








## ARTIGO ORIGINAL/ORIGINAL ARTICLE

# Headache – What Service Do We Provide? Evaluation of Quality Indicators in Primary Health-Care Units

## Cefaleia – Que Serviço Prestamos?

## Avaliação de Indicadores de Qualidade em Cuidados de Saúde Primários

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### Abstract

**Introduction:** Quality of care for headache patients is a universal concern. This study was developed in the context of the collaborative project between Lifting The Burden (LTB) and the European Headache Federation (EHF). Its aim was to evaluate the adequacy of a set of quality indicators for headache care in 15 primary care units in the central region of Portugal.

**Material and Methods:** The quality indicators were evaluated through the use of questionnaires developed by LTB and EHF for previous studies in specialized centres. In each unit, a sample of healthcare providers (HCP) and a sample of headache patients were enquired. Additionally, a sample of clinical records of different headache patients in each unit was also randomly selected and audited.

**Results and Discussion:** The questionnaires were reported as easy to apply in these settings, however the HCPs' evaluation revealed ambiguous results. The results that arose discussion suggested that most clinical records were lacking essential information (namely temporal profile of headache or a definitive diagnosis according the International Classification of Headache Disorders) and tools such as diagnostic diaries, instruments for outcome assessment in headache were not routinely used. Positive findings in this study were the routine practice of follow-up in headache patients, equality of access of care in these units and the overall expressed satisfaction of patients with their management.

**Conclusion:** This study suggested that the indicators promoted by LTB and

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EHF can be useful in evaluating headache service quality in the primary care level. Additionally, they demonstrated common trends and deficits that can serve as guide for improving quality in these units, in future interventions.

**Resumo**

**Introdução:** A qualidade de tratamento da cefaleia é uma preocupação universal. Este estudo foi desenvolvido no contexto do projeto colaborativo entre a Lifting The Burden (LTB) e a European Headache Federation (EHF). O seu objetivo foi avaliar a implementação de indicadores de qualidade no tratamento da cefaleia em 15 unidades de Cuidados de Saúde Primários na região centro de Portugal.

**Material e Métodos:** Os indicadores de qualidade foram avaliados através da utilização de questionários já desenvolvidos pela LTB e EHF para estudos prévios em centros especializados. Em cada unidade, foram inquiridas uma amostra de profissionais de saúde e uma amostra de utentes com cefaleia. Adicionalmente, foi também auditada uma amostra aleatória de registos de utentes de cada unidade acompanhados por cefaleia.

**Resultados e Discussão:** Os questionários utilizados revelaram-se facilmente aplicáveis neste contexto, contudo os inquéritos de profissionais demonstraram resultados ambíguos. Os resultados mais discutíveis sugeriram que a maioria dos registos clínicos carecia de informação diagnóstica essencial (nomeadamente perfil temporal da cefaleia ou diagnóstico baseado na Classificação Internacional de Cefaleias) e que ferramentas como diários de cefaleias e instrumentos para avaliar resultados do tratamento não eram utilizados por rotina. Os achados mais positivos foram a prática de acompanhamento rotineiro nos doentes com cefaleia, equidade de acesso a cuidados de saúde nestas unidades e a satisfação dos utentes relativamente ao tratamento.

**Conclusão:** Este estudo revelou que os indicadores testados poderão ter utilidade na avaliação da qualidade de tratamento da cefaleia nos cuidados de saúde primários. Adicionalmente, os indicadores demonstraram tendências comuns entre unidades e também lacunas que poderão servir de guia para melhorar a sua qualidade, em intervenções futuras.

**Introduction**

The assessment of healthcare quality has, in its practice, continuously proved its importance as a contribution to achieve optimal care.

Nowadays, headache disorders represent a major cause of public ill-health, being the third highest cause of disability worldwide.<sup>1,2</sup> However, until date, a concrete and globally accepted definition of quality in headache care is not yet established, without which deficiencies on this level cannot be correctly recognized. Furthermore, currently available guidelines are limited to the diagnosis and treatment of specific types of headache.

Consequently, there still exist many gaps in the education of health professionals and in the adequacy of healthcare for these patients worldwide.<sup>3-5</sup> This is a

problem that affects particularly primary health care levels, where headache care should be based.<sup>5</sup>

This study intends to expand the work initiated in a collaborative project between Lifting The Burden (LTB) and the European Headache Federation (EHF), within the framework of the Global Campaign Against Headache,<sup>3,4</sup> conducted by LTB in conjunction with the World Health Organization (WHO), whose aim is to assess the quality of care for patients with headache worldwide. At an early stage of the global project, after conducting a literature review,<sup>5,6</sup> a multidimensional definition of quality in headache care was proposed, based on nine different domains (**Table 1**):

*“Good-quality headache care achieves accurate diagnosis and individualized management, has appropriate referral pathways, educates patients about their headaches and their*

*management, is convenient and comfortable, satisfies patients, is efficient and equitable, assesses outcomes and is safe”.*<sup>7</sup>

In order to access quality of care, a set of quality indicators for each of these nine domains would be necessary. Therefore, with this definition as a starting point, the group developed a list of 30 quality indicators in total, along with a set of related assessment instruments, designed to be applicable in different countries and settings.<sup>7</sup> The adequacy of these indicators was assessed in a pilot study by conducting questionnaires for patients and healthcare providers (HCP) in two headache-care specialist centres in Portugal and Germany.<sup>8</sup> Subsequently, a broader study was conducted, expanding the evaluation of these indicators at a European level involving a total of 14 specialized centres.<sup>9</sup>

At the present moment (and with the present research),

this study aims to create the link of this investigation with the primary care level, as what the collaborative project itself designates as non-specialized centres in headache care.<sup>9</sup> The application of these quality-of-care indicators to patients with headache in various primary care units in the central region of Portugal (“*Unidades de Cuidados de Saúde Personalizados*” and “*Unidades de Saúde Familiar*”) will allow, for the first time, to test in this area the same quality definition already assessed in specialized centres and to identify any possible gaps on this level, with the goal to implement a set of global strategies for improving care for patients with headache. All data collected in this study will also be integrated in a multinational study currently being developed, which will eventually allow to our results with the ones obtained in parallel in countries like Germany, Latvia and Turkey.

**Table 1.** The nine domains of quality in a headache service promoted by LTB and EHF (from reference<sup>7-9</sup>)

<b>Domain A:</b>	Diagnostic accuracy, therefore asking whether diagnoses were made according to the IHS criteria, documented during the first visit and reviewed during the follow-ups and supported by the diagnostic diaries.
<b>Domain B:</b>	Issues of the individualized management including waiting time, use of diaries and instruments of headache related disability in treatment plans.
<b>Domain C:</b>	Availability and use of urgent and specialist referral pathways.
<b>Domain D:</b>	Patient’s education and reassurance.
<b>Domain E:</b>	Convenience, comfort and welcoming of the clinic.
<b>Domain F:</b>	Patient’s satisfaction.
<b>Domain G:</b>	Equity and efficiency of the headache care including access to care, wastage of resources, rate of technical investigations and costs.
<b>Domain H:</b>	Outcome measures including clinical parameters but also measures of disability and quality of life.
<b>Domain I:</b>	Safety of care.

IHS - International Headache Society

## Material and Methods

### Ethics Committee approval

The present project was approved by the Centre Regional Health Administration Ethics Committee (ARS Centro).

All collected data were authorised by each study participant by signed informed consents, which safeguarded their anonymity and the confidentiality of data.

### Study Settings

Thirty-three different primary health-care units were invited to participate, representing, as far as possible, the geographically distinct realities in the central region of Portugal.<sup>10</sup> Fifteen units accepted to participate in the study (**Table 2**) and conducted the data collection over the period of 3 months between October and December 2019. In each unit, a general practitioner was

nominated as research assistant, in order to conduct data collection on a local level.

