]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.4	I needed to check the tutorial in order to understand the visualization [Accelerometry]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.5	I needed to check the tutorial in order to understand the visualization [Weight]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.6	I needed to check the tutorial in order to understand the visualization [Blood Pressure]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.7	I needed to check the tutorial in order to understand the visualization [Circumference Measures]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.8	I needed to check the tutorial in order to understand the visualization [Sleep Quality]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

V4.9	I needed to check the tutorial in order to understand the visualization [Postpartum Depression]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.10	I needed to check the tutorial in order to understand the visualization [Breastfeeding]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.1	I understood the information presented on the visualization [Physical Activity]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.2	I understood the information presented on the visualization [Sedentary Behavior]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.3	I understood the information presented on the visualization [Thread mill]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.4	I understood the information presented on the visualization [Accerelometry]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.5	I understood the information presented on the visualization [Weight]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.6	I understood the information presented on the visualization [Blood Pressure]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.7	I understood the information presented on the visualization [Circumference Measures]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.8	I understood the information presented on the visualization [Sleep Quality]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.9	I understood the information presented on the visualization [Postpartum Depression]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

V5.10	I understood the information presented on the visualization [Breast-feeding]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V6	I could use the following features:	☐ Check a point's information by using the tooltips ☐ Check augmented version of the visualization ☐ Close variable's tab ☐ Open the participant's Dashboard ☐ Plot multiple participants
V7	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.12: Conclusion page where overall feedback from participants was asked

C2	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

B.2 Summarized Answers for the Preliminary Evaluation, performed by one specialist currently working on the trial

Table B.13: Results from the preliminary formal evaluation conducted for the main views and visualizations present on the interface. These relate to a previous version of the system where the Questionnaire Status visualization was a standalone view and some temporal visualizations were still unavailable.

		Needs Tutorial	Easy to Understand	Tasks Accomplished	Useful	Comments
Views	Dashboard	n.a.	●	3/3	●	
	Questionnaire Status	●	●	1/1	●	Should be able to order by ID and filter participants
	Participant Info Analysis	●	○	6/6	●	
Part. Info. Analysis	Participant's Visualization	n.a.	●	4/4	●	
	Filtering	n.a.	●	3/3	●	Change lost contact calculation
	Variable Selection		●	4/4	●	
	Dimensionality Reduction	●	○	4/5	○	Could not change colors
	Temporal Visualizations		●	5/5	●	
Temporal Visualizations	Physical Activity		●	n.a.	●	
	Sedentarism	.	●	n.a.	●	
	Thread Mill		●	n.a.	●	Y Axis should be distance
	Accelerometer		●	n.a.	●	Y Axis should show physical activity
	BMI		●	n.a.	●	Should also show weight
	Blood Pressure		●	n.a.	●	
	Body Measures		●	n.a.	●	
	Sleep		●	n.a.	●	
	Postpartum Depression		●	n.a.	●	
	Breastfeeding		●	n.a.	●	

●: applies, ○: partially applies, " ": does not apply, n.a.: not asked

B.3 Evaluation with Specialists

Table B.14: Personal information questions (Evaluation with Specialists)

P1	Age	
P2	Gender	☐ Male ☐ Female ☐ Other
P3	Education	☐ High School Student ☐ Graduated School ☐ Graduation Student ☐ MSc Degree ☐ PhD Degree
P4	Field of work	
P5	Do you have any experience with interactive systems? (check all applicable options)	☐ I have experience with usual web systems (shopping, social networks, banking) ☐ I have experience with systems necessary for my professional activities ☐ I have experience with computer games ☐ I navigate and make search on the web
P6	Do you have any experience with systems used for the visualization of clinical trials? (check all applicable options)	☐ No Experience ☐ Professional Experience ☐ Other ☐ Unprofessional Experience
P7	How familiar are you with LINDA?	☐ Unfamiliar ☐ A little familiar ☐ Familiar ☐ Very familiar ☐ Extremely familiar
P8	How long have you been involved with LINDA?	

