Research Project: Derivation and validation of a predictive model for disease activity in patients with Juvenile Idiopathic Arthritis and evaluation of its applicability in telemedicine

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Abstract

Background

Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory condition affecting children and adolescents. Its management is challenging due to limited access to specialized care. Telemedicine has emerged as a promising solution to these barriers, particularly during the COVID-19 pandemic. However, predictive models for JIA disease activity that can be applied in telemedicine settings are lacking.

Objectives

The primary objective of this research project is to derive and validate a predictive model for JIA disease activity in patients under 18 years old and evaluate its applicability in telemedicine.

Methods

First, an observational, retrospective study will be conducted using data from 19,000 consultations of JIA at Portuguese centers recorded in the Reuma.pt platform. Machine learning techniques will be applied to develop a predictive model of JIA disease activity. The derived model will be externally validated with data from 2,000 consultations of JIA patients at Brazilian centers on Reuma.pt. The model's performance will be assessed using sensitivity, specificity, and area under the ROC curve (AUC). Refinements will be made to ensure the model's accuracy and applicability to the Brazilian context. Finally, an impact analysis will be evaluated through a prospective cost-effectiveness analysis by implementing the predictive model in clinical practice in Brazilian and Portuguese JIA pediatric patients. Patients will be categorized into low, moderate, or high risk of disease activity. Those at low risk will be allocated to telemedicine consultations, while others will receive in-person care. The analysis will compare telemedicine's cost-effectiveness and patient satisfaction versus traditional in-person follow-ups using standardized questionnaires.

Conclusion

The study aims to demonstrate that a predictive model can enhance the cost-effectiveness of JIA management by optimizing telemedicine services, improving patient outcomes, and ensuring appropriate resource utilization.

Introduction

Juvenile Idiopathic Arthritis (JIA) is a group of heterogeneous diseases characterized by chronic inflammatory arthritis lasting over six weeks. It affects approximately 2 million children and adolescents under sixteen years old worldwide, with an estimated prevalence in Europe ranging from 16 to 160 cases per 100,000 and in Brazil 196 cases per 100,000.[1-5] The ILAR (International League of Associations for Rheumatology) 2001 classification criteria is the most commonly used in clinical practice.[6]

The treatment guidelines for JIA include using nonsteroidal anti-inflammatory (NSAIDs) drugs and glucocorticoids for oligoarthritis, interleukin-1 and interleukin-6 inhibitors for systemic juvenile idiopathic arthritis, and disease-modifying antirheumatic drugs (DMARDs) or biologics for polyarthritis. Involving caregivers and patients in decision-making and ongoing multidisciplinary support, including physiotherapy, nutrition, and psychology, is recommended.[7,8]

In continental countries, managing JIA poses a significant challenge. In the USA, for example, a quarter of patients have to travel more than 90 km to see a specialist, leading to substantial financial losses for families due to the time and resources spent on medical care.[9.10] Caregivers and patients with systemic arthritis experience about 10% absenteeism from work and school annually.[11] In Brazil, the limited number of specialized professionals is an issue, with only one pediatric rheumatologist for every million inhabitants, which is half the number recommended by international pediatric rheumatology organizations.[12.13]

Telemedicine emerges as a viable solution to overcome geographical and resource barriers. It allows for more efficient disease management, potentially reducing costs while improving patients' quality of life. [14] During the COVID-19 pandemic, telemedicine became widely used for managing JIA, although without a standardized care protocol, patients generally reported high satisfaction with its use.[15] A 2022 study among pediatric rheumatology providers revealed that 85.9% had minimal telemedicine experience pre-pandemic.[16] Still, only 2.0% had not conducted video visits during the pandemic.[16] Most providers used standardized exam approaches, like pGALS (paediatric Gait, Arms, Legs and Spine musculoskeletal assessment)[17], and engaged patients or caregivers for virtual exams. However, 65.7% felt unable to gather all necessary information for a complete clinical assessment, preferring in-person visits for urgent or complex cases.[16] Routine follow-up visits, injection teaching, and lab discussions seem appropriate for telemedicine, while flare concerns and urgent follow-ups are better suited for in-person visits.[16]

The EULAR task force formulated points for developing and implementing remote care, emphasizing that tailored, shared decision-making should combine remote and face-to-face visits based on patient needs and preferences.[18] Telemedicine follow-ups in adult rheumatology can be as effective as conventional visits for managing rheumatoid arthritis (RA) with low disease activity or in remission. A randomized trial showed similar disease control with patient-reported outcomes(PRO)-based telemedicine strategies, and rheumatology nurses were as effective as rheumatologists. [19]

Telemedicine has also shown promising results for psoriatic arthritis (PsA) and ankylosing spondylitis (AS). During the COVID-19 pandemic, remote follow-ups using digital platforms

for PROs maintained disease control, pain levels, and general health outcomes similar to traditional care. This suggests that telemedicine can ensure therapeutic continuity and quality care while offering a flexible alternative to frequent hospital visits. [20]

Also, several studies in adult rheumatology have explored developing prediction models of inactive/active disease with the use of machine learning (ML) .[21-22] For instance, in RA, ML models, including random forests, support vector machines, and deep learning techniques, have been utilized to predict disease activity using data from electronic medical records (EMR).[23] A study that achieved an AUC score of 0.91 using an adaptive deep neural network to predict low disease activity in RA patients used patient characteristics, clinical and patient-reported outcomes, laboratory values, and medication as input features. DAS28-BSR was a target to predict active RA and future numeric individual disease activity by classification and regression.[23] Other ML models were employed to predict remission in RA patients treated with biologics, demonstrating the potential of these technologies to enhance clinical decision-making.[21] Similarly, ML algorithms in systemic lupus erythematosus (SLE) predict disease activity and identify critical clinical features. Studies using models like random forests, logistic regression, support vector machines, and deep learning have analyzed clinical data to predict hospitalization risk and diagnose disease from EMR data. This highlights ML's potential to improve SLE management through better prediction and stratification of disease activity.[24] However, despite the existence of predictive models for inactive disease in RA and SLE using ML, there are no studies evaluating the use of these models in the context of telemedicine.