### Study Population

At each unit, we inquired the service staff (attending and resident doctors), other HCPs (nurses, psychologists, physiotherapists, others), the service manager and the administrative staff. A transversal consecutive sample of headache patients was inquired as well (a convenience sample of at least 10 headache patients per unit was proposed). The patients sample included every patient who had an appointment during the data collection period, had active complaints of headache, was able to read and accepted participating in the study and signed the informed consent document.

Additionally, we analysed the information from the records of a retrospective random sample of 10 headache

**Table 2.** Participating Primary Care Units.

Primary care unit	ACES	Local assistant
UCSP de Cantanhede	Baixo Mondego	Daniela Fernandes
USF Pulsar	Baixo Mondego	Rita Marques
UCSP Celas	Baixo Mondego	Joana Gonçalves
USF Buarcos	Baixo Mondego	Mafalda Diogo
USF Fernando Namora	Baixo Mondego	Mariana Loureiro
USF VitaSaurium	Baixo Mondego	Rita Pereira
USF São João de Ovar	Baixo Vouga	Inês Silva
USF Arte Nova	Baixo Vouga	Maria Cunha
USF Moliceiro	Baixo Vouga	Ana Catarina Fortunato
USF Viseu Cidade	Dão Lafões	Rafaela Cabral
USF Serra da Lousã	Pinhal Interior Norte	Ana Rita Cibrão and Luís Amaral
USF Trevim Sol	Pinhal Interior Norte	Sophia Martins
USF Santiago	Pinhal Litoral	Ana Margarida Gonçalves
USF Fonte do Rei	Pinhal Litoral	Joana Cebola
UCSP Arnaldo Sampaio	Pinhal Litoral	Catarina Oliveira

ACES: "Agrupamento de Centros de Saúde" (Group of Healthcare Units); UCSP: "Unidade de Cuidados de Saúde Personalizados" (Personalized Healthcare Unit); USF: "Unidade de Saúde Familiar" (Family Health Unit).

patients in each unit other than those seen prospectively. The selection of these clinical records included every patient followed by headache complaints in the past 5 years and was carried out using the computer coding system in use in each of the participating units (*SClínico*<sup>®</sup> and *MedicineOne*<sup>®</sup>).

### Study Instruments

A total of five different questionnaires were used, being one assigned to each group (doctors, other HCPs, the service manager, the administrative staff, and headache patients)

**[Additional Files 1 and 2].** The patient's assessment took the form of an exit questionnaire, which they were asked to fill at the end of their appointment. These questionnaires were adapted from the originally used ones in previous studies conducted by the LTB and EHF, based on the quality indicators proposed by these entities (**Table 3**). Additionally, some informative items (**Table 3**) were extracted from the patients' records in a retrospective review. **Table 3** summarizes the set of quality indicators and related methods of implementation in the present research.

**Table 3.** Quality Indicators and methods of implementation (adapted from previous studies conducted in specialized centres by EHF and LTB)<sup>7-9</sup>

Indicator	Measure	Application
<b>Domain A. Accurate diagnosis is essential for optimal headache care</b>		
<b>A1</b>	Patients are asked about onset of their headaches	Review of randomly selected clinical records from a retrospective sample of headache patients
<b>A2</b>	Is the duration of the presenting complaint recorded in the patient's record?	
<b>A3</b>	Diagnosis is according to current ICHD criteria.	
<b>A4</b>	Is the diagnosis based on the ICHD terminology?	
<b>A5</b>	A working diagnosis is made at the first visit.	Is a working diagnosis recorded in patient's record at first visit?
<b>A6</b>	A definitive diagnosis is made at first or subsequent visit.	
<b>A7</b>	Is a definitive diagnosis recorded in the patient's record?	Enquiry of doctors
<b>A8</b>	Is s diagnostic review during follow-up routinely undertaken?	
<b>A9</b>	Diagnosis is reviewed during later follow-up.	Enquiry of service manager and doctors
<b>A10</b>	Does the service have a diagnostic diary available and are doctors aware of its availability?	

AHCP - Health-care provider, ICHD - International Classification of Headache Disorders

<sup>a</sup> Patient's satisfaction was defined either from the options "yes"/"no", or as "too much"/"about right"/"too little", or as "very good"/"good"/"adequate"/"poor"/"very poor"

<sup>b</sup> Serious adverse events are those that cause death or are life-threatening, terminate or put at risk a pregnancy, or that cause hospitalization, prolonged illness, disability and/or malignancy

**Table 3.** Quality Indicators and methods of implementation (adapted from previous studies conducted in specialized centres by EHF and LTB)<sup>7-9</sup> (Continuation)

Indicator	Measure	Application	
<b>Domain B. Individualized management is essential for optimal headache care</b>			
B1	Waiting-list times for appointments are related to the urgency of need	a. Is there a formal triage system in the service? b. Does it expedite appointments in cases of perceived urgency?	Enquiry of doctors, service manager and administrative staff
B2	Sufficient time is allocated to each visit for the purpose of good management	a. Record of actual time (minutes) per visit by patient b. Record of satisfaction <sup>a</sup> expressed by patient with actual time	Enquiry of prospective consecutive sample of headache patients
		c. Record of satisfaction expressed by HCP with actual time	Enquiry of HCPs
B3	Patients are asked about the temporal profile of their headaches	Is the frequency (days/months) of symptoms recorded in the patient's record of subsequent appointments?	
B4	Treatment plans follow evidence-based guidelines, reflecting diagnosis	Are prescribed drugs (names, doses and quantities) recorded in patient's record?	Review of randomly selected clinical records from a retrospective sample of headache patients
B5	Treatment plans include psychological approaches to therapy when appropriate	Does an access route to psychological therapies exist and are doctors aware of its availability?	Enquiry of service manager and HCPs
B6	Treatment plans reflect disability assessment	a. Does the service have an instrument for disability assessment available and are HCPs aware of its availability? b. Is it appropriate to assess disability in headache patients?	Enquiry of service manager and HCPs
B7	Patients are followed up to ascertain optimal outcome	A follow-up diary and/or calendar is available?	
<b>Domain C. Appropriate referral pathways are essential for optimal headache care</b>			
C1	Referral pathway is available from primary to specialist care	Is there a usable referral pathway available and are doctors and appointments administrator aware of its existence?	Enquiry of doctors, service manager and administrative staff
C2	Urgent referral pathway is available when necessary	Is there a usable urgent referral pathway available and are doctors and appointments administrator aware of its existence?	Enquiry of doctors, service manager and administrative staff
<b>Domain D. Education of patients about their headaches and their management is essential for optimal headache care</b>			
D1	Patients are given the information they need to understand their headache and its management	a. Are information leaflets available for headache patients and are doctors and appointments administrator aware of their existence?	Enquiry of doctors, service manager and administrative staff
		b. Did the doctor provide the patient with information? c. Was the information understandable? d. Was the amount of information about right?	Enquiry of prospective consecutive sample of headache patients
D2	Patients are given appropriate reassurance	Record of satisfaction <sup>a</sup> expressed by patients with reassurance given	Enquiry of prospective consecutive sample of headache patients
<b>Domain E. Convenience and comfort are part of optimal headache care</b>			
E1	The service environment is clean and comfortable	a. Record of satisfaction <sup>a</sup> expressed by patients with cleanliness and comfort	Enquiry of prospective consecutive sample of headache patients
		b. Record of satisfaction expressed by HCPs with cleanliness and comfort	Enquiry of HCPs
E2	The service is welcoming	Record of satisfaction <sup>a</sup> expressed by patients with welcome	Enquiry of prospective consecutive sample of headache patients
E3	Waiting times in the clinic are acceptable	a. Record of actual waiting time (minutes) by patient b. Record of satisfaction <sup>a</sup> expressed by patients with waiting time	Enquiry of prospective consecutive sample of headache patients
		c. Record of satisfaction expressed by HCPs with waiting time	Enquiry of HCPs

