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How are patients with chronic urticaria interested in using information and communication technologies to guide their healthcare? A UCARE study

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ABSTRACT

Background: Patients with chronic urticaria (CU) are increasingly using information and communication technologies (ICTs) to manage their health. What CU patients expect from ICTs and which ICTs they prefer remains unknown. We assessed why CU patients use ICTs, which ones they prefer, and what drives their expectations and choices.

Methods: In this cross-sectional study, 1841 patients across 17 countries were recruited at UCAREs (Urticaria Centers of Reference and Excellence). Patients with CU who were >12 years old completed a 23-item questionnaire.

Results: Most patients were interested in receiving disease information (87.3%), asking physicians about CU (84.1%), and communicating with other patients through ICTs (65.6%). For receiving disease information, patients preferred one-to-one and one-to-many ICTs, especially web browsers. One-to-one ICTs were also the ICTs of choice for asking physicians about urticaria and for communicating with other patients, and e-mail and WhatsApp were the preferred ICTs, respectively. Many-to-many ICTs such as Facebook, Instagram, LinkedIn, and Twitter were least preferred for all 3 purposes. Living in rural areas and higher education were linked to higher odds of being interested in receiving disease information, asking physicians, and communicating with patients through ICTs.

Conclusions: Most patients and especially patients with higher education who live in rural areas are interested in using ICTs for their healthcare, but prefer different ICTs for different purposes, ie,

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web browsers for obtaining information, e-mail for asking physicians, and WhatsApp for communicating with other patients. Our findings may help to improve ICTs for CU.

Keywords: Chronic urticaria, Information and communication technologies, Internet, e-mail, WhatsApp

INTRODUCTION

Chronic Urticaria (CU) is a skin disorder characterized by wheals, angioedema, or both, for more than 6 weeks.¹ The prevalence is approximately 1%,² and a recent systematic review and meta-analysis reported an overall lifetime CU prevalence of 4.4% with Latin America and Asia showing a higher point prevalence than other regions.³ Importantly, CU persists for several years and results, in many patients, in severely impaired quality of life.⁴⁻⁷

Information and communication technologies (ICTs) are used to communicate, manipulate, and store data by electronic means. In healthcare, ICTs support the exchange, knowledge transfer, electronic storage, and processing of information to promote health and to manage chronic illnesses and treat disease.^{8,9} These technologies include e-mail, short message service (SMS), text messaging, video chat (eg, Skype or Hangouts) and online social media (eg, Facebook or Twitter) as well as computing and mobile devices (smartphones and tablets) that perform a wide range of communication and information functions.¹⁰ With ICTs, users have worldwide access and are capable of immediate interaction with others, which was previously not possible. Notably, over the past decade, the usage of ICTs has increased dramatically among adolescents and young adults.¹¹

Given their increasing usage, ICTs have become critical for obtaining information from healthcare providers (HCPs) and patients alike.¹² Specifically, these technologies have become central to patient education, disease self-management, remote monitoring of patients, and collection of daily data,^{13,14} all of which have enhanced healthcare by creating time/cost efficiencies, which are

much needed in clinical practice and improving clinical outcomes.^{12,15} Previous studies found WhatsApp, e-mail, and SMS to be the most popular forms of electronic communication for receiving and seeking information as well as communicating with physicians among patients with chronic diseases.^{16,17}

Until very recently, it was largely unknown how and why patients with CU use ICTs and their expectations had not been assessed. To address this knowledge gap, the global network of Urticaria Centers of Reference and Excellence (UCAREs)¹⁸ performed an international study and reported first results.¹⁹ Specifically, we showed that virtually all CU patients included had access to ICTs and very often used these on a daily basis, mostly on a one-to-one and one-to-many basis. The use of ICTs for obtaining health and CU-specific information was extremely high in all countries analyzed, with web browsers being the preferred ICT platform. These findings were not a surprise given the high burden of CU; patients seek knowledge about CU and want to know about its causes, course, possible trigger factors, and available treatment options, as well as prognosis. Moreover, this need is mirrored by the fact that CU patient-physician consultations are particularly long and frequent.¹⁵

Here, we report on additional study outcomes, focusing on why patients with CU use ICTs, which ones they prefer when retrieving information, and what drives their expectations and choices. Specifically, we assessed their interest in and preference for ICTs (1) to receive disease information, (2) to ask physicians about urticaria, and (3) to communicate with other CU patients. We also aimed to identify characteristics of those interested/not interested in ICT usage for these purposes.