Table B.15: Questions about the use of video tutorials and hints available on the interface (Evaluation with Specialists)

T1	I saw the hints available on the home screen	☐ Yes ☐ No ☐ Some
T2	I saw the tutorials available on the hints screen	☐ Yes ☐ No ☐ Some
T3	I saw the general use tutorial	☐ Yes ☐ No

Table B.16: User Experience Questionnaire (Evaluation with Specialists)

annoying	☐	☐	☐	☐	☐	enjoyable
not understandable	☐	☐	☐	☐	☐	understandable
creative	☐	☐	☐	☐	☐	dull
easy to learn	☐	☐	☐	☐	☐	difficult to learn
valuable	☐	☐	☐	☐	☐	inferior
boring	☐	☐	☐	☐	☐	exciting
not interesting	☐	☐	☐	☐	☐	interesting
unpredictable	☐	☐	☐	☐	☐	predictable
fast	☐	☐	☐	☐	☐	slow
inventive	☐	☐	☐	☐	☐	conventional
obstructive	☐	☐	☐	☐	☐	supportive
good	☐	☐	☐	☐	☐	bad
complicated	☐	☐	☐	☐	☐	easy
unlikable	☐	☐	☐	☐	☐	pleasing
usual	☐	☐	☐	☐	☐	leading edge
unpleasant	☐	☐	☐	☐	☐	pleasant
secure	☐	☐	☐	☐	☐	not secure
motivating	☐	☐	☐	☐	☐	demotivating
meets expectations	☐	☐	☐	☐	☐	does not meet expectations
inefficient	☐	☐	☐	☐	☐	efficient
clear	☐	☐	☐	☐	☐	confusing
impractical	☐	☐	☐	☐	☐	practical
organized	☐	☐	☐	☐	☐	cluttered
attractive	☐	☐	☐	☐	☐	unattractive
friendly	☐	☐	☐	☐	☐	unfriendly
conservative	☐	☐	☐	☐	☐	innovative

Table B.17: SUS questions from the survey (Evaluation with Specialists)

SUS1	I think that I would like to use this system frequently	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS2	I found the system unnecessarily complex	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS3	I thought the system was easy to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS4	I think that I would need the support of a technical person to be able to use this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS5	I found the various functions in this system were well integrated	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS6	I thought there was too much inconsistency in this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS7	I would imagine that most people would learn to use this system very quickly	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS8	I found the system very cumbersome to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS9	I felt very confident using the system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS10	I needed to learn a lot of things before I could get going with this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

Table B.18: Specific questions for the Questionnaire Status visualization (Evaluation with Specialists)

QS1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
QS2	I understood the meaning of each line in the visualization	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS3	I understood how to interact with the visualization, clicking on participants to open a detailed view of each	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS3.5	I could use the following features:	☐ Interact with the visualization, clicking in participants to highlight them and open a more detailed view of each ☐ Order lines by ID and number of completed questionnaires ☐ Distinguish between incomplete questionnaires from when they were missing when the participant has still not arrived at the phase yet ☐ Distinguish between completed questionnaires and ones that had their other versions completed ☐ Mouse over a questionnaire to check its information ☐ Use the shift to select multiple participants simultaneously
QS4	I found the visualization useful as an overview of LINDA's progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
QS5	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.19: Overview questions for the Participants Information Analysis View (Evaluation with Specialists)

PV1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
PV2	I understood the meaning of every functionality (filtering, selection of variables, results)	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV3	The item generated on the left side of the screen for each filter, variable and phase selected helped me to understand what was being selected without needing to return to their menus	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV4	The tool helped me discover information that would be hard to obtain otherwise	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PV5	I could use the following features:	☐ Filter participants ☐ Select variables and phases ☐ Check results from DR ☐ Export data ☐ Select groups of participants ☐ Check a participant's graphs from variables such as physical activity, weight and accelerometry ☐ Check questionnaire status
PV6	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.20: Specific questions for the Participants Overview visualization inside the Participants Information Analysis View (Evaluation with Specialists)

PO1	The participants visualization helped me understand how my actions influenced the participants selected	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
PO2	I could use the following features:	☐ Selection of a participant by its ID ☐ Selection of participants by their groups (included, filtered, removed) ☐ Selection os multiple participants using the shift ☐ Removal or re-addition of participants by the buttons on the upper right of the screen ☐ Removal or re-addition of participants by dragging them outside or inside the central area ☐ Save a group of participants selected and load them after changing the selection
PO3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.21: Specific questions for the filtering of participants inside the Participants Information Analysis View (Evaluation with Specialists)

F1	I thought there were few filtering options available	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.1	It was not clear to me what was being filtered [Field Centers]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.2	It was not clear to me what was being filtered [Randomization Group]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F2.3	It was not clear to me what was being filtered [Lost Contact]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.1	The visualizations helped in my comprehension of how the filter worked [Field Centers]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.2	The visualizations helped in my comprehension of how the filter worked [Randomization Group]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.3	The visualizations helped in my comprehension of how the filter worked [Lost Contact]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F3.4	In the Lost Contact filter, eu could understand the difference between selecting participants in contact for n days (with less inactivity) and selecting participants without contact for n days (with more inactivity)	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
F4	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.22: Specific questions for the selection of variables and phases inside the Participants Information Analysis View (Evaluation with Specialists)