AHCP - Health-care provider, ICHD - International Classification of Headache Disorders

<sup>a</sup> Patient's satisfaction was defined either from the options "yes"/"no", or as "too much"/"about right"/"too little", or as "very good"/"good"/"adequate"/"poor"/"very poor"<sup>b</sup> Serious adverse events are those that cause death or are life-threatening, terminate or put at risk a pregnancy, or that cause hospitalization, prolonged illness, disability and/or malignancy

**Table 3.** Quality Indicators and methods of implementation (adapted from previous studies conducted in specialized centres by EHF and LTB)<sup>7-9</sup> (Continuation)

Indicator	Measure	Application	
<b>Domain F. Achieving patient satisfaction is part of optimal headache care</b>			
F1	Patients are satisfied with their management	Record of satisfaction <sup>a</sup> expressed by patients with overall management	Enquiry of prospective consecutive sample of headache patients
<b>Domain G. Optimal headache care is efficient and equitable</b>			
G1	Procedures are followed to ensure resources are not wasted	Does a protocol to limit wastage exist?	Enquiry of service manager
G2	Costs of the service are measured as part of a cost-effectiveness policy	Does a record of input costs exist?	Enquiry of service manager
G3	There is equal access to headache services for all who need it	Does a policy to ensure equal access exist?	Enquiry of service manager and HCPs
<b>Domain H. Outcome assessment is essential in optimal headache care</b>			
H1	Outcome measures are based on self-reported symptom burden (headache frequency, duration and intensity)	Is there an outcome measure based on self-reported symptom burden available and are HCPs aware of its existence?	Enquiry of service manager and HCPs
H2	Outcome measures are based on self-reported disability burden	Is there an outcome measure based on self-reported disability burden available and are HCPs aware of its existence?	
H3	Outcome measures are based on self-reported quality of life	Is there an outcome measure based on self-reported quality of life available and are HCPs aware of its existence?	
<b>Domain I. Optimal headache care is safe</b>			
I1	Patients are not over-treated	Are prescribed drugs (names, doses and quantities) recorded in patient's record?	Review of randomly selected clinical records from a retrospective sample of headache patients
I2	Systems are in place to be aware of serious adverse events <sup>b</sup>	a. Are serious adverse events recorded in patients' records?	Review of randomly selected clinical records from a retrospective sample of headache patients
		b. Is there a protocol for reporting serious adverse events?	Enquiry of service manager and HCPs

AHCP - Health-care provider, ICHD - International Classification of Headache Disorders

<sup>a</sup> Patient's satisfaction was defined either from the options "yes"/"no", or as "too much"/"about right"/"too little", or as "very good"/"good"/"adequate"/"poor"/"very poor"

<sup>b</sup> Serious adverse events are those that cause death or are life-threatening, terminate or put at risk a pregnancy, or that cause hospitalization, prolonged illness, disability and/or malignancy

### Data collection

Data collection occurred between the 30<sup>th</sup> of September and the 13<sup>th</sup> of December 2019. All data were collected at each unit by one local research assistant. Each questionnaire was filled out anonymously. Patients received their questionnaires at the end of their appointment (their age, gender and primary diagnosis were pre-recorded in the data bank, excluding any personal identifying data) and returned them along with the signed informed consent to the on assigned researcher.

HCPs filled their questionnaires via an online form (GoogleDocs®), sent out per email by each unit's allocated

researcher. No identification data was included in any of the questionnaires.

### Data management and analysis

Data were locally registered into the provided spreadsheets. The filled-in spreadsheets were then merged and analysed by the principal researcher.

Demographic and clinical data were provided as numerical values and summarised as percentages or mean values with standard deviations (SDs). A descriptive analysis of all data was made using Microsoft EXCEL® 2016.

## Results

A total of 223 HCPs and 93 patients were inquired in this study. Each participating unit had a similar structure, including in this research between 2 to 14 doctors, 1 to 10 other HCPs, 1 to 7 administrative staff and 1 manager (except for 3 units whose manager answer was not received).

The mean age of the inquired patients was of 46.3 years (ranging from 7 to 86 years) and the mean duration of the presenting headache disorder was of 3 years and 3 months (ranging from 1 day to 25 years). The

spectrum of diagnoses was comparable across units. In total, 48.4% of cases had a diagnosis of primary headache (25.8% had migraine and 22.6% had tension-type headache), 21.5% had a diagnosis of secondary headache and 30.1% had no record of specific diagnose other than the headache complaint. Each unit also analysed 10 random records of other headache patients, retrospectively.

The characteristics of the 15 participating units and their corresponding samples are summarized in **Table 4**.

**Table 4.** Characterization of the sample.

Primary Care Units		Unit A	Unit B	Unit C	Unit D	Unit E	Unit F	Unit G	Unit H	Unit I	Unit J	Unit K	Unit L	Unit M	Unit N	Unit O
Service staff	Manager (n)	1	0	1	1	1	0	1	1	1	0	1	1	1	1	1
	Administrative staff (n)	3	2	5	3	2	3	3	2	4	1	2	4	4	4	7
	Doctors (n)	5	5	4	3	4	14	7	8	7	5	2	10	2	7	11
	Other HCPs (n)	10	2	6	4	5	2	3	7	4	3	1	6	3	6	6
Patients	Patients (n)	1	10	0	1	10	7	2	10	6	4	2	10	10	10	10
	Mean age (years) ± SD	63	46.9 ± 19.4	-	50	34.8 ± 10.8	44.7 ± 20.1	39 ± 7.1	47.2 ± 14.8	42.7 ± 15.1	34.3 ± 7.4	61 ± 14.1	31.1 ± 19	54.7 ± 26.3	56 ± 14.2	42.9 ± 19.9
	Mean duration of headache (months) ± SD	-	1.6 ± 3.7	-	300	49.5 ± 77.4	0.5 ± 1.1	0.6 ± 0.6	1.8 ± 2.5	1.5 ± 2.2	-	5.0 ± 1.4	0.5 ± 0.7	57.7 ± 54.4	13 ± 37.6	
	Diagnoses (n)															
	Migraine	0	3	0	0	3	1	1	1	2	4	1	2	5	0	1
	TTH	1	1	0	0	4	5	1	1	2	0	0	3	0	3	0
	Trigeminal neuralgia	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Cluster headache	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	MOH	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Other	0	0	0	0	2	1	0	3	2	0	1	5	0	6	0
Non-specified	0	6	0	1	1	0	0	5	0	0	0	0	5	1	9	
Records reviewed (n)	10	10	10	10	10	10	10	10	10	10	10	10	10	10	10	

HCPs - healthcare providers, MOH - medication-overuse headache, SD - standard deviation, TTH - tension type headache

In this section, a summary description of the findings for each quality indicator will be provided, including the overall mean of positive answers and range of values for the units with highest and lowest results. All findings of the study are described in detail in **Table 5**.

Domain A. Accurate diagnosis is essential for optimal headache care. The record of the duration of the complaint was present in 52.0% (min: 30.0%; max: 70.0%) of the reviewed clinical records and only 41.3% (min: 0%; max: 90.0%) made use of the International

Classification of Headache Disorders (ICHD) terminology. On the other hand, 72.0% (min: 30.0%; max: 100%) of the review records contained a working diagnose on the first visit, 62.0% had a definitive diagnosis or scheduled appointment for review (min: 20.0%; max: 100%) and 96.8% (min: 85.7%; max: 100%) of the inquired HCPs reported reviewing the diagnosis routinely after follow-up. Nonetheless, only 23.0% (min: 0%; max: 75.0%) of them reported supporting the diagnosis with the use of diagnostic headache diaries.