METHODS

Study design and population

The design and conduct of this study have been previously described in detail.¹⁹ Briefly, this was an anonymous, cross-sectional survey study (**see questionnaire in the supplement**). Here, we included additional patients totaling 1841 from primary healthcare centers, university hospitals, and specialized clinics (either public or private) that belong to the UCARE network. The healthcare facilities involved were located in Germany, Argentina, Brazil, China, Denmark, Ecuador, Greece, India, Iran, Peru, Poland, Russia, Spain, Switzerland, the Netherlands, the United Arab Emirates, and Turkey (**Supplemental Table S1**). Patients were ≥ 12 years old and previously diagnosed with chronic spontaneous urticaria (CSU) or chronic inducible urticaria (CIndU) by a physician. Those with other dermatological diseases or intellectual disabilities were excluded.

Procedures

A 23-item questionnaire, designed, evaluated, and reviewed by an expert panel of physicians assessed the participants' interest in (1) receiving urticaria information, (2) asking physicians health-related queries, and (3) communicating with other urticaria patients through specific ICTs. The questionnaire collected demographic (age, gender, education level, living area, etc) and clinical information (urticaria type, years with diagnosis, etc.) from each patient. Furthermore, participants were asked to quantify their interest using a scale (not interested, slightly interested, moderately interested, very interested, and extremely interested) and specific ICTs (blog or forum, e-mail, Facebook, Instagram, LinkedIn, Skype, SMS, Twitter, YouTube, web browser, and WhatsApp; questionnaire is contained in the **Supplement**).

Ethical considerations

This study was approved by the ethics committee "Comité de ética e Investigación en Seres Humanos" (CEISH), Guayaquil, Ecuador (IRB number HCK-CEISH-19-0059) and by a committee for each participating UCARE center. Each

participant provided consent to completion of the anonymous survey, and confidentiality was maintained throughout the study.

Statistical analysis

For the purpose of data analyses, ICTs were grouped into 3 categories:²⁰

- 1) one-to-one (dialogic): e-mail, Skype, SMS, and WhatsApp.
- 2) one-to-many (informative): blogs or forums, YouTube, and web browsers.
- 3) many-to-many (social): Facebook, Instagram, LinkedIn, and Twitter.

In addition, the interest scale was dichotomized as "very-to-extremely interested" (very interested and extremely interested) and "not very-to-moderately interested" (not interested, slightly interested, and moderately interested).

A binomial logistic regression analysis was performed to predict the likelihood of participants being very to extremely interested or not in receiving information, asking physicians questions, and communicating with other patients through any ICT category given the effects of age, gender, education level, geographic area, and years following diagnosis. All data were analyzed using SPSS version 24.0 software (SPSS Inc., Chicago, IL, USA).

RESULTS

Patient population

A total of 1841 urticaria patients were included with a female/male gender distribution ratio of 2.31 and a mean age of 40.7 years (**Table 1**). Most patients (81.8%) had CSU, and 36.6% had CIndU (18.6% had both). Most patients had either an undergraduate degree (35.1%) or secondary school diploma (32.0%), and half were employed (50.3%). In addition, most participants were Europeans (50.7%), followed by Latin Americans (26.5%) and Asians (22.8%) (**Supplemental Table S1**).

Most CU patients are interested in using ICTs to receive information about their disease and in communicating with physicians and other CU patients

Approximately, 9 of 10 patients (87.3%) were interested in the use of ICTs to receive CU information; most were also interested in the use of ICTs to ask physicians about CU (84.1%) and to communicate with other patients (65.6%).