SV1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
SV2	The histograms helped me understand what was being selected	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SV3	I understood the meaning of the variable's histograms	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SV4	I could use the following features:	☐ Selection of variables ☐ Selection of phases ☐ Open variables, showing histograms and selection options for their sub-variables ☐ Selection of a group of participants by clicking on a bar inside a histogram
SV3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.23: Specific questions for the dimensionality reduction results inside the Participants Information Analysis View (Evaluation with Specialists)

DR1	Did you use the tutorial?	☐ Yes, but even without seeing it I would have understood the visualization ☐ Yes, only after seeing it I understood the visualization ☐ Yes, but even after seeing it I haven't understood the visualization ☐ No, but even without seeing it I understood the visualization ☐ No, and I didn't understand the visualization
DR2	I understood the meaning behing the positioning of points	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
DR3	The visualization helped me gather insights on LINDA's progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
DR4	I could use the following features:	☐ Selection of participants ☐ Selection of multiple participants using shift ☐ Selection of multiple participants by selecting an area in the graph ☐ Selection of a variable in order to define it as the color of each point ☐ Change the currently selected phase for visualization in the timeline ☐ Change the colors used in the color scale ☐ Alter the technique of dimensionality reduction used (from PCA to t-SNE)
DR3	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.24: Specific questions for the Dashboard interface (Evaluation with Specialists)

D1	I could use the following features:	☐ Check a participant's information ☐ Check, on the weight graph, markers for labor and randomization dates ☐ Check variable's graphs from the participant, such as physical activity, weight and accelerometry ☐ Print a participant's graph
D2	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.25: Specific questions for the visualizations created for temporal variables of the study (Evaluation with Specialists)

V1	I thought the visualizations were important for tracking the participants' progress	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V2	I found the colors indicating metrics and categories unnecessary	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V3	I found the graphs useful for comparison between participants	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.1	I needed to check the tutorial in order to understand the visualization [Physical Activity]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.2	I needed to check the tutorial in order to understand the visualization [Sedentary Behavior]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.3	I needed to check the tutorial in order to understand the visualization [Thread mill]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.4	I needed to check the tutorial in order to understand the visualization [Accelerometry]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.5	I needed to check the tutorial in order to understand the visualization [Weight]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.6	I needed to check the tutorial in order to understand the visualization [Blood Pressure]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.7	I needed to check the tutorial in order to understand the visualization [Circumference Measures]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.75	I needed to check the tutorial in order to understand the visualization [Eating Habits]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

V4.8	I needed to check the tutorial in order to understand the visualization [Sleep Quality]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.9	I needed to check the tutorial in order to understand the visualization [Postpartum Depression]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V4.10	I needed to check the tutorial in order to understand the visualization [Breastfeeding]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.1	I understood the information presented on the visualization [Physical Activity]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.2	I understood the information presented on the visualization [Sedentary Behavior]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.3	I understood the information presented on the visualization [Thread mill]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.4	I understood the information presented on the visualization [Accerelometry]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.5	I understood the information presented on the visualization [Weight]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.6	I understood the information presented on the visualization [Blood Pressure]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.7	I understood the information presented on the visualization [Circumference Measures]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.75	I understood the information presented on the visualization [Eating Habits]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

V5.8	I understood the information presented on the visualization [Sleep Quality]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.9	I understood the information presented on the visualization [Postpartum Depression]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V5.10	I understood the information presented on the visualization [Breastfeeding]	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
V6	I could use the following features:	☐ Check a point's information by using the tooltips ☐ Check augmented version of the visualization ☐ Close variable's tab ☐ Open the participant's Dashboard ☐ Plot multiple participants ☐ Check for a graph's alternative versions
V7	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)	

Table B.26: Conclusion page where overall feedback from participants was asked (Evaluation with Specialists)

C2	Leave your opinion about the visualization (usefulness, problems encountered, and suggestions)

B.4 Evaluation with Non-experts

Table B.27: Personal information questions from the survey (Evaluation with Non-experts)

P1	Age	
P2	Gender	☐ Male ☐ Female ☐ Other
P3	Education	☐ High School Student ☐ Graduated School ☐ Graduation Student ☐ MSc Degree ☐ PhD Degree
P4	Field of work	
P5	Do you have any experience with interactive systems? (check all applicable options)	☐ I have experience with usual web systems (shopping, social networks, banking) ☐ I have experience with systems necessary for my professional activities ☐ I have experience with computer games ☐ I navigate and make search on the web
P6	Do you have any experience with systems used for data visualization? (check all applicable options)	☐ No Experience ☐ Professional Experience ☐ Other ☐ Unprofessional Experience
P7	How familiar are you with LINDA?	☐ Unfamiliar ☐ A little familiar ☐ Familiar ☐ Very familiar ☐ Extremely familiar