Although some studies have evaluated various telehealth interventions for juvenile idiopathic arthritis (JIA)[25], such as monitoring symptoms using health apps, electronic diaries, and web-based portals and promoting physical activity through web-based programs or wearable activity trackers, and the feasibility and acceptance of teleconsultations itself, to the best of our knowledge, there are no studies assessing the use of predictive models for disease activity in this context.

Identifying which JIA patients have inactive disease or a lower likelihood of disease reactivation in the short term remains critical for better prioritization of patients who would benefit most from telemedicine consultations.

Objectives

Main Objective

- Derive and validate a predictive model of disease activity in patients with JIA under 18 years old on the next consultation, primarily using PRO and inflammatory markers, which can subsequently be applied in identifying patients at low risk of active disease who could have more benefit from telemedicine services.

Specific Objectives

- Derivation of the Predictive Model
    - Derive a predictive model of disease activity to be applied in telemedicine, using machine learning models, and internally validate the developed predictive

model using k-fold cross-validation on a sample of 19,000 visits from Portuguese centers registered in reuma.pt of patients with JIA.

- Validation and Refinement of the Model
    - External validate the predictive model in a sample of 2,000 visits from Brazilian patients on the reuma.pt register. Refine the model to ensure its applicability and accuracy in the Brazilian context.
- Impact Analysis
    - Apply the predictive model to a cohort of JIA patients in Portugal and the refined model to a cohort of JIA patients in Brazil. To evaluate the cost-effectiveness in clinical practice of applying the predictive model to identify patients with a low probability of JIA active disease, evaluating the cost-effectiveness of telemedicine and the adequate identification of patients with low disease activity.

Methods

Study Design

- **Model Derivation:** Observational, retrospective study for deriving a predictive model of disease activity risk in Portuguese JIA patients.
- **Model Validation and Refinement:** Observational, retrospective study for validating and refining the predictive model in Brazilian JIA patients.
- **Impact Analysis:** Prospective cost-effectiveness analysis of using telemedicine for JIA patients with a low probability of active disease determined by the developed predictive model.

Study Plan

- **Model Derivation**

  Data Collection
    - Reuma.pt is a long-term prospective registry created by the Portuguese Society of Rheumatology (SPR). By the end of 2022, it had registered 31,022 rheumatic patients and 267,611 consultations across 84 participating centers, including public and private institutions in Portugal (mainland, Madeira, and the Azores) and Brazil. It collects structured clinical information from rheumatic patients across various health domains and has been available for data entry since 2008. A patient self-completion platform was developed in 2013, allowing patients to complete condition-relevant questionnaires. Reuma.pt has recorded approximately 21,000 patient visits for JIA, with 2,000 collected in Brazilian centers, providing a rich data source, including PRO, inflammatory markers, and information on disease activity at each visit.[26]
    - Data accumulated from Reuma.pt from 2008 to 2024 will be used to derive the predictive model of inactive disease for telemedicine, encompassing approximately 19,000 consultations of JIA patients at the

72 Portuguese centers, according to ILAR classification criteria (Appendix 1).

- Reuma.pt participant centers will be asked to complete missing data in the register whenever possible. Multiple data imputations will complete missing data if necessary, as this methodology considers the imputation's variability and uncertainty.
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Inclusion Criteria

- Diagnosis of JIA according to ILAR classification criteria
- Age under 18 at the time of consultation
- Sufficient data to calculate JADAS-27-ESR or JADAS-27-CRP (Appendix 2) during the appointment
- Attended one of the 72 centers of reuma.pt in Portugal

Exclusion Criteria

- None

Variables - The following variables will be collected systematically from all Portuguese center database appointments in Reuma.pt:

Demographic Characteristics

- Date of birth and date of consultation
- Gender
- Ethnicity

Clinical Characteristics

- JIA category from ILAR classification
- Age at disease onset
- Age at diagnosis
- Presence of ANA
- Rheumatoid Factor
- Anti-CCP
- HLA-B27
- Comorbidities
- Presence of enthesitis, uveitis, and other extra-articular manifestations

From Each Appointment

- Erythrocyte Sedimentation Rate (ESR)
- C-reactive protein (CRP)
- Disease Activity, measured by JADAS27
- Number of swollen or tender joints
- Physician Global Assessment, measured on a 10 cm Visual Analog Scale
- Parent/Patient Global Assessment, measured on a 10 cm Visual Analog Scale
- Pain Visual Analog Scale
- Childhood Health Assessment Questionnaire (C-HAQ) for children aged < 18 years (Appendix 3)
- Medications in use at each appointment

Model Development

- Apply the random forests machine learning method or other similar method to construct a simple and easy-to-use model in clinical practice that predicts disease activity in JIA patients based on the collected data.

- **Model Validation and Refinement**

  Data Collection
  - Use accumulated data from reuma.pt from 2018 to 2024 in the 12 Brazilian centers of approximately 2,000 consultations of patients with JIA diagnosis, according to ILAR classification criteria.

  Inclusion Criteria
  - Diagnosis of JIA according to ILAR classification criteria
  - Age under 18 at the time of consultation
  - Sufficient data to calculate JADAS-27-ESR or JADAS-27-CRP (Appendix 2) during the appointment
  - Attended one of the 12 centers of reuma.pt in Brazil

  Exclusion Criteria
  - None

  Variables
  - Variables to be collected to validate the model from all Brazilian center database appointments in Reuma.pt will be the same as those used to derive the model from the Portuguese center database appointments.

  Model Development
  - Model Validation: Test the model using a separate dataset, represented by the 2,000 Brazilian visits, to assess its prediction sensibility and specificity and calculate the area under the ROC curve.
  - Model Refinement: If necessary, adjust the model based on validation results to improve its performance and adaptability to the specific characteristics of Brazilian patients.