**Table 5.** Results of the questionnaires (% of positive answers)

Primary Care Units		Unit A	Unit B	Unit C	Unit D	Unit E	Unit F	Unit G	Unit H	Unit I	Unit J	Unit K	Unit L	Unit M	Unit N	Unit O	Global Mean $\pm$ SD
A1.	Duration of complaint is recorded	40	70	60	40	60	70	30	50	40	60	60	60	30	60	50	52 $\pm$ 13.2
A2.	ICHD terminology is used	80	70	40	90	30	30	60	0	0	60	30	50	30	20	30	41.3 $\pm$ 26.7
A3.	Working diagnose at first visit is recorded	80	100	70	60	70	80	30	80	50	70	60	70	100	100	60	72 $\pm$ 19.4
A4.	Definitive diagnosis or appointment for review	70	70	60	40	40	70	80	70	60	20	50	60	100	100	40	62 $\pm$ 22.1
A5.	Routinely diagnostic review during follow-up (doctors)	100	100	100	100	100	85.7	100	100	100	100	100	90	100	85.7	90.9	96.8 $\pm$ 5.6
A6.	Diagnostic diaries are available (manager + doctors)	16.7	20	20	0	20	21.4	25	62.5	75	0	0	9.1	33.3	0	41.7	23 $\pm$ 22.5
B1a.	Formal triage system exists (manager + HCPs)	11.1	42.9	20	14.3	0	11.8	9.1	0	41.7	0	0	13.3	28.6	0	36.8	15.3 $\pm$ 15.5
B1b.	It expedites appointments of urgent cases (manager + HCPs)	22.2	28.6	0	28.6	0	17.7	27.3	0	58.3	0	0	0	28.6	0	36.8	16.5 $\pm$ 18.2
B2a.	Time per visit (minutes), mean $\pm$ SD	30	24 $\pm$ 9.4	-	45	23.8 $\pm$ 9	22.1 $\pm$ 5.7	35 $\pm$ 21.2	25 $\pm$ 13.0	41.7 $\pm$ 17.5	18.8 $\pm$ 8.5	30 $\pm$ 14.1	19.2 $\pm$ 12.6	24.5 $\pm$ 6.9	19 $\pm$ 7.7	19.5 $\pm$ 9.8	27 $\pm$ 8.4
B2b.	Satisfaction with time per visit (patients)	0	100	-	100	90	100	100	90	100	100	100	100	90	100	100	90.7 $\pm$ 26.5
B2c.	Satisfaction with time per visit (HCPs)	33.3	85.7	20	0	22.2	43.8	30	38.5	18.2	12.5	33.3	37.5	0	46.2	12.5	28.9 $\pm$ 21.4
B3	Frequency of symptoms is recorded	30	70	40	30	20	60	20	30	30	30	50	20	0	10	10	30 $\pm$ 18.9
B4.	Prescribed drugs are recorded	70	70	90	30	80	90	70	60	80	90	50	90	60	40	70	69.3 $\pm$ 18.7
B5.	Access route to psychological therapies exists (manager + doctors)	62.5	71.4	81.8	25	30	93.8	90.9	53.3	41.7	100	50	64.7	100	50	77.8	66.2 $\pm$ 24.5
B6a.	Instrument for disability assessment is available (manager + HCPs)	56.3	0	45.5	12.5	10	6.3	36.4	26.7	16.7	25	0	11.8	66.7	14.3	11.1	22.6 $\pm$ 20.2
B6b.	It is appropriate to assess disability caused by headache. (manager + HCPs)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B7.	Follow-up diary/ calendar available (manager + HCPs)	18.8	14.3	18.2	12.5	40	25	45.5	20	41.7	0	0	17.7	33.3	7.1	38.9	22.2 $\pm$ 14.8

HCPs - healthcare providers, ICHD - International Classification of Headache Disorders, SD - standard deviation



**Table 5.** Results of the questionnaires (% of positive answers) (Continuation)

Primary Care Units		Unit A	Unit B	Unit C	Unit D	Unit E	Unit F	Unit G	Unit H	Unit I	Unit J	Unit K	Unit L	Unit M	Unit N	Unit O	Global Mean $\pm$ SD
C1.	Referral pathway exists (manager + HCPs)	88.9	71.4	90	85.7	71.4	94.1	90.9	90	83.3	83.3	100	93.3	100	100	89.5	88.8 $\pm$ 8.9
C2.	Urgent referral pathway exists (manager + HCPs)	77.8	71.4	90	85.7	71.4	70.6	81.8	80	83.3	50	80	60	100	83.3	68.4	76.9 $\pm$ 12.2
D1a.	Information leaflets are available (HCPs)	6.3	0	9.1	12.5	0	18.8	18.2	20	18.2	0	0	18.8	16.7	14.3	27.8	12.1 $\pm$ 9.0
D1b.	Doctor provides patient with information (patients)	100	100	-	100	90	100	100	100	100	100	100	100	100	100	100	99.3 $\pm$ 2.7
D1c.	Information given understandable (patients)	100	70	-	100	100	85.7	100	100	100	100	100	100	100	100	100	96.8 $\pm$ 8.6
D1d.	Amount of information about right (patients)	0	60	-	100	100	85.7	100	90	100	100	100	100	100	100	90	87.6 $\pm$ 27.5
D2.	Patients were given reassurance (patients)	100	50	-	100	100	100	100	100	100	100	100	100	100	100	100	96.4 $\pm$ 13.3
E1a.	Service environment clean and comfortable (HCPs)	20	0	33.3	85.7	33.3	25	60	42.9	0	50	100	87.5	80	69.2	11.8	46.6 $\pm$ 32.7
E1b.	Service environment clean and comfortable (patients)	100	60	-	100	100	100	100	100	83.3	100	100	100	100	100	100	96.0 $\pm$ 11.3
E2.	Satisfaction with welcome (patients)	100	100	-	100	100	100	100	100	100	100	100	100	100	100	100	100 $\pm$ 0
E3a.	Waiting time (minutes), mean $\pm$ SD	10	7 $\pm$ 6.7	-	10	20.7 $\pm$ 13.4	25.7 $\pm$ 13	22.5 $\pm$ 10.6	47.2 $\pm$ 73.3	18.3 $\pm$ 6.8	20 $\pm$ 13.5	32.5 $\pm$ 3.5	26.2 $\pm$ 25.7	34 $\pm$ 22.7	14.5 $\pm$ 4.4	22.5 $\pm$ 20.3	22.2 $\pm$ 10.8
E3b.	Satisfaction with waiting time (patients)	100	90	-	100	100	71.4	50	80	83.3	75	100	80	60	80	100	83.6 $\pm$ 16.0
E3c.	Satisfaction with waiting time (HCPs)	80	100	60	57.1	77.8	93.75	80	92.3	63.6	75	100	93.8	80	92.3	94.1	82.7 $\pm$ 14.1
F1.	Satisfaction with overall management (patients)	100	90	-	100	100	100	100	100	100	100	100	100	100	100	100	99.3 $\pm$ 2.7
G1.	Protocol to limit wastage exists (manager)	0	-	0	0	100	-	100	0	0	-	100	100	0	0	100	41.7 $\pm$ 51.5
G2.	Record of input costs exists (manager)	0	-	0	0	100	-	100	100	0	-	0	100	100	100	100	58.3 $\pm$ 51.5
G3.	Policy to ensure equal access exists (manager + HCPs)	68.8	100	72.7	62.5	77.8	100	72.7	93.3	91.7	87.5	75	88.2	83.3	78.6	100	83.5 $\pm$ 12.1