CU patients prefer the use of web browsers to receive information about their disease

One-to-many (50.7%) and one-to-one (51.5%) were the preferred ICT categories for CU patients who were very/extremely interested in receiving information about their disease (Fig. 1).

Web browsers were the highest rated ICT for this purpose, with 44.5% of patients being very or extremely interested in their use for receiving CU information.

Only 21.5% of CU patients were very or extremely interested in the use of many-to-many ICTs for this purpose. In fact, 60.4% of patients were not interested at all in the use of many-to-many ICTs to obtain CU information. Living in rural areas, and higher education presented higher odds of being interested to receive information through every ICT type (Table 3, Supplemental Table S2, and S4A-S4B). ICT category preferences for receiving CU information by country are shown in Supplemental Table S3.

Characteristics	Overall participants (n = 1841) n (%)
Age, mean (SD)	40.7 (14.6)
Gender	
Male	556 (30.2)
Female	1285 (69.8)
Living area	
Rural	465 (25.3)
Urban	1376 (74.7)
Education level	
No education	12 (0.7)
Primary/middle school	153 (8.3)
Secondary/high school	590 (32.0)
Undergraduate/college	647 (35.1)
Postgraduate studies	436 (23.7)
Employment status	
Employed	926 (50.3)
Self-employed	193 (10.5)
Unemployed	90 (4.9)
Retired	177 (9.6)
Student	222 (12.1)
Homemaker	207 (11.2)
Disabled	26 (1.4)
Urticaria type	
CSU	1164 (63.2)
CIndU	331 (18.0)
CSU & CIndU	342 (18.6)
Years with diagnosis	3.7 (5.4)

Table 1. Demographic and clinical information of surveyed population. CIndU = chronic inducible urticaria; CSU = chronic spontaneous urticaria; SD, standard deviation

CU patients prefer the use of e-mail to ask physicians about urticaria

Most CU patients preferred one-to-one ICTs for asking physicians about urticaria (57.6%; Fig. 1). E-mail was the highest rated ICT for this purpose with 33.8% of patients being very or extremely interested in its use, followed by web browsers with 28.7%.

Again, living in rural areas and higher education were drivers of high levels of interest in the use of all ICT categories for asking physicians about urticaria (Table 3, Supplemental S4A-S4B, S5). Country-specific ICT category preferences for this purpose are shown in Supplemental Table S6.

CU patients prefer the use of WhatsApp for ICT-based communication with other patients

One-to-one was the preferred ICT category of CU patients who were very or extremely interested in communicating with other patients (33.0%; Fig. 1). WhatsApp was the highest rated ICT for this purpose with 24.8% of patients being very or extremely interested in its use for communicating with other patients, followed by web browsers with 19% (Table 2).

Interest in using almost all ICT categories for communication with other CU patients was driven, again, by rural living and higher education (Table 3, Supplemental Table S4A-S4B, S7). Supplemental Table S8 shows country-specific

preferences for ICT category use for communicating with patients.

DISCUSSION

Previously, we reported that almost all CU patients have access to ICTs and most use these regularly for health and disease-related information.¹⁹ Here, we found that most patients with CU were interested in the use of ICTs for receiving information, asking physicians, and communicating with other patients about urticaria. Of note, patients prefer different ICTs for these 3 purposes: web browsers for obtaining information; email for asking physicians; and WhatsApp for communicating with other patients.

Obtaining information

Almost all CU patients used ICTs for obtaining health and disease-related information.¹⁹ One-to-many ICTs, specifically web browsers were most frequently used, and the high usage of web browsers by >75% of patients was consistent with other chronic diseases.^{16,21} Interestingly, one-to-one ICTs such as email and WhatsApp were also held to be of high interest to patients who are looking for information on their urticaria. Fewer patients use email and WhatsApp compared to web browsers; this may indicate a lack of information initiatives for these ICTs with a residual need to develop them.