- **Impact Analysis**

  Patient Recruitment:
  - Patients from Hospital Infantil João Paulo II in Brazil and from Hospital Egas Moniz in Portugal - will be invited to participate in the study at the next consultation after ethical committees approval.
  - A previous study on the cost-effectiveness of a telehealth intervention for rheumatoid arthritis in Denmark demonstrated an annual cost reduction of 695 euros per patient with no significant difference in clinical outcomes between the groups.[27] We did not identify any prior cost-effectiveness analyses of telemedicine use in juvenile idiopathic arthritis (JIA). Based on the observed cost reduction in rheumatoid arthritis in Denmark and using an alpha of 0.05 and a beta of 0.20, we estimated the need for eleven patients in each group (telemedicine versus in-person consultations) to perform a comparative study. The inclusion of approximately 40 participants is expected at each of the centers.

- For patients in Brazil who are under seven years old, assent will be obtained through a comic book format signed by the minor, verbal assent, and an informed consent form (ICF) signed by the guardians. For patients aged between 13 and 17, both written and verbal assent from the minor, along with the guardians' ICF will be required. In Portugal, informed consent will be obtained from the legal representative for minors under 16 years old, along with verbal assent from the minor. For those over 16, the patient's ICF and legal representative's consent will be required.

Inclusion Criteria:

- Diagnosis of JIA according to ILAR classification criteria.
- Age under 18 at the time of consultation.
- Attended either a Brazilian or Portuguese pediatric rheumatology center participating in the study.
- Appropriated age consent of patients and guardians.

Exclusion Criteria:

- None.

Variables

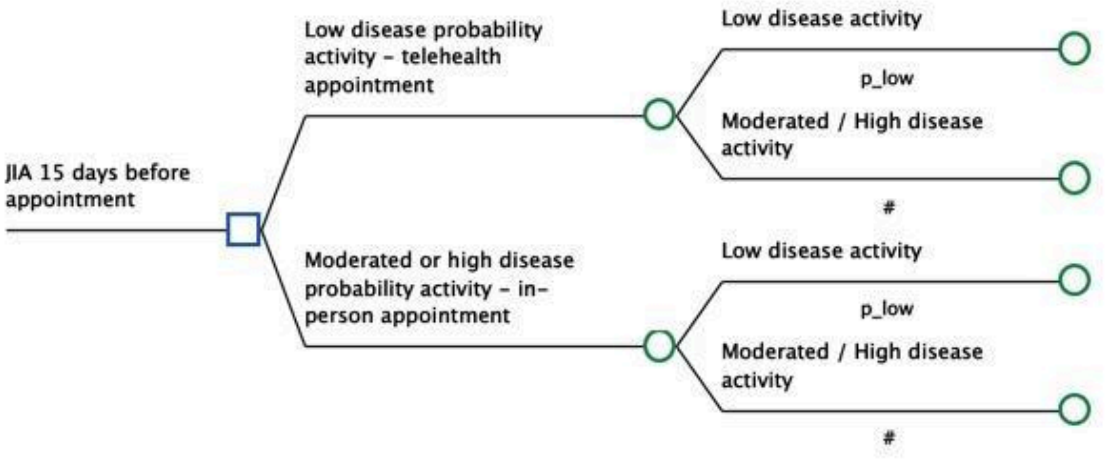
Variables to be collected at each appointment will be all those used to derive and validate the model plus:

- pGALS exam applied either to in-person or telemedicine consultations
- Cost patronized questionnaire (appendix 4)
- TUQ questionnaire (appendix 5)

Implementation

Application of the Predictive Model:

- Use the validated predictive model to categorize JIA patients as having low, moderate, or high risk of disease activity.
- Patients with a low probability of active disease will be allocated to telemedicine consultations.
- Patients with a moderate or high probability of active disease will be allocated to in-person consultations.
- After a teleconsultation, the next consultation will always be conducted in person.



Follow-up time after the first appointment

- 12 months

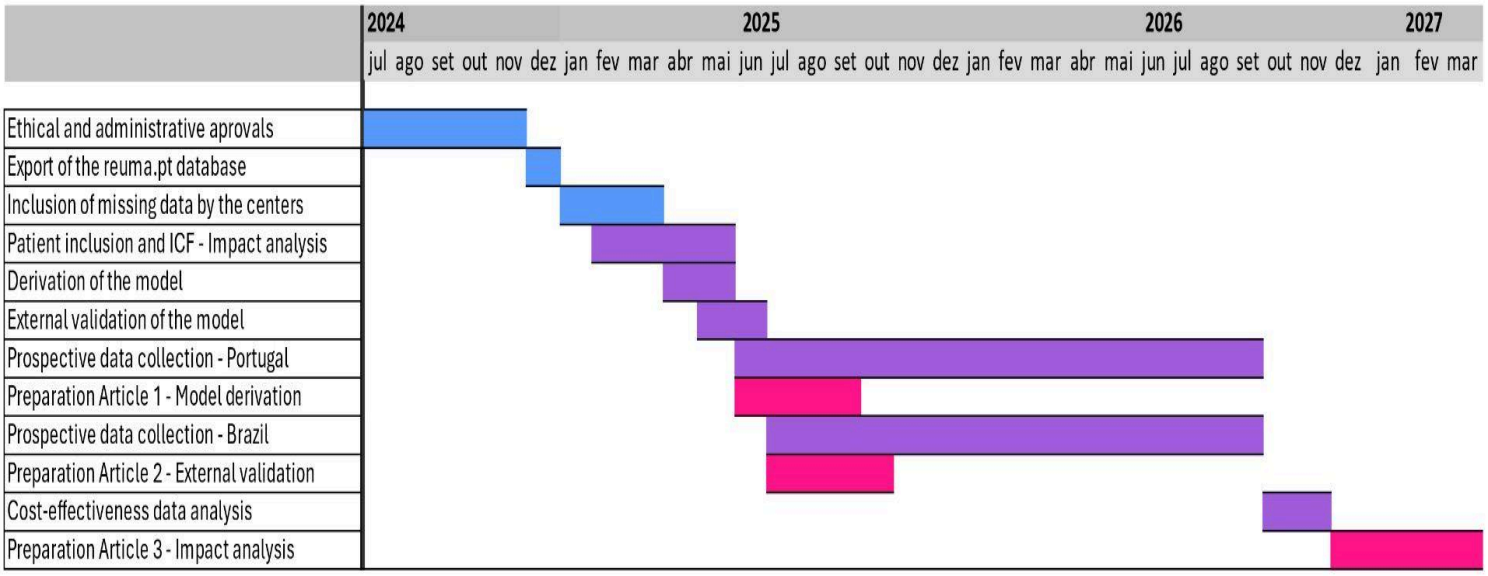
Cost-Effectiveness Analysis:

- Collect data at each appointment on costs related to loss of workdays for caregivers, loss of school days for patients, transportation costs, and food expenses on the day of the consultation, with a patronized questionnaire - preliminary version (appendix 4)
- Compare the costs and benefits of telemedicine versus in-person care.
- Conduct cost-effectiveness analyses to determine telemedicine's incremental cost-effectiveness ratio (ICER) compared to traditional care.

Satisfaction Analysis:

- Conduct patient satisfaction analyses using telemedicine through TUQ questionnaire,[28, 29] a validated Patient Reported Experience Measures (PREMs) for telemedicine (appendix 5), to assess patient and caregiver satisfaction with telemedicine services.
- Collect data on patient convenience, perceived quality of care, and overall satisfaction.

Timeline



Ethics

The project will be submitted for administrative approval of reuma.pt - Sociedade Portuguesa de Reumatologia, since the reuma.pt project already have ethical approval in each center and all patients included have ICF applied, and ethical approval by participating institutions:

Faculdade de Medicina da Universidade do Porto
Hospital Infantil João Paulo II - Fundação Hospitalar do Estado de Minas Gerais
Hospital Egas Moniz - Centro Hospitalar de Lisboa Ocidental

Discussion

Integrating telemedicine into managing JIA presents an opportunity to improve care delivery, particularly in geographically large and resource-limited settings. This study aims to develop a predictive model to identify JIA patients with low disease activity to be used in clinical practice for different populations, enhancing accessibility, cost-effectiveness, and quality of care through telemedicine. Given the challenges many families face in traveling long distances to see specialists and the limited number of pediatric rheumatologists, particularly in countries like Brazil, telemedicine, guided by a predictive model, offers a promising solution to bridge the gap in healthcare access and ensure continuous disease management.

The anticipated outcomes of this study are as follows: The predictive model can be utilized in clinical practice for different populations to identify patients with low disease activity who would benefit the most from telemedicine. This would reduce travel-related costs and save time for patients and caregivers, as well as minimize absenteeism from work and school. The improved cost-effectiveness of JIA management through targeted use of telemedicine would enhance continuity of care, allowing for more frequent monitoring and timely interventions. This would optimize resource utilization and improve patient satisfaction. The study will also include recommendations for integrating telemedicine into routine care for JIA patients with low disease activity risk, ultimately leading to enhanced patient and caregiver satisfaction.

However, potential risks include limitations in conducting comprehensive physical examinations remotely, which may lead to incomplete assessments and underestimation of disease activity. Not all patients may have access to the necessary technology or reliable internet connectivity, exacerbating healthcare disparities. There will probably be a high number of missing data in the reuma.pt platform. These will be supplemented through information to be completed by local centers register and, if necessary, multiple data imputations. Limitations may include data variability and the representativeness of patients in JIA remission. Despite these challenges, with careful implementation and ongoing evaluation, telemedicine, supported by a predictive model, can significantly enhance JIA management, offering a flexible and cost-effective alternative to traditional in-person visits.

Conclusion

This study aims to demonstrate that using a predictive model to allocate JIA patients to telemedicine or in-person consultations can enhance the cost-effectiveness of care, improve patient outcomes, and ensure appropriate resource utilization.

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Appendix

Appendix 1

ILAR classification criteria for JIA in patients under 16 years

Subtype of JIA	Duration of symptoms	Inclusion criteria	Exclusion criteria
Systemic arthritis (systemic JIA)	≥2 weeks	Arthritis in ≥1 joint and fever (with at least 3 days of a quotidian pattern), plus ≥1 of the following features: ■ Evanescent erythematous rash ■ Generalized lymphadenopathy ■ Hepatomegaly and/or splenomegaly ■ Serositis	■ A personal history of or first-degree relative affected by psoriasis ■ A personal history of or first-degree relative affected by certain conditions (including ERA, ankylosing spondylitis, sacroiliitis with IBD, reactive arthritis, and/or acute anterior uveitis) ■ Arthritis starting after 6 years of age in a male patient who is positive for HLA-B27 ■ Positive testing for RF*
Oligoarticular arthritis (oligoarticular JIA)	≥6 weeks	Arthritis affecting 1 to 4 joints during the first 6 months of disease Considered persistent oligoarticular JIA if patients continue to have arthritis in 1 to 4 joints, versus extended oligoarticular JIA if patients go on to develop arthritis in ≥4 joints	■ A personal history of or first-degree relative affected by psoriasis ■ A personal history of or first-degree relative affected by certain conditions (including ERA, ankylosing spondylitis, sacroiliitis with IBD, reactive arthritis, and/or acute anterior uveitis) ■ Arthritis starting after 6 years of age in a male patient who is positive for HLA-B27 ■ Positive testing for RF* ■ Features consistent with systemic JIA¶

Polyarticular arthritis (polyarticular JIA)	≥6 weeks	Arthritis affecting ≥5 joints affected during the first 6 months of disease Further categorized as being positive or negative for RF*	■ A personal history of or first-degree relative affected by psoriasis ■ A personal history of or first-degree relative affected by certain conditions (including ERA, ankylosing spondylitis, sacroiliitis with IBD, reactive arthritis, and/or acute anterior uveitis) ■ Arthritis starting after 6 years of age in a male patient who is positive for HLA-B27 ■ Features consistent with systemic JIA¶
Psoriatic arthritis (psoriatic JIA)	≥6 weeks	Simultaneous arthritis and psoriasis **or** arthritis plus ≥2 of the following: ■ Dactylitis ■ Nail pitting or onycholysis ■ Psoriasis in a first-degree relative	■ A personal history of or first-degree relative affected by certain conditions (including ERA, ankylosing spondylitis, sacroiliitis with IBD, reactive arthritis, and/or acute anterior uveitis) ■ Arthritis starting after 6 years of age in a male patient who is positive for HLA-B27 ■ Positive testing for RF* ■ Features consistent with systemic JIA¶
Enthesitis-related arthritis (ERA)	≥6 weeks	Arthritis and enthesitis **or** enthesitis plus ≥2 of the following: ■ The presence of or history of sacroiliac joint tenderness and/or inflammatory back pain ■ HLA-B27 positivity ■ Onset of arthritis in a male over 6 years of age ■ Acute anterior uveitis ■ History in a first-degree relative of ankylosing spondylitis, ERA, sacroiliitis with IBD, reactive arthritis, or acute anterior uveitis	■ A personal history of or first-degree relative affected by psoriasis ■ Positive testing for RF* ■ Features consistent with systemic JIA¶