HCPs - healthcare providers, ICHD - International Classification of Headache Disorders, SD - standard deviation

**Table 5.** Results of the questionnaires (% of positive answers) (Continuation)

Primary Care Units		Unit A	Unit B	Unit C	Unit D	Unit E	Unit F	Unit G	Unit H	Unit I	Unit J	Unit K	Unit L	Unit M	Unit N	Unit O	Global Mean $\pm$ SD
H1.	An outcome measure based on self-reported symptom burden is available (manager + HCPs)	0	14.3	9.1	0	0	6.3	0	0	8.3	0	0	5.9	33.3	0	5.6	5.5 $\pm$ 8.9
H2.	An outcome measure based on self-reported disability burden is available (manager + HCPs)	0	0	0	0	10	6.3	0	0	8.3	0	0	0	0	21.4	0	3.1 $\pm$ 6.1
H3.	An outcome measure based on self-reported quality of life is available (manager + HCPs)	6.3	0	0	0	0	6.3	0	6.7	0	0	0	5.9	0	14.3	0	2.6 $\pm$ 4.3
I1.	Prescribed drugs are recorded	70	70	90	30	80	90	70	60	80	90	50	90	60	40	70	69.3 $\pm$ 18.7
I2a.	Serious adverse events are recorded	0	50	40	0	0	10	30	10	20	10	0	20	0	30	0	14.7 $\pm$ 16.4
I2b.	A protocol exists for reporting serious adverse events (manager + HCPs)	43.75	42.9	0	0	90	75	63.6	46.7	75	75	100	52.9	100	64.3	83.3	60.8 $\pm$ 30.9

HCPs - healthcare providers, ICHD - International Classification of Headache Disorders, SD - standard deviation

Domain B. Individualized management is essential for optimal headache care. Only 15.3% (min: 0%; max: 42.9%) of the inquired HCPs reported that their unit had a formal triage system. The mean duration to patients' visits (according to the patients' questionnaires) was of 27 minutes (min: 18.8 minutes; max: 45 minutes). Whereas 90.7% (min: 0%; max: 100%) of the patients expressed their satisfaction with the duration of their visits, only 28.9% (min: 0%; max: 85.7%) of the HCPs considered the duration time per appointment enough. The frequency of symptoms was recorded in 30.0% (min: 0%; max: 70.0%) of the reviewed records and the record of the prescribed drugs was available in 69.3% (min: 30.0%; max: 90.0%) of the cases. An access route to psychological therapies was provided according to 66.2% (min: 25.0%; max: 100%) of the inquired HCPs. Here, a significant variation of answers between different units was observed, with a standard deviation of 24.5%. Only 22.6% (min: 0%; max: 66.7%) and 22.2% (min: 0%; max: 45.5%) of HCPs reported having, respectively, an instrument for disability assessments or follow-up calendars available in their units.

Domain C: Appropriate referral pathways are essential for optimal headache care. Referral pathways to specialized healthcare centres were provided according to 88.8% (min: 71.4%; max: 100%) of the inquired HCPs, including urgent referral pathway in 76.9% (min: 50.0%; max: 100%) of the cases.

Domain D. Education of patients about their headaches and their management is essential for optimal care. Only 12.0% (min: 0%; max: 27.8%) of HCPs reported having information leaflets available in their units. Nevertheless, 99.3% (min: 90.0%; max: 100%) of the patients reported that their doctor provided them information regarding their headache, 96.8% (min: 70.0%; max: 100%) considered it understandable and 87.6% (min: 0%; max: 100%) of them considered this information to be enough. Additionally, 96.4% (min: 50.0%; max: 100%) of patients also reported receiving appropriate reassurance by their primary care doctor.

Domain E. Convenience and comfort are part of optimal headache care. Although only 46.6% (min: 0%; max: 100%) of the HCPs were satisfied with the quality of the service environment, 96.0% (min: 60.0%; max:

100%) of the patients considered that it was clean and comfortable and 100% of them expressed that they felt welcome. The mean waiting time (reported by the patients' questionnaires) was of 22.2 minutes (min: 7 minutes; max: 47.2 minutes). Regarding the average waiting times, 83.6% (min: 50%; max: 100%) of patients and 82.7% (min: 60.0%; max: 100%) of HCPs expressed being satisfied.

Domain F. Achieving patient satisfaction is part of optimal headache care. Overall satisfaction with the management was expressed by 99.3% (min: 90.0%; max: 100%) of the patients.

Domain G. Optimal headache care is efficient and equitable. Only 41.7% (min: 0%; max: 100%) of HCPs reported having protocols to avoid wastage of resources on their units and 58.3% (min: 0%; max: 100%) of them had records of running costs. Regarding these two indicators, a significant variation of answers was observed between different units (with a standard deviation of 51.5% on both cases). On the other hand, 83.5% (min: 68.8%; max: 100%) of HCPs referred that equal access to headache services in their units was ensured for all who might need it.

Domain H. Outcome assessment is essential in optimal headache care. Only 5.5% (min: 0%; max: 33.3%), 3.1% (min: 0%; max: 21.4%) and 2.6% (min: 0%; max: 14.6%) of HCPs reported having outcome assessment instruments on symptoms, disability burden or on quality of life, respectively, available in their units.

Domain I. Optimal headache care is safe. Records of serious adverse events were available in 14.6% (min: 14.7%; max: 50.0%) of the reviewed cases and 60.8% (min: 0%; max: 100%) of HCPs reported having formal protocols to ensure reporting of serious adverse events in their units. For this last indicator, many different results were obtained between different units (with a standard deviation of 30.9%).

## Discussion

The present study was developed as an extension of previous studies published in the domain of quality of headache care performed in specialized centres. Although an evaluation of the service quality in the participating primary care units was performed, the main purpose of this study was to evaluate the feasibility of the quality indicators themselves and the set of instruments by which they were assessed in these settings, in

order to conclude whether they can also be applied at a primary-care level.

All research assistants, who conducted the study locally at each unit, reported that the patients' questionnaires were easily accepted and understood and were not overly time-consuming, which allowed for their completion at the end of each appointment. The HCPs' questionnaires were broadly accepted as well. However, knowing that most questions would imply "yes or no" answers (e.g: "*Is there a formal triage system in your unit?*"), we often obtained contradictory answers within each unit. This raised the question whether such items led to different interpretations between HCPs or if some had incorrect notions about the type of service provided in their unit. For this reason, an optimization of the methods of assessment of these indicators may be necessary for further evaluations in the context of primary care level. Regarding the local assistants' role, the major difficulty reported by them at the end of the study was the limited time period for data collection, given the fact that only patients with headache could be included on the sample and most of the patients who worked on their daily activity were not eligible. This difficulty also raised another question: knowing that headache disorders are currently one of the highest causes of disability worldwide,<sup>1,2</sup> how often do patients devalue their complaints or do not manifest them in appointments with their primary care doctors?

Although the 15 participating units represented diverse backgrounds within the central region of Portugal,<sup>10</sup> findings between them in this study were apparently comparable. Some common trends in practice were evident, giving a brief idea of the current standards of headache care service in this region.