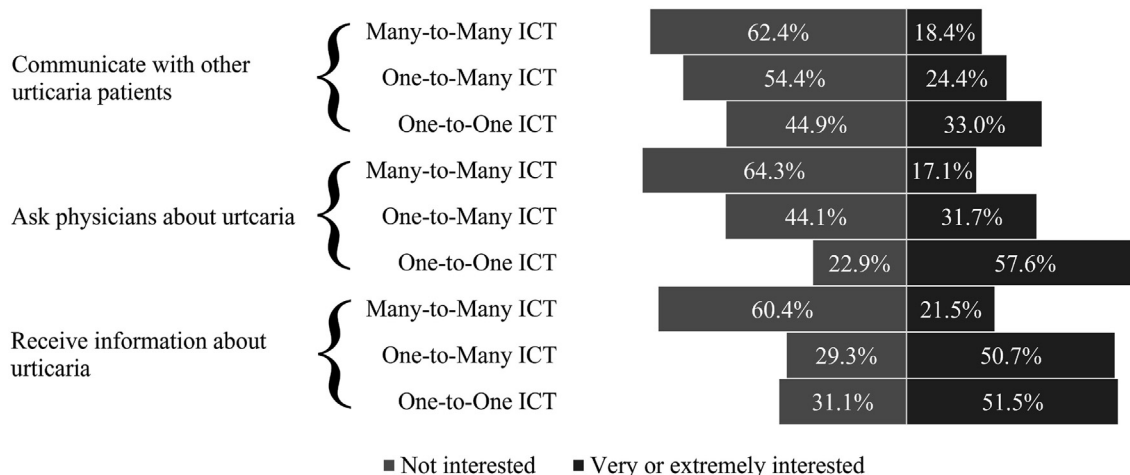


Fig. 1 Frequencies of patients being “very to extremely interested” or “not interested” at all in communicating with other urticaria patients, asking, and receiving information about urticaria through each ICT category. ICT = Information and communication technologies. **Note:** many-to-many ICTs (Facebook, Instagram, LinkedIn, and Twitter), one-to-many (blogs or forums, YouTube, and web browsers), and one-to-one (e-mail, Skype, SMS, and WhatsApp)

	Not interested n (%)	Slightly interested n (%)	Moderately interested n (%)	Very interested n (%)	Extremely interested n (%)
Interest in receiving information through ICTs					
Many-to-many					
Facebook	1235 (67.1%)	20 (1.1%)	201 (10.9%)	211 (11.5%)	83 (4.5%)
Instagram	1513 (82.2%)	19 (1.0%)	91 (4.9%)	90 (4.9%)	76 (4.1%)
LinkedIn	1711 (92.9%)	18 (1.0%)	22 (1.2%)	35 (1.9%)	10 (0.5%)
Twitter	1669 (90.7%)	18 (1.0%)	49 (2.7%)	36 (2.0%)	13 (0.7%)
One-to-many					
Blog/forum	1526 (82.9%)	12 (0.7%)	81 (4.4%)	91 (4.9%)	79 (4.3%)
Web browser	600 (32.6%)	9 (0.5%)	323 (17.5%)	524 (28.5%)	295 (16.0%)
YouTube	1209 (65.7%)	15 (0.8%)	179 (9.7%)	209 (11.4%)	160 (8.7%)
One-to-one					
E-mail	833 (45.2%)	16 (0.9%)	216 (11.7%)	332 (18.0%)	296 (16.1%)
Skype	1690 (91.8%)	27 (1.5%)	32 (1.7%)	31 (1.7%)	15 (0.8%)
SMS	1221 (66.3%)	24 (1.3%)	171 (9.3%)	152 (8.3%)	99 (5.4%)
WhatsApp	1060 (57.6%)	22 (1.2%)	156 (8.5%)	294 (16.0%)	231 (12.5%)
Interest in asking physicians about urticaria through ICTs					
Many-to-many					
Facebook	1307 (71.0%)	15 (0.8%)	183 (9.9%)	150 (8.1%)	72 (3.9%)
Instagram	1568 (85.2%)	15 (0.8%)	75 (4.1%)	78 (4.2%)	44 (2.4%)
LinkedIn	1717 (93.3%)	7 (0.4%)	54 (2.9%)	13 (0.7%)	7 (0.4%)
Twitter	1694 (92.0%)	20 (1.1%)	33 (1.8%)	43 (2.3%)	9 (0.5%)
One-to-many					
Blog/forum	1549 (84.1%)	12 (0.7%)	83 (4.5%)	87 (4.7%)	54 (2.9%)
Web browser	868 (47.1%)	11 (0.6%)	294 (16.0%)	333 (18.1%)	195 (10.6%)
YouTube	1392 (75.6%)	14 (0.8%)	161 (8.7%)	83 (4.5%)	54 (2.9%)