Undifferentiated arthritis	≥6 weeks	Patient does not meet the above criteria **or** if they fulfill criteria for 2 or more categories	

HLA: human leukocyte antigen; IBD: inflammatory bowel disease; ILAR: International League of Associations for Rheumatology; JIA: juvenile idiopathic arthritis; RF: rheumatoid factor.

* Positive testing for RF is defined as having a positive immunoglobulin M RF test on at least 2 occasions checked at least 3 months apart within the first 6 months of disease.

¶ Examples include fever, evanescent rash, and elevated ferritin.

Adapted from: Petty RE, Southwood TR, Manners P, et al. International League of Associations for Rheumatology classification of juvenile idiopathic arthritis: Second revision, Edmonton, 2001. J Rheumatol 2004; 31:390.

Appendix 2

JADAS 27

	JADAS 27
Physician Global assessment	0-10 cm VAS
Parent/patient global assessment	0-10 cm VAS
Active joint count (range)	Simple 0-27 joint
Acute-phase reactant (range)	Normalized ESR 0-10^{+} Or normalized CRP 0-10^{++}
Score range	0-57

JADAS 27 - Juvenile Arthritis Disease Activity Score 27-joint reduced count; ESR erythrocyte sedimentation rate; CRP C-reactive protein;

$^{+}$According to the formula (value in mm/hour - 20)/10 - where values <20 mm/hour are converted to 0, and values >120 mm/hour are converted to 120.

$^{++}$According to the formula (value in mg/liter - 10)/10 - where values <10 mg/liter are converted to 0, and values >110 mm/hour are converted to 110.

From: Bulatović Calasan M, de Vries LD, Vastert SJ, Heijstek MW, Wulffraat NM. Interpretation of the Juvenile Arthritis Disease Activity Score: responsiveness, clinically important differences and levels of disease activity in prospective cohorts of patients with juvenile idiopathic arthritis. Rheumatology (Oxford). 2014 Feb;53(2):307-12. doi: 10.1093/rheumatology/ket310. Epub 2013 Oct 24. PMID: 24162034.

Mourão AF, Santos MJ, Melo-Gomes J, Martins FM, Costa JA, Ramos F, Brito I, Duarte C, Figueira R, Figueiredo G, Furtado C, Lopes A, Oliveira M, Rodrigues A, Salgado M, Sousa M, Branco JC, Fonseca JE, Canhão H. Using the Juvenile Arthritis Disease Activity Score based on erythrocyte sedimentation rate or C-reactive protein level: results from the Portuguese register. Arthritis Care Res (Hoboken). 2014 Apr;66(4):585-91. doi: 10.1002/acr.22215. PMID: 25354266.

Appendix 3

Questionário de Avaliação de Saúde em Crianças (CHAQ)

Nome: _____ Data: ___ / ___ / _____

Neste questionário estamos interessados em avaliar como a doença do seu filho(a) afecta as suas actividades diárias. Nas questões seguintes, por favor marque a resposta que melhor descreve as actvidades habituais do seu filho(a) (em média durante um dia inteiro) **DURANTE A SEMANA PASSADA. ASSINALE SÓ AQUELAS DIFICULDADES OU LIMITAÇÕES QUE SÃO DEVIDAS À DOENÇA.** Se a maioria das crianças da idade do seu filho não fazem uma certa actividade, por favor marque-a como "Não Aplicável". **Por exemplo, se o seu filho tem dificuldade ou é incapaz de desempenhar uma certa actividade porque é muito novo e não porque esteja LIMITADO PELA DOENÇA, por favor marque-a como "Não Aplicável".**

	Sem NENHUMA dificuldade	Com ALGUMA Dificuldade	Com MUITA dificuldade	INCAPAZ de fazer	Não Aplicável
VESTIR-SE E ARRANJAR-SE					
O seu filho é capaz de:					
- Vestir-se, incluindo atar os atacadores e abotoar os botões ?	☐	☐	☐	☐	☐
- Lavar o cabelo ?	☐	☐	☐	☐	☐
- Tirar as meias ?	☐	☐	☐	☐	☐
- Cortar as unhas das mãos ?	☐	☐	☐	☐	☐
LEVANTAR-SE					
O seu filho é capaz de:					
- Levantar-se duma cadeira baixa ou do chão ?	☐	☐	☐	☐	☐
- Entrar e sair da cama ou levantar-se no berço?	☐	☐	☐	☐	☐
ALIMENTAR-SE					
O seu filho é capaz de :					
- Cortar a carne ?	☐	☐	☐	☐	☐
- Levar uma chávena ou um copo à boca?	☐	☐	☐	☐	☐
- Abrir uma caixa nova de papa ou cereais ?	☐	☐	☐	☐	☐
ANDAR					
O seu filho é capaz de:					
- Andar na rua, em terreno plano ?	☐	☐	☐	☐	☐
- Subir cinco degraus ?	☐	☐	☐	☐	☐

*** Por favor marque qualquer APOIO ou INSTRUMENTO que o seu filho use habitualmente para alguma das actividades acima indicadas:**