Table B.28: Questions about the use of video tutorials and hints available on the interface (Evaluation with Non-experts)

T1	I saw the hints available on the home screen	☐ Yes ☐ No ☐ Some
T2	I saw the tutorials available on the hints screen	☐ Yes ☐ No ☐ Some
T3	I saw the general use tutorial	☐ Yes ☐ No

Table B.29: Practical Tasks from the survey (Evaluation with Non-experts)

PT1.1	Select participants with IDs: 230424, 260109, 220513, 260107, 220469.
PT1.1.d	How difficult it was to perform this task?
PT1.2	Save the group of participants selected.
PT1.2.d	How difficult it was to perform this task?
PT2.1	Enter the menu "Filter Participants". Filter all field centers except Porto Alegre.
PT2.1.d	How difficult it was to perform this task?
PT2.2	Filter participants from the "Control" randomization group.
PT2.2.d	How difficult it was to perform this task?
PT2.3	Filter participants with lost contact bigger than approximately 300 days.
PT2.3.d	How difficult it was to perform this task?
PT2.4	How many participants were filtered in total?
PT3.1	Deselect the group of participants currently selected. Now, select participants 240327, 240287 and 260086. Remove these participants from the selection.
PT3.1.d	How difficult it was to perform this task?
PT3.2	Return to the previously saved selection.
PT3.2.d	How difficult it was to perform this task?
PT4	Enter the menu "Questionnaire Status". How many incomplete questionnaires participant 230424 has?
PT4.d	How difficult it was to perform this task?
PT5.1	Enter the menu "Select Variables". Hover one of the participants selected in the Participants Overview visualization. What happened?
PT5.2	Select variables "Physical Activity", "Weight", "Accelerometry" for phases "Basal 1" and "1 Year Visit". Has this action removed any participant from the selection?
PT5.2.d	How difficult it was to perform this task?
PT6.1	Select the menu "See Results". In the color option, select the variable "Lost Contact".
PT6.1.d	How difficult it was to perform this task?
PT6.2	Choose one of the selected participants and select one or more participant near it in PCA. Use the graphs on the right to point any similarity between them.
PT6.2.d	How difficult it was to perform this task?

Table B.30: User Experience Questionnaire (Evaluation with Non-experts)

annoying	☐	☐	☐	☐	☐	enjoyable
not understandable	☐	☐	☐	☐	☐	understandable
creative	☐	☐	☐	☐	☐	dull
easy to learn	☐	☐	☐	☐	☐	difficult to learn
valuable	☐	☐	☐	☐	☐	inferior
boring	☐	☐	☐	☐	☐	exciting
not interesting	☐	☐	☐	☐	☐	interesting
unpredictable	☐	☐	☐	☐	☐	predictable
fast	☐	☐	☐	☐	☐	slow
inventive	☐	☐	☐	☐	☐	conventional
obstructive	☐	☐	☐	☐	☐	supportive
good	☐	☐	☐	☐	☐	bad
complicated	☐	☐	☐	☐	☐	easy
unlikable	☐	☐	☐	☐	☐	pleasing
usual	☐	☐	☐	☐	☐	leading edge
unpleasant	☐	☐	☐	☐	☐	pleasant
secure	☐	☐	☐	☐	☐	not secure
motivating	☐	☐	☐	☐	☐	demotivating
meets expectations	☐	☐	☐	☐	☐	does not meet expectations
inefficient	☐	☐	☐	☐	☐	efficient
clear	☐	☐	☐	☐	☐	confusing
impractical	☐	☐	☐	☐	☐	practical
organized	☐	☐	☐	☐	☐	cluttered
attractive	☐	☐	☐	☐	☐	unattractive
friendly	☐	☐	☐	☐	☐	unfriendly
conservative	☐	☐	☐	☐	☐	innovative

Table B.31: SUS questions from the survey (Evaluation with Non-experts)

SUS1	I think that I would like to use this system frequently	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS2	I found the system unnecessarily complex	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS3	I thought the system was easy to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS4	I think that I would need the support of a technical person to be able to use this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS5	I found the various functions in this system were well integrated	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS6	I thought there was too much inconsistency in this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS7	I would imagine that most people would learn to use this system very quickly	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS8	I found the system very cumbersome to use	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS9	I felt very confident using the system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
SUS10	I needed to learn a lot of things before I could get going with this system	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree