


















SHORT COMMUNICATION

Should we measure quality of life among people with HIV? A multicentre survey of physicians' opinions in Spain

Rebeca Izquierdo^{1,2}  | Inés Suárez-García^{2,3,4}  | Teresa Gómez-García^{1,2}  |
Cristina Marco-Sánchez¹  | Julián Puente-Ferreiro¹  | Cristina Moreno^{1,2}  |
Asunción Díaz^{1,2}  | Noemí Cabello-Clotet^{2,5,6}  | David Vinuesa^{2,7}  |
José Luis Blanco^{2,8}  | Estrella Melús⁹ | Cristina Gómez-Ayerbe¹⁰  |
Julián Olalla¹¹  | Melchor Riera^{2,12}  | José Ignacio Bernardino^{2,13}  |
Juan Carlos de López Bernaldo de Quirós^{2,14}  | Santiago Moreno^{2,15,16}  |
Inma Jarrín^{1,2}  | on behalf of the CoRIS cohort[†]

Correspondence

Rebeca Izquierdo, National Centre for Epidemiology, Instituto de Salud Carlos III, Avenida Monforte de Lemos, 5, 28029, Madrid, Spain.
Email: r.izquierdo@externos.isciii.es

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Abstract

Objectives: We assessed the opinions of physicians caring for people with HIV (PWH) from the multicentre Spanish CoRIS cohort regarding the assessment of health-related quality of life (HRQoL).

Methods: We designed an online self-administered questionnaire comprising 27 structured questions across four domains: (i) sociodemographic and clinical data; (ii) usefulness of measuring HRQoL; (iii) information, training and resource needed; and (iv) whether and how HRQoL should be measured. Physicians completed the questionnaire between April and June 2023.

Results: Of 131 physicians surveyed [53.8% men, median age 52 years (interquartile range: 42–60)], 90.9% and 88.6% agreed that measuring HRQoL is useful for both PWH and medical decision-making, respectively. However, 67.2% needed training on what HRQoL is and how to measure it, 79.4% required information on validated tools, and 80.9% felt that clinical guidelines are needed. Overall, 90.1% of physicians agreed that HRQoL should be measured among PWH. Most physicians (82.8%) supported using specific scales for PWH, with 74.1% recommending annual measurement, 49.1% suggesting that nurses from HIV units conduct the assessments, and 43.1% favouring personal interviews during medical visits. At the time of the survey, 55.3% of physicians did not measure HRQoL in any patients due to time or resource constraints (75.8%).

Rebeca Izquierdo and Inés Suárez-García contributed equally to this work.

[†]Group authorship: centres and investigators involved in CoRIS cohort are listed in the Acknowledgments.

For affiliations refer to page 6

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Conclusions: Despite the recognized importance of HRQoL measurement in PWH, Spanish physicians encounter barriers such as time constraints and limited resources. Developing clear guidelines, using tailored scales, and integrating digital tools along with multidisciplinary support could enhance routine HRQoL assessments and improve patient-centred care.

KEYWORDS

health professional attitudes, HIV, patient-reported outcome measures, physicians, quality of life (HRQoL), Spain

INTRODUCTION

An ongoing paradigm shift is under way due to the chronic nature of HIV infection. The focus is being shifted from a disease-based approach to a person-centred chronic care perspective, recognizing the need for an intersection between HIV and chronic care models [1]. Person-centred care involves a more humanistic approach, prioritizing disease prevention, health promotion and personalized medical care, focusing on the individual needs and how HIV infection affects daily life [2]. This approach also takes into consideration the importance of the health-related quality of life (HRQoL) among people with HIV (PWH) [3].

The World Health Organization (WHO) emphasizes the importance of assessing HRQoL in PWH in its latest global health strategy on HIV [4], highlighting well-being as a fundamental aspect and advocating for a person-centred approach.

The HRQoL of PWH refers to their subjective perception of well-being and life satisfaction. HRQoL can be influenced by multi-dimensional factors, including physical and mental health, social support, stigma and discrimination, the impact of health on daily life activities, and subjective general health perception [5]. This subjective self-evaluation has become an important measure in the clinical care of patients with chronic diseases and is included in the assessment of therapeutic interventions and cost-effectiveness analyses, among other applications [6].

There is a growing interest worldwide, particularly in high-income countries, in utilizing validated patient-reported outcomes (PROMs) to assess the self-reported HRQoL of PWH in clinical settings [7]. The 2023 revision of the European AIDS Clinical Society (EACS) guidelines also includes recommendations for the use of PROMs in HIV clinical care [8]. On an individual level, the routine use of PROMs such as quality of life and self-reported symptoms improves clinical decision-making, symptom recognition, patient-clinician communication, and the identification and addressing of quality of life-related issues [9]. However, despite the potential benefits that

such PROMs could offer to routine clinical care, this area remains in the developmental stage [10].

In this study, our aim was to assess the opinions of physicians attending PWH within the Spanish nationwide CoRIS cohort regarding the measurement of HRQoL, with the goal of identifying areas for improvement in health-care practice.

METHODS

Study population

We included all physicians providing care for PWH from the centres participating in the CoRIS cohort. CoRIS is a prospective multicentre cohort comprising adult PWH, naive to antiretroviral treatment at study entry. Participants were recruited from 48 centres across 14 autonomous regions within the Spanish public healthcare system [11]. Two centres were excluded as they were neither enrolling new patients nor providing follow-up data. Thus, at the time of the study, there were 225 physicians in CoRIS, distributed across 46 centres.

Questionnaire design and administration

An ad hoc questionnaire was designed, comprising 27 structured questions organized into four domains: (i) sociodemographic and clinical data; (ii) the perceived usefulness of measuring HRQoL; (iii) the need for information, training and resources for HRQoL measurement; and (iv) whether and how HRQoL should be measured. Questions in domains (ii) and (iii) were answered using a five-point Likert scale. Questions in domain (iv) included both single-choice and yes/no questions.

The online version of the questionnaire was evaluated by five physicians from CoRIS, and minor adjustments to the wording of questions were made based on their input. The final version of the questionnaire in Spanish is shown in the supplementary material (SM 1) and was

estimated to take 5–7 min for completion. An English translation is also included in the supplementary material (SM 2).

The questionnaire was e-mailed to all physicians on 2 April 2023, and responses were collected until June 2023. Physicians who did not respond received a reminder email. Responses were anonymized for the investigators analysing the data.

Statistical analysis

Descriptive analysis was conducted using frequency tables for categorical variables and median and interquartile range (IQR) for continuous variables. Differences in physicians' opinion by sex (male, female), age (<40, 40–55 and > 55 years), years of experience treating PWH (<15, 15–24 and ≥ 25) and the number of PWH followed up in the hospitals where they work (≤1000