Bengala	☐	Instrumentos usados para se vestir (gancho de botões, puxador de fechos, calçadeira comprida, etc.)	☐
- Andarilho	☐	- Adaptador de lápis ou utensílios especiais	☐
- Muleta	☐	- Cadeira mais alta	☐
- Cadeira de rodas	☐	- Outros (Indique:……)	☐

*** Por favor indique em que tipo de actividades o seu filho habitualmente necessita da ajuda de outra pessoa, DEVIDO À DOENÇA:**

- Vestir-se e arranjar-se	☐	- Alimentar-se	☐
- Levantar-se	☐	- Andar	☐

	Sem NENHUMA dificuldade	Com ALGUMA Dificuldade	Com MUITA dificuldade	INCAPAZ de fazer	Não Aplicável
HIGIENE					
O seu filho é capaz de:					
- Lavar e enxugar o corpo inteiro?	☐	☐	☐	☐	☐
- Tomar um banho de banheira (entrar e sair da banheira)?	☐	☐	☐	☐	☐
- Sentar-se e levantar-se na sanita ou no bacio ?	☐	☐	☐	☐	☐
- Lavar os dentes com a escova ?	☐	☐	☐	☐	☐
- Pentear/escovar o cabelo ?	☐	☐	☐	☐	☐
ALCANÇAR					
O seu filho é capaz de:					
- Alcançar e tirar para baixo um objecto pesado, como um jogo grande ou livro, situado em local um pouco acima da sua cabeça ?	☐	☐	☐	☐	☐
- Dobrar-se para apanhar roupa ou um papel do chão?	☐	☐	☐	☐	☐
- Vestir uma camisola pela cabeça ?	☐	☐	☐	☐	☐
- Virar o pescoço para olhar para trás por cima do ombro ?	☐	☐	☐	☐	☐
AGARRAR					
O seu filho é capaz de:					
- Escrever ou rabiscar com uma caneta ou um lápis ?	☐	☐	☐	☐	☐
- Abrir portas de carros ?	☐	☐	☐	☐	☐
- Abrir frascos que já tenham sido abertos antes ?	☐	☐	☐	☐	☐
- Abrir e fechar torneiras ?	☐	☐	☐	☐	☐
- Abrir uma porta quando tem que rodar a maçaneta?	☐	☐	☐	☐	☐
ACTIVIDADES					
O seu filho é capaz de:					
- Fazer recados e compras ?	☐	☐	☐	☐	☐
- Entrar e sair de um carro, de um carro de brincar ou da carrinha da escola?	☐	☐	☐	☐	☐
- Andar de bicicleta ou triciclo ?	☐	☐	☐	☐	☐
- Fazer tarefas domésticas (lavar pratos, fazer a cama, limpar o quarto, aspirar, despejar o lixo, etc)	☐	☐	☐	☐	☐
- Correr e brincar ?	☐	☐	☐	☐	☐

*** Por favor marque qualquer APOIO ou INSTRUMENTO que o seu filho use nas actividades acima indicadas**:

- Assento de sanita elevado	☐	- Barra de apoio na banheira	☐
- Assento de banheira	☐	- Utensílios de cabo longo para apanhar objectos	☐
- Dispositivo para abrir frascos (que tenham sido anteriormente abertos)	☐	- Utensílios de cabo longo para usar na casa de banho	☐

*** Por favor indique em que tipo de actividades o seu filho habitualmente necessita de ajuda de outra pessoa, DEVIDO À DOENÇA:**

- Higiene	☐	- Agarrar e abrir coisas	☐
- Alcançar	☐	- Recados e pequenas tarefas	☐

DOR: Estamos tambem interessados em saber se o seu filho tem ou não sido afectado pela dor devida à sua doença.

Que intensidade de dor pensa que o seu filho teve devido à sua doença, NA SEMANA PASSADA?

Coloque uma marca na linha abaixo, para indicar a gravidade da dor

SEM Dor 0 — 100 DOR muito forte

AVALIAÇÃO GLOBAL: Considerando todas as formas como a artrite afecta o seu filho, indique como ele está a passar colocando uma marca na linha abaixo

Muito Bem 0 — 100 Muito MAL

Appendix 4 - Preliminary version

Questionário de Avaliação Econômica para Teleconsulta - Versão Portugues do Brasil

Seção 1: Informações Demográficas

1. Município de origem do paciente: _____

2. Distância (em quilômetros) do local de atendimento: _____

3. Relação do Cuidador com o Paciente

[ ] Pai/Mãe [ ] Guardião [ ] Outro (Especifique): _____

4. Ocupação do Cuidador

[ ] Empregado(a) em Tempo Integral [ ] Empregado(a) em Tempo Parcial

[ ] Autônomo(a) [ ] Desempregado(a) [ ] Do Lar [ ] Estudante [ ] Aposentado(a)

[ ] Outro (Especifique): _____

5. Local de Residência

[ ] Urbano [ ] Rural

Seção 2: Custos da Teleconsulta

6. Tempo Gasto na Teleconsulta (minutos): _____

7. Custos com Internet para a Teleconsulta:

[ ] Nenhum [ ] Valor específico: R$ _____

8. Outros Custos Relacionados à Teleconsulta (por exemplo, contas de telefone, equipamentos):

[ ] Nenhum [ ] Especifique e estime o custo: _____

Seção 3: Custos de Tempo

9. Tempo Gasto pelo Cuidador na Teleconsulta (minutos): _____

10. Perda de Dias de Trabalho pelo Cuidador Devido à Teleconsulta:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

11. Perda de Dias Escolares pelo Paciente Devido à Teleconsulta

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

12. Salário Líquido Mensal Estimado do Cuidador (opcional): R$ _____

Seção 4: Satisfação Geral e Custos Percebidos

13. Satisfação Geral com a Teleconsulta

[ ] Muito Satisfeito(a) [ ] Satisfeito(a) [ ] Neutro(a) [ ] Insatisfeito(a) [ ] Muito Insatisfeito(a)

14. Percepção da Carga Financeira da Teleconsulta

[ ] Nenhuma Carga [ ] Pequena Carga [ ] Carga Moderada [ ] Carga Significativa [ ] Carga Severa