On a general level, many of the evaluated quality indicators provided results deserving reflexion. Most of the reviewed clinical records were lacking essential information (such as duration and frequency of symptoms or an accurate diagnosis according ICHD terminology, each with a mean of positive answers of 52%, 30% and 41.3% respectively). The results of the study suggest that formal triage systems were not available in the evaluated units (mean of positive answers of 15.3%). Although the availability of formal triage systems may help expediting appointments in cases of urgency, such indicator might be more relevant

for accessing headache service quality in specialized centres rather than in primary care centres, where many other not-related disorders are dealt with. Most HCPs reported not making use of tools such as diagnostic headache diaries (mean of positive answers of 23%), instruments for disability assessment (mean of positive answers of 22.6%) or follow-up calendars (mean of positive answers of 22.2%). Knowing that a correct diagnosis of primary headache disorders can only be supported by the patient's history,<sup>2,11</sup> the use of diagnostic diaries for headache patients should be a priority in primary care, by allowing the patient to keep record of symptoms, temporal patterns and acute medication use/overuse prior to formal diagnosis.<sup>11</sup> Assessment of impact can support a patient's management by establishing the need and priority for treatment.<sup>11</sup> Lastly, follow-up calendars for headache patients can also be helpful, by encouraging compliance to prophylactic medication, allowing the patient to keep record of use/overuse of acute medication, effect of treatment and overall progress,<sup>11</sup> providing more objective data to allow better treatment decisions. Such tools have already been developed by LTB and EHF and are recommended for routine use in the primary care level.<sup>11</sup> Results also reveal that outcome measure instruments are also not available in evaluated units (either based on symptom burden, disability burden or quality of life, each with a mean of positive answers of 5.5%, 3.1% and 2.6% respectively). Although the focus of most of primary care units is the treatment of the patients' symptoms, evaluation of their outcomes can also be of great utility.<sup>11</sup> Accurate recording of outcomes, more than simply being an example of good recordkeeping, serves as a support for patient follow-up and guides the achievement of best future outcomes. Furthermore, the lack of use of recognised outcome measures represents a missed opportunity for these units to self-evaluate their outcomes against benchmarks and knowing how to work towards better quality of care. For this purpose and in order to aid primary care centres, LTB developed *The Headache Under Response to Treatment* (HURT) questionnaire as a tool for measuring outcomes to guide follow-up<sup>12</sup> and *The Headache-Attributed Lost Time* (HALT) Indices as a tool for measuring outcomes in disability burden in follow-up.<sup>13</sup>

On the other hand, this study also reached many positive findings regarding quality of headache care in the primary care level, in this region. Results showed that diagnostic review during follow-up appointments was routinely practiced (mean of positive answers of 96.8%), referral pathways to specialized levels of care were available (mean of positive answers of 88.8%) and equal access to healthcare was ensured (mean of positive answers of 83.5%).

Additionally, the study was able to uncover other difficulties in certain participating units when compared to the others. Firstly, some HCPs reported not having availability of access routes to psychological therapies for headache patients in their units (mean of positive answers of 66.2% with a standard deviation of 24.46%), which are currently recommended for pain management in many cases of chronic headache.<sup>11</sup> Records of input costs and protocols to limit wastage were also reported as unavailable in many units (each with a mean of positive answers of 41.7% and 58.3% respectively and standard deviation of 51.49% on both cases). Although these two indicators were initially proposed by EHF and LTB for measuring efficiency of treatment in specialized centres,<sup>7</sup> it is likely that they alone cannot provide sufficient information on quality of treatment of headache in primary care centres, since these units often deal with many other resource-demanding chronic disorders.<sup>14</sup> Yet the fact that some units are able to accomplish better results can be explored and experience-sharing between units can be a tool for improvement. Protocols for reporting serious adverse events were also reported as missing in some units (mean of positive answers of 60.8% with a standard deviation of 30.9%). For this reason, while reviewing the clinical records from these units, it was not possible to conclude whether no serious adverse events had occurred or if these had simply not been recorded.

Contrasting with the discussed findings, patients' answers regarding headache care service quality were tendentially very positive in every unit and most of them expressed being satisfied with their overall management (mean of positive answers of 99.3%). An interesting finding was that patients expressed more satisfaction with the duration of their appointments and with the quality of the service environment (mean of positive answers of 90.7%

and 96% respectively) than their HCPs (mean of positive answers of 28.9% and 46.6% respectively). Similar findings were obtained in previous studies in specialized centres.<sup>9</sup> Reflecting upon these results, it is possible that many of the evaluated quality indicators may have little influence on patient's overall satisfaction regarding headache care, when accessed on a primary care level. This study itself was not able to identify which factors have more impact on patient's satisfaction or dissatisfaction, therefore, a more detailed evaluation on this may be important, in order to assess service quality in the future. It is also important to take in consideration that the positivity of these results raised some questions. Firstly, given the study settings, even though questionnaires were answered individually and anonymously, one must consider the possibility of some of the patients' answers being positively influenced by their personal relationship with their primary care doctor. Secondly, only the patients who attended their appointments were inquired in this study. Therefore, it was not possible to establish a comparison with answers from other headache patients who missed their scheduled appointment or who did not have one, and whether this factor was correlated or not with their satisfaction. For this reason, a broader sample may be relevant for further investigations, including patients who had a recent appointment because of headache complaints but are not being attended on at the moment of data collection.

The strength of this study came from the inclusion of various and diverse primary care units in the central region of Portugal, which in turn allowed to better represent the population. On the other hand, to develop a study of this kind in such settings implied many limitations. Given the restricted time period for data collection, many units were not able reach the minimum goal of 10 inquired patients per unit. This led to, in many cases, a sample too small to allow a valid comparison between different units, making it merely descriptive and suggestive rather than looking for statistically significant data. Therefore, this study ended up paying more attention to the results as a whole and trying to understand the common aspects of practice in this level of care. This study also lacked a more detailed evaluation of the quality of diagnosis and treatments. For such evaluation, the protocol

developed by LTB and EHF would require the collaboration of an external expert in headache disorders to participate in the retrospective review of clinical records. However, given the lack of resources, this examination was simplified and undertaken by the nominated local research assistants. Nonetheless, this study's findings were able to uncover many opportunities for improvement in the management of headache in primary care level, providing guidance for these units to achieve better quality of treatment. All results were shared with the participating units during the development of this work. This information is, however, ready to be shared within primary care units in Portugal, along with the recommendations from EHF and LTB for headache management in primary care. Ultimately, these results will also provide a foundation for comparison with studies currently being developed in other countries, in order to achieve a more complete understanding of the relevance of these indicators in accessing quality of headache service in primary care centres.

## Conclusion

This was the first study to evaluate the headache quality indicators promoted by EHF and LTB at the primary care level in Portugal. It revealed that the promoted quality indicators have utility in evaluating headache service quality in the primary care level and that the proposed methods to assess them proved easy to apply in this context. Although EHF and LTB recommend the same quality indicators both for specialized centres and non-specialized centres, this study also showed that special attention should be paid in some items when comparing results between the two levels of care, given their different structures.

Regarding quality of treatment in the evaluated units, this study was able to demonstrate various common trends and deficits that might serve as guidance for improving quality in future interventions. It highlighted the lack of complete clinical records (including description of temporal profile of headache and diagnosis based on the ICHD) and routine use of diagnostic headache diaries as priority concerns for this purpose. ■



	Codificação
<b>5. A quantidade de informação que recebeu foi...</b> <ul style="list-style-type: none"> <li>• ...insuficiente?</li> <li>• ...adequada?</li> <li>• ...demasiada?</li> <li>• não aplicável</li> </ul>	D1
<b>6. Foi tranquilizado pelo médico</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	D2
<b>7. Ficou satisfeito com a limpeza e conforto da Unidade de Saúde?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	E1
<b>8. Sentiu-se bem-vindo na consulta do médico?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	E2
<b>9. Quanto tempo esperou até entrar na consulta?</b> Aproximadamente _____ minutos	E3
<b>10. O tempo de espera foi ...</b> <ul style="list-style-type: none"> <li>• ...excessivamente longo?</li> <li>• ... demasiado longo?</li> <li>• ...razoável?</li> </ul>	E3
<b>11. Globalmente, o que pensa do tratamento que recebeu para as suas cefaleias (dores de cabeça)?</b> <ul style="list-style-type: none"> <li>• muito bom</li> <li>• bom</li> <li>• adequado</li> <li>• mau</li> <li>• muito mau</li> </ul>	F1

Se desejar efectuar comentários adicionais, por favor utilize este espaço ou o verso da folha.