(continued)

	Not interested n (%)	Slightly interested n (%)	Moderately interested n (%)	Very interested n (%)	Extremely interested n (%)
One-to-one					
E-mail	814 (44.2%)	10 (0.5%)	309 (16.8%)	341 (18.5%)	281 (15.3%)
Skype	1509 (82%)	27 (1.5%)	71 (3.9%)	63 (3.4%)	32 (1.7%)
SMS	1227 (66.6%)	21 (1.1%)	135 (7.3%)	218 (11.8%)	114 (6.2%)
WhatsApp	849 (46.1%)	21 (1.1%)	182 (9.9%)	390 (1.2%)	325 (17.7%)
Interest in communicating with other urticaria patients through ICTs					
Many-to-many					
Facebook	1242 (67.5%)	26 (1.4%)	196 (10.6%)	159 (8.6%)	106 (5.8%)
Instagram	1588 (86.3%)	26 (1.4%)	66 (3.6%)	61 (3.3%)	54 (2.9%)
LinkedIn	1724 (93.6%)	10 (0.5%)	31 (1.7%)	27 (1.5%)	6 (0.3%)
Twitter	1691 (91.9%)	20 (1.1%)	34 (1.8%)	21 (1.1%)	34 (1.8%)
One-to-many					
Blog/forum	1510 (82.0%)	11 (0.6%)	96 (5.2%)	103 (5.6%)	58 (3.2%)
Web browser	1119 (60.8%)	25 (1.4%)	184 (10.0%)	193 (10.5%)	157 (8.5%)
YouTube	1489 (80.9%)	18 (1.0%)	87 (4.7%)	96 (5.2%)	51 (2.8%)
One-to-one					
E-mail	1131 (61.4%)	27 (1.5%)	257 (14.0%)	181 (9.8%)	133 (7.2%)
Skype	1604 (87.1%)	35 (1.9%)	52 (2.8%)	59 (3.2%)	21 (1.1%)
SMS	1321 (71.8%)	17 (0.9%)	182 (9.9%)	97 (5.3%)	74 (4.0%)
WhatsApp	1083 (58.8%)	25 (1.4%)	204 (11.1%)	253 (13.7%)	204 (11.1%)

Table 2. (Continued) Distribution of participants per degree of interest in using individual ICTs for health-related purposes. *ICT = information and communication technologies; SMS = short message service. Notes:* Due to missing data in some answers, adding up the percentages for specific ICTs or categories may not add up to 100%

Asking physicians

Email is a unique one-to-one addition to the conventional methods of consultation, one which improves communication and enhances management of chronic diseases.²² In chronic diseases, when patients were asked which ICTs they prefer

for asking physicians questions about their disease, e-mail was consistently rated very high.^{23,24} In multiple studies, young and highly educated patients were more interested in using email to communicate with their HCPs.^{25,26} Our findings were consistent with the aforementioned results.