Seção 5: Comentários Adicionais

15. Por favor, forneça quaisquer comentários ou sugestões adicionais sobre os aspectos econômicos das teleconsultas:

- _____
- _____
- _____

Questionário de Avaliação Econômica para Consulta Presencial - Versão Portugues do Brasil

Seção 1: Informações Demográficas

1. Município de origem do paciente: _____

2. Distância (em quilômetros) do local de atendimento: _____

3. Relação do Cuidador com o Paciente:

[ ] Pai/Mãe [ ] Guardião [ ] Outro (Especifique): _____

4. Ocupação do Cuidador:

[ ] Empregado(a) em Tempo Integral [ ] Empregado(a) em Tempo Parcial

[ ] Autônomo(a) [ ] Desempregado(a) [ ] Do lar [ ] Estudante [ ] Aposentado(a)

[ ] Outro (Especifique): _____

5. Local de Residência:

[ ] Urbano [ ] Rural

Seção 2: Custos da Consulta Presencial

6. Meio de Transporte:

[ ] Carro Particular [ ] Transporte Público [ ] Táxi/Uber [ ] Caminhada/Bicicleta

[ ] Outro (Especifique): _____

7. Custos de Transporte:

- Quem Pagou pelo Transporte:

[ ] Paciente [ ] Prefeitura

-Se Pago pelo Paciente, Valor das Passagens ou Combustível:

[ ] Valor das Passagens (ida e volta): R$ _____

[ ] Valor do Combustível: R$ _____

- Se Pago pela Prefeitura, Meio de Transporte Utilizado:

[ ] Ambulância [ ] Carro do Município [ ] Passagem de Ônibus (paga pelo Município)

- Se Passagem de Ônibus Paga pelo Município, Custo das Passagens:

[ ] Ida e volta: R$ _____

8. Despesas com Alimentação no Dia da Consulta:

[ ] Nenhum [ ] Valor específico: R$ _____

9. Foi necessário permanecer mais de um dia em outro município para o atendimento?

[ ] Sim [ ] Não

- Se sim, número de dias: _____

- Custos com Alojamento:

Quem Pagou pelo Alojamento:**

[ ] Paciente [ ] Prefeitura

Se Pago pelo Paciente, Valor do Alojamento (por dia): R$ _____

Local do Alojamento:

[ ] Hotel [ ] Pousada [ ] Casa de Familiar/Amigo [ ] Outro (Especifique): _____

Seção 3: Custos de Tempo

10. Tempo Gasto pelo Cuidador na Consulta Presencial - incluindo viagem e tempo de espera: _____ horas e _____ minutos

11. Perda de Dias de Trabalho pelo Cuidador Devido à Consulta Presencial:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

12. Perda de Dias Escolares pelo Paciente Devido à Consulta Presencial:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

13. Salário Líquido Mensal Estimado do Cuidador (opcional):R$ _____

Seção 4: Satisfação Geral e Custos Percebidos

14. Satisfação Geral com a Consulta Presencial:

[ ] Muito Satisfeito(a) [ ] Satisfeito(a) [ ] Neutro(a) [ ] Insatisfeito(a) [ ] Muito Insatisfeito(a)

15. Percepção da Carga Financeira da Consulta Presencial:

[ ] Nenhuma Carga [ ] Pequena Carga [ ] Carga Moderada [ ] Carga Significativa [ ] Carga Severa

Seção 5: Comentários Adicionais

16. Por favor, forneça quaisquer comentários ou sugestões adicionais sobre os aspectos econômicos das consultas presenciais:

- _____

- _____

- _____

Questionário de Avaliação Económica para Teleconsulta - Versão Portugues de Portugal

Seção 1: Informações Demográficas

1. Município de origem do paciente: _____

2. Distância (em quilômetros) do local de atendimento: _____

3. Relação do Cuidador com o Paciente:

[ ] Pai/Mãe [ ] Guardião [ ] Outro (Especifique): _____

4. Ocupação do Cuidador

[ ] Empregado(a) a Tempo Integral [ ] Empregado(a) a Tempo Parcial

[ ] Trabalhador(a) Independente [ ] Desempregado(a) [ ] Dono(a) de Casa

[ ] Estudante [ ] Reformado(a) [ ] Outro (Especifique): _____

5. Local de Residência

[ ] Urbano [ ] Rural

Seção 2: Custos da Teleconsulta

6. Tempo Gasto na Teleconsulta (minutos):_____

7. Custos com Internet para a Teleconsulta:

[ ] Nenhum [ ] Valor específico: € _____

8. Outros Custos Relacionados à Teleconsulta (por exemplo, contas de telefone, equipamentos):

[ ] Nenhum [ ] Especifique e estime o custo: € _____

Seção 3: Custos de Tempo

9. Tempo Gasto pelo Cuidador na Teleconsulta: _____

10. Perda de Dias de Trabalho pelo Cuidador Devido à Teleconsulta:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

11. Perda de Dias Escolares pelo Paciente Devido à Teleconsulta:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

12. Salário Líquido Mensal Estimado do Cuidador : € _____

Seção 4: Satisfação Geral e Custos Percebidos

13. Satisfação Geral com a Teleconsulta:

[ ] Muito Satisfeito(a) [ ] Satisfeito(a) [ ] Neutro(a) [ ] Insatisfeito(a) [ ] Muito Insatisfeito(a)

14. Perceção da Carga Financeira da Teleconsulta:

[ ] Nenhuma Carga [ ] Pequena Carga [ ] Carga Moderada

[ ] Carga Significativa [ ] Carga Severa

Seção 5: Comentários Adicionais

15. Por favor, forneça quaisquer comentários ou sugestões adicionais sobre os aspetos económicos das teleconsultas:

- _____

- _____

- _____

Questionário de Avaliação Económica para Consulta Presencial - Versão Portugues de Portugal