Muito obrigado por completar este questionário.

## Additional File 2. Original Questionnaires for Healthcare Providers (in Portuguese)

## Projeto de Investigação: Avaliação da Qualidade do Serviço de Saúde na área das Cefaleias

**Unidade de Saúde:** \_\_\_\_\_

No âmbito da Campanha Global contra as Cefaleias (*Global Campaign against Headache*), alguns centros de Cefaleias da Dinamarca, Alemanha, Portugal, Estados Unidos e a Universidade de Oxford no Reino Unido estão a colaborar para definir como se pode medir a *qualidade* dos serviços de saúde na área das Cefaleias. Este é o primeiro passo no sentido de efetuar melhorias nos serviços de saúde nesta área, a nível local, nacional e internacional.

Foi determinada uma definição multi-dimensional de qualidade, assim como uma série de indicadores de qualidade e estes necessitam agora ser avaliados por uma auditoria a várias Unidades de Saúde, em cada um dos centros colaborantes. Os profissionais de saúde e os utentes vão ser convidados a preencher um questionário breve e será efectuada uma auditoria à base de dados clínica do centro. Uma parte fundamental deste teste é perguntar às pessoas (isto é, utentes) que visitaram recentemente as Unidades de Saúde que colaboram neste projeto quais as suas perspectivas e impressões sobre o serviço que obtiveram na abordagem das suas cefaleias.

Este questionário é dirigido aos profissionais de saúde e técnicos administrativos, que serão questionados sobre o serviço que fornecem, em termos de cefaleias. Por “serviço” entendemos qualquer fornecimento de apoio em cefaleias por médicos de medicina geral e familiar, enfermeiros, psicólogos, fisioterapeutas e até técnicos administrativos, numa perspectiva mais logística e organizacional.

Por favor, complete o questionário seguinte marcando a resposta mais relevante à questão que lhe é colocada (responda apenas às perguntas que considerar que se adequam à sua atividade). Uma vez que tenha completado o questionário, entregue-o ao coordenador do estudo na sua Unidade de Saúde, que o fará depois chegar aos investigadores principais.

Se este estudo tiver sucesso, será seguido por um estudo maior e definitivo. Em última instância, os indicadores de qualidade, uma vez validados, serão utilizados para melhorar a prestação de serviços às pessoas com queixas de cefaleia.

### Questionário - Secretário(a)/Técnico(a) administrativo(a)

**Por favor, forneça alguma informação sobre si. É:**

A) Secretário(a)                      B) Técnico(a) administrativo(a)

**Data de preenchimento:**    \_\_\_ / \_\_\_ / 20\_\_\_

	Codificação
<p>1. Existe um sistema formal de triagem no seu Centro (qualquer sistema que identifique as necessidades do doente durante o primeiro contacto telefónico e que reaja de acordo com estas necessidades)?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B1a
<p>2. O seu sistema de triagem está desenhado para identificar casos potencialmente urgentes para antecipar a consulta?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B1a



	Codificação
<b>3. No seu Centro existe uma via de referência para Centros de cuidados diferenciados?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	C1b
<b>4. Há uma via de referência urgente, quando necessário?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não aplicável</li> </ul>	C2b

Se desejar efectuar comentários adicionais, por favor utilize este espaço ou o verso da folha.

Muito obrigado por completar este questionário.

### Questionário - Médico(a)

Por favor, forneça alguma informação sobre si. É Médico(a):

A) Da Equipa da Unidade de Saúde                      B) Interno ou Estagiário

Data de preenchimento: \_\_\_\_ / \_\_\_\_ / 20 \_\_\_\_

	Codificação
<b>1. Os diagnósticos efectuados na primeira consulta são revistos nas consultas de seguimento?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não efectuamos seguimento</li> </ul>	A5
<b>2. Há diários de diagnóstico de cefaleias disponíveis no seu Centro de Cefaleias?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	A6b
<b>3. Existe um sistema formal de triagem no seu Centro (qualquer sistema que identifique as necessidades do doente durante o primeiro contacto telefónico e que reaja de acordo com estas necessidades)?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 5</li> <li>• não sei -&gt; siga para a questão 5</li> </ul>	B1a
<b>4. O seu sistema de triagem está desenhado para identificar casos potencialmente urgentes para antecipar a consulta?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	B1a
<b>5. Há tempo suficiente em cada consulta para assegurar uma gestão adequada?</b> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B2c

	Codificação
<p><b>6. No seu Centro existe uma via de acesso a terapêuticas psicológicas? (podendo ser oferecidas no próprio centro ou por referência direta para outro serviço)</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	B4b
<p><b>7. No seu Centro existe um instrumento para avaliar incapacidade?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 9</li> <li>• não sei -&gt; siga para a questão 9</li> </ul>	B5a
<p><b>8. O instrumento que o seu Centro tem disponível é específico para avaliar a incapacidade determinada pelas Cefaleias?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	B6a
<p><b>9. No seu Centro existe um diário ou calendário de seguimento disponível?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B6d
<p><b>10. No seu Centro existe uma via de referência para Centros de cuidados diferenciados?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 12</li> <li>• não sei -&gt; siga para a questão 12</li> </ul>	C1b
<p><b>11. Há uma via de referência urgente, quando necessário?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	C2b
<p><b>12. No seu Centro há folhetos informativos disponíveis para os doentes com Cefaleias?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	D1
<p><b>13. Está satisfeito com a limpeza e conforto do ambiente no seu Centro?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	E1b
<p><b>14. Geralmente considera que o tempo de espera no dia da consulta dos doentes é aceitável?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	E3b
<p><b>15. O seu Centro é equitativamente acessível a todos os doentes que dele necessitem?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	G4
<p><b>16. O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação do impacto dos sintomas?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	H1b

	Codificação
<p>17.O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da incapacidade?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	H2b
<p>18.O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da qualidade de vida?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	H3b
<p>19.No seu Centro existe um protocolo (regras e procedimentos escritos) para reportar efeitos adversos graves que possam ocorrer?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> <li>• não sei</li> </ul>	I2b

Se desejar efectuar comentários adicionais, por favor utilize este espaço ou o verso da folha.

Muito obrigado por completar este questionário.

### Questionário - Coordenador(a) do Centro

Por favor, indique qual a sua qualificação:

A) Médico

B) Enfermeiro

C) Qualificação não clínica

Data de preenchimento: \_\_\_ / \_\_\_ / 20\_\_\_

	Codificação
<p>1. Há diários de diagnóstico de cefaleias disponíveis no seu Centro?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	A6a
<p>2. Existe um sistema formal de triagem no seu Centro (qualquer sistema que identifique as necessidades do doente durante o primeiro contacto telefónico e que reaja de acordo com estas necessidades)?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 4</li> </ul>	B1a
<p>3. O seu sistema de triagem está desenhado para identificar casos potencialmente urgentes para antecipar a consulta?</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B1a
<p>4. No seu Centro existe uma via de acesso a terapêuticas psicológicas? (podendo ser oferecidas no próprio centro ou por referência direta para outro serviço)</p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B4a