Variable	Interest in receiving information through ICT type OR (95% CI)	Interest in asking physicians about urticaria through ICT type OR (95% CI)	Interest in communicating with other patients through ICT type OR (95% CI)
Many-to-many			
Age	0.98 (0.97-0.98)	0.97 (0.97-0.98)	0.96 (0.95-0.97)
Living area			
Urban	0.75 (0.57-0.97)	0.71 (0.54-0.95)	0.62 (0.47-0.81)
Education level			
Undergraduate studies	2.25 (1.34-3.79)	1.65 (0.99-2.75)	1.63 (0.96-2.75)
Postgraduate studies	1.97 (1.14-3.39)	1.36 (0.80-2.34)	1.81 (1.05-3.13)
One-to-Many			
Age	0.98 (0.97-0.98)	0.99 (0.98-0.99)	0.97 (0.97-0.98)
Years with urticaria	1.03 (1.01-1.05)	1.00 (0.98-1.02)	1.00 (0.99-1.03)
Living area			
Urban	0.88 (0.70-1.10)	0.64 (0.51-0.81)	0.63 (0.49-0.81)
Education level			
Secondary/Highschool	2.74 (1.84-4.01)	2.00 (1.28-3.13)	2.22 (1.32-3.72)
Undergraduate/college	4.18 (2.80-6.23)	2.90 (1.87-4.51)	3.18 (1.91-5.30)
Postgraduate studies	2.39 (1.58-3.62)	1.93 (1.22-3.07)	2.36 (1.38-4.03)
One-to-One			
Age	0.99 (0.98-0.99)	0.99 (0.98-0.99)	0.99 (0.98-0.99)
Living area ^a			
Urban	0.61 (0.48-0.77)	0.78 (0.63-0.99)	0.90 (0.71-1.14)
Education level ^b			
Secondary/Highschool	2.36 (1.60-3.47)	2.05 (1.41-2.97)	1.71 (1.14-2.67)
Undergraduate/college	3.45 (2.34-5.08)	3.59 (2.47-5.23)	2.02 (1.32-3.08)
Postgraduate studies	2.34 (1.57-3.49)	3.02 (2.04-4.47)	2.21 (1.43-3.42)

Table 3. Characteristics of ICT users reporting to be very or extremely interested in receiving urticaria information, asking physicians about urticaria and communicating with other urticaria patients through ICT type. **Notes** many-to-many ICTs (Facebook, Instagram, LinkedIn and Twitter), one-to-many (blogs or forums, YouTube and web browsers), and one-to-one (e-mail, Skype, SMS and WhatsApp). Regression analyses were adjusted for variables such as age, gender, education level, living area and years with urticaria. Bolded values are significant at 0.05 significance level. OR, odds ratio; CI, confidence interval a. Reference living area is "rural" b. Reference education level category is "No education/Primary school"

Communication with other CU patients

WhatsApp is the most popular global mobile messenger application and is cost-effective, fast, reliable, and easy to use. In a literature review, WhatsApp was shown to be an effective tool for both communication and learning between HCPs and the general public.²⁷ Many physicians have incorporated WhatsApp into their everyday practice, given its practical advantages.²⁸ Moreover, at UCARE centers, we have observed a 50% increase in the usage of WhatsApp during the COVID-19 pandemic in our clinics.¹⁹ It is the second most frequently used ICT following cell phones.¹⁹ In our study, WhatsApp rated very high for communication with other CU patients. This information may help patient organizations to make use of this ICT in connecting CU patients.

Usage of ICTs among different groups

Usage of ICTs differed depending on age, living area, and educational level. Younger age was a significant predictor of high interest (very/extremely) in the usage of every ICT type for the 3 specific purposes studied. Similar results have been reported where younger generations had the highest overall ICT usage compared to older cohorts.¹⁷

We expected lower levels of ICT usage in countries that were highly regulated such as Iran; however, we found that Argentina had lower usage, too. Given limited access to specialists in rural areas, ICTs could be useful, especially in developing countries where there is evidence that ICT usage helps to prevent disease.²⁹

Predictably, higher levels of education were associated with increased ICT usage for the 3 areas studied. While data suggest women use social networks more than men,³⁰ we did not find any difference in ICT usage between genders even though the prevalence of CU is higher in women, which was confirmed by our results.