Seção 1: Informações Demográficas

1. Município de origem do paciente: _____

2. Distância (em quilômetros) do local de atendimento: _____

3. Relação do Cuidador com o Paciente:

[ ] Pai/Mãe [ ] Guardião [ ] Outro (Especifique): _____

4. Ocupação do Cuidador

[ ] Empregado(a) a Tempo Integral [ ] Empregado(a) a Tempo Parcial

[ ] Trabalhador(a) Independente [ ] Desempregado(a) [ ] Dono(a) de Casa

[ ] Estudante [ ] Reformado(a) [ ] Outro (Especifique): _____

5. Local de Residência

[ ] Urbano [ ] Rural

Seção 2: Custos da Consulta Presencial

6. Meio de Transporte:

[ ] Carro Particular [ ] Transporte Público [ ] Táxi/Uber [ ] Caminhada/Bicicleta

[ ] Outro (Especifique): _____

7. Custos de Transporte

- Quem Pagou pelo Transporte: [ ] Paciente [ ] Câmara Municipal

- Se Pago pelo Paciente, Valor das Passagens ou Combustível:

[ ] Valor das Passagens (ida e volta): € _____

[ ] Valor do Combustível: € _____

- Se Pago pela Câmara Municipal, Meio de Transporte Utilizado:

[ ] Ambulância [ ] Carro da Câmara [ ] Bilhete de Autocarro (paga pela Câmara)

- Se Bilhete de Autocarro Paga pela Câmara, Custo das Passagens:

[ ] Ida e volta: € _____

8. Despesas com Alimentação no Dia da Consulta:

[ ] Nenhum [ ] Valor específico: € _____

9. Foi necessário permanecer mais de um dia noutro município para o atendimento?

[ ] Sim [ ] Não

- Se sim, número de dias: _____
- Custos com Alojamento:
  Quem Pagou pelo Alojamento: [ ] Paciente [ ] Câmara Municipal
  Se Pago pelo Paciente, Valor do Alojamento (por dia): € _____
  Local do Alojamento:
  [ ] Hotel [ ] Pousada [ ] Casa de Familiar/Amigo
  [ ] Outro (Especifique): _____

Seção 3: Custos de Tempo

10. Tempo Gasto pelo Cuidador na Consulta Presencial (incluindo viagem e tempo de espera): _____ horas e _____ minutos

11. Perda de Dias de Trabalho pelo Cuidador Devido à Consulta Presencial:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

12. Perda de Dias Escolares pelo Paciente Devido à Consulta Presencial:

[ ] Nenhum [ ] Meio dia [ ] Dia inteiro [ ] Mais de um dia (Especifique): _____

13. Salário Líquido Mensal Estimado do Cuidador :€ _____

Seção 4: Satisfação Geral e Custos Percebidos

14. Satisfação Geral com a Consulta Presencial:

[ ] Muito Satisfeito(a) [ ] Satisfeito(a) [ ] Neutro(a)

[ ] Insatisfeito(a) [ ] Muito Insatisfeito(a)

15. Perceção da Carga Financeira da Consulta Presencial:

[ ] Nenhuma Carga [ ] Pequena Carga [ ] Carga Moderada

[ ] Carga Significativa [ ] Carga Severa

Seção 5: Comentários Adicionais

16. Por favor, forneça quaisquer comentários ou sugestões adicionais sobre os aspetos económicos das consultas presenciais:

- _____

- _____

- _____

Appendix 5

TELEHEALTH USABILITY QUESTIONNAIRE (TUQ)

QUESTIONÁRIO DE USABILIDADE EM TELESSAÚDE (TUQ BRAZIL)

#	Afirmações	N/A	1 2 3 4 5 6 7
1.	Telessaúde melhora meu acesso aos serviços de saúde.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
2.	Com a telesaúde eu ganho tempo por não precisar me deslocar a um hospital ou clínica especializada.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
3.	A telesaúde supre as minhas demandas de assistência de saúde.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
4.	Foi simples usar esse sistema.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
5.	Foi fácil aprender a usar o sistema.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
6.	Acredito que eu poderia retornar mais rapidamente às minhas atividades usando este sistema.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
7.	A maneira como interajo com este sistema é agradável.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
8.	Eu gosto de usar esse sistema.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
9.	O sistema é simples e fácil de entender.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
10.	Este sistema é capaz de fazer tudo o que eu gostaria que ele fosse capaz de fazer.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
11.	Posso facilmente conversar com o profissional de saúde usando	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO

	o sistema de telessaúde.		
12.	Eu consigo ouvir o profissional claramente usando esse sistema.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
13.	Eu senti que consegui me expressar de forma efetiva.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
14.	Ao utilizar o sistema de telesaúde, eu consigo ver o profissional de saúde, tão bem quanto se estivéssemos nos vendo pessoalmente.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO

15.	Eu acho que os atendimentos fornecidos pelo sistema de telessaúde são iguais aos atendimentos realizados pessoalmente.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
16.	Sempre que eu errei utilizando o sistema, eu consegui corrigir o erro de forma fácil e rápida.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
17.	O sistema forneceu mensagens de erro que me disseram claramente como corrigir os problemas.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
18.	Eu me sinto a vontade para me comunicar com o profissional de saúde usando o sistema de telessaúde.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
19.	Telessaúde é uma maneira aceitável de utilizar serviços de saúde.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
20.	Eu usaria serviços de telessaúde de novo.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO
21.	No geral, estou satisfeito com este sistema de telessaúde.	☐	DISCORDO ☐ ☐ ☐ ☐ ☐ ☐ ☐ CONCORDO

Neste questionário, 1 - discordo bastante, 2 - discordo, 3 - discordo parcialmente, 4 - não concordo nem discordo, 5 - concordo parcialmente, 6 - concordo, 7 - concordo bastante.

Para determinar a usabilidade do sistema de telessaúde, calcule o total e determine a média dos valores obtidos em todas as afirmações. Quanto maior a média geral, maior a usabilidade do sistema de telessaúde.

Citar como: Santos MR, Malaguti C, Cabral LA, Soares AL, Neves LHG, Sena LA, Parmanto B, Sauers AL, José A, Oliveira CC. The Brazilian version of the telehealth usability questionnaire (TUQ Brazil): translation, cross-cultural adaptation, and psychometric properties. Rev Assoc Med Bras. 2023 Nov 13;69(12):e20230228. doi: 10.1590/1806-9282.20230228.