	Codificação
<p><b>5. No seu Centro existe um instrumento para avaliar incapacidade?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 7</li> </ul>	B5a
<p><b>6. O instrumento que o seu Centro tem disponível é específico para avaliar a incapacidade determinada pelas Cefaleias?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B6a
<p><b>7. No seu Centro existe um diário ou calendário de seguimento disponível?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	B6c
<p><b>8. No seu Centro existe uma via de referênciação para Centros de cuidados diferenciados?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não -&gt; siga para a questão 10</li> </ul>	C1a
<p><b>9. Há uma via de referênciação urgente, quando necessário?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	C2a
<p><b>10.No seu Centro há folhetos informativos disponíveis para os doentes com Cefaleias?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	D1
<p><b>11.Existe um protocolo (regras e procedimentos escritos) que limitem o desperdício de recursos no seu Centro?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	G1
<p><b>12.No seu Centro existe um registo de custos correntes?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	G3
<p><b>13.O seu Centro é equitativamente acessível a todos os doentes que dele necessitem?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	G4
<p><b>14.O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação do impacto dos sintomas?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	H1a
<p><b>15.O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da incapacidade?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	H2a
<p><b>16.O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da qualidade de vida?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	H3a
<p><b>17.No seu Centro existe um protocolo (regras e procedimentos escritos) para reportar efeitos adversos graves que possam ocorrer?</b></p> <ul style="list-style-type: none"> <li>• sim</li> <li>• não</li> </ul>	I2a

**Se desejar efectuar comentários adicionais, por favor utilize este espaço ou o verso da folha.**

**Muito obrigado por completar este questionário.**

### Questionário - Outros Profissionais de Saúde

Por favor, forneça alguma informação sobre si. É:

A) Enfermeiro(a)

B) Psicólogo(a)

C) Fisioterapeuta

D) Outro(a)

Data de preenchimento: \_\_\_\_ / \_\_\_\_ / 20\_\_\_\_

	Codificação
1. Há tempo suficiente em cada consulta para assegurar uma gestão adequada? • sim • não	B2c
2. No seu Centro existe uma via de acesso a terapêuticas psicológicas? (podendo ser oferecidas no próprio centro ou por referência direta para outro serviço) • sim • não	B4b
3. No seu Centro existe um instrumento para avaliar incapacidade? • sim • não -> siga para a questão 5 • não sei -> siga para a questão 5	B5b
4. O instrumento que o seu Centro tem disponível é específico para avaliar a incapacidade determinada pelas Cefaleias? • sim • não	B6a
5. No seu Centro existe um diário ou calendário de seguimento disponível? • sim • não	B6d
6. No seu Centro há folhetos informativos disponíveis para os doentes com Cefaleias? • sim • não • não sei	D1
7. Está satisfeito com a limpeza e conforto do ambiente no seu Centro? • sim • não	E1b
8. Geralmente considera que o tempo de espera no dia da consulta dos doentes é aceitável? • sim • não	E3b
9. O seu Centro é equitativamente acessível a todos os doentes que dele necessitem? • sim • não	G4
10. O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação do impacto dos sintomas? • sim • não • não sei	H1
11. O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da incapacidade? • sim • não • não sei	H2b
12. O seu Centro tem uma medida de resultados disponível que seja baseada na auto-avaliação da qualidade de vida? • sim • não • não sei	H3b
13. No seu Centro existe um protocolo (regras e procedimentos escritos) para reportar efeitos adversos graves que possam ocorrer? • sim • não • não sei	I2b

Se desejar efectuar comentários adicionais, por favor utilize este espaço ou o verso da folha.

Muito obrigado por completar este questionário.

**Responsabilidades Éticas**

**Conflitos de Interesse:** Os autores declaram a inexistência de conflitos de interesse na realização do presente trabalho.

**Fontes de Financiamento:** Não existiram fontes externas de financiamento para a realização deste artigo.

**Confidencialidade dos Dados:** Os autores declaram ter seguido os protocolos da sua instituição acerca da publicação dos dados de doentes.

**Proteção de Pessoas e Animais:** Os autores declaram que os procedimentos seguidos estavam de acordo com os regulamentos estabelecidos pelos responsáveis da Comissão de Investigação Clínica e Ética e de acordo com a Declaração de Helsínquia da Associação Médica Mundial.

**Proveniência e Revisão por Pares:** Não comissionado; revisão externa por pares.

**Ethical Disclosures**

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**Confidentiality of Data:** The authors declare that they have followed the protocols of their work center on the publication of data from patients.

**Protection of Human and Animal Subjects:** The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki).

**Provenance and Peer Review:** Not commissioned; externally peer reviewed.

**References / Referências**

- Steiner TJ, Birbeck GL, Jensen RH, Katsarava Z, Stovner LJ, Martelletti P. Headache disorders are third cause of disability worldwide. *J Headache Pain.* 2015;16:58. doi: 10.1186/s10194-015-0544-2
- Headache Classification Committee of the International Headache Society. The International Classification of Headache Disorders, 3rd edition. *Cephalalgia.* 2018;38:1–211. doi: 10.1177/0333102413485658.
- Steiner TJ, World Headache Alliance. Lifting the burden: The global campaign against headache. *Lancet Neurol.* 2004;3:204–5. doi: 10.1016/S1474-4422(04)00703-3.
- Steiner TJ. Lifting the burden: The global campaign to reduce the burden of headache worldwide. *J Headache Pain.* 2005;6:373–7. doi: 10.1007/s10194-005-0241-7.
- World Health Organization; Lifting The Burden. Atlas of headache disorders and resources in the world 2011 [Internet]. WHO: Geneva; 2011 [accessed 2020 Mar 18]. Available from: <http://www.who.int>
- Peters M, Perera S, Loder E, Jenkinson C, Gouveia RG, Jensen R, et al. Quality in the provision of headache care. 1: Systematic review of the literature and commentary. *J Headache Pain.* 2012;13:437–47. doi: 10.1007/s10194-012-0466-1.
- Peters M, Jenkinson C, Perera S, Loder E, Jensen R, Katsarava Z, et al. Quality in the provision of headache care. 2: Defining quality and its indicators. *J Headache Pain.* 2012;13:449–57. doi: 10.1007/s10194-012-0465-2.
- Katsarava Z, Gouveia RG, Jensen R, Gaul C, Schramm S, Schoppe A, et al. Evaluation of headache service quality indicators: pilot implementation in two specialist-care centres. *J Headache Pain.* 2015;16:53. doi: 10.1186/s10194-015-0537-1
- Schramm S, Uluduz D, Gouveia RG, Jensen R, Siva A, Uygungoglu U, et al. Headache service quality: evaluation of quality indicators in 14 specialist-care centres. *J Headache Pain.* 2016;17:111. doi: 10.1186/s10194-016-0707-9.
- ARS Centro. Perfil Regional de Saúde da Região Centro [Internet]. ARS Centro, Portugal; 2018 [accessed 2020 Mar 19]. Available from: <http://www.arscentro.min-saude.pt>
- Steiner TJ, Jensen R, Katsarava Z, Linde M, MacGregor EA, Osipova V, et al. Aids to management of headache disorders in primary care (2nd edition): On behalf of the European Headache Federation and Lifting the Burden: The Global Campaign against Headache. *J Headache Pain.* 2019;20:57. doi: 10.1186/s10194-018-0899-2.
- Steiner TJ, Buse DC, Al Jumah M, Westergaard ML, Jensen RH, Reed ML, et al. The headache under-response to treatment (HURT) questionnaire, an outcome measure to guide follow-up in primary care: development, psychometric evaluation and assessment of utility. *J Headache Pain.* 2018;19:15. doi: 10.1186/s10194-018-0842-6.
- Steiner TJ, Lipton RB. The Headache-Attributed Lost Time (HALT) Indices: measures of burden for clinical management and population-based research. *J Headache Pain.* 2018;19:12. doi: 10.1186/s10194-018-0837-3.
- Ministério da Saúde. Retrato da Saúde [Internet]. Ministério da Saúde, Portugal; 2018 [accessed 2020 Mar 19]. Available from: <https://www.sns.gov.pt>