The future

Results here support the development of validated disease content for easy-to-use ICTs that are CU-specific, focus on one-to-one and one-to-many communication, and include patient-reported

outcomes to help assess disease severity and course, particularly during the current pandemic. New ICTs should be user friendly. Techno-complexity has negative consequences and would ultimately lead to nonadherence and greater stress in all age groups, particularly the elderly.³¹ In all, new ICTs could provide patients with optimized, tailored disease information and communications which would ultimately improve CU management and outcomes.

Strengths and limitations

Our study included participants of different ages, genders, and education levels across many regions. Moreover, our network had the capacity to obtain a high sample globally. However, there were study limitations. The study design was cross-sectional and therefore cause-and-effect relationships could not be detected. Our 23-item survey has not been validated. Participants knew the purpose of this study in advance. In addition, accessibility of ICTs varies between countries. Given the high rate of EU participants, differences between countries/continents could not be detected. Randomized trials are necessary to determine the efficacy and cost effectiveness of new ICT tools in promoting CU control as well as providing sources of information about disease and self-management.

CONCLUSIONS

While a number of ICT types have become universal in modern medical practice, the results of our study demonstrated that one-to-one and one-to-many ICTs were the most preferred types for CU patients to receive disease information and to communicate with their physicians and other patients. Urticaria specialists and accredited centers could, in coordination with ICT designers, introduce personalized technological solutions for each patient. Additionally, feedback loops could be integrated to improve tailoring and allow content to be adapted to changing needs.

Abbreviations

ICT: information and communication technologies; CU: chronic urticaria; CSU: chronic spontaneous urticaria; CIndU: chronic inducible urticaria; HCP: healthcare providers; SMS: short message service.

Ethics statement

The authors declare that this manuscript complies with the ethics in publishing guidelines. This study was approved by the ethics committee "Comité de ética e Investigación en Seres Humanos" (CEISH), Guayaquil, Ecuador (IRB number HCK-CEISH-19-0059) and by a committee for each participating UCARE center. Each participant provided consent to completion of the anonymous survey, and confidentiality was maintained throughout the study.

Author contributions

All authors declare that they have made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; drafted the article or reviewed it critically for important intellectual content; and given final approval of the version to be published.

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Availability of data and materials

All study materials and data were available to all study centers and physicians.

Declaration of competing interest

I Cherrez-Ojeda has no conflicts of interest. **E Vanegas** has no conflicts of interest. **A Cherrez** has no conflicts of interest. **M Felix** has no conflicts of interest. **K Weller** is or recently was a speaker and/or advisor for, and/or has received research funding from: Biocryst, CSL Behring, Dr. Pflieger, FAES, Moxie, Novartis, Shire/Takeda, and Uriach. **M Magerl** is or recently was a speaker and/or advisor for, and/or has received research funding from Biocryst, CSL Behring, Kalvista Pharmaceuticals, Moxie, Novartis, Pharming, and Shire/Takeda. **RR Maurer** has no conflicts of interest. **VL Mata** has no conflicts of interest. **A Kasperska-Zajac** has no conflicts of interest. **A Sikora** has no conflicts of interest. **D Fomina** is or recently was a speaker and/or advisor for, and/or has received research funding from: AstraZeneca, CSL Behring, Glaxo SmithKline, MSD, Novartis, Sanofi, and Shire/Takeda. **E Kovalkova** has no conflicts of interest. **K Godse** has no conflicts of interest. **N Dheeraj Rao** has no conflicts of interest. **M Khoshkhui** has no conflicts of interest. **S Rastgoo** has no conflicts of interest. **RFJ Criado** has no conflicts of interest. **M Abuzakouk** has no conflicts of interest. **D Grandon** has no conflicts of interest. **MBA van Doorn** is or recently was a speaker and/or advisor for, and/or has received research funding from Abbvie, BMS, Celgene, Janssen Cilag, LEO Pharma, Lilly, MSD, Novartis, Pfizer, and Sanofi-Genzyme. **S Valle** has no conflicts of interest. **E Magalhães de Souza Lima** has no conflicts of interest. **SF Thomsen** is or recently was a speaker and/or advisor for, and/or has received research funding from: Abbvie, AstraZeneca, Celgene, Eli

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Appendix A. Supplementary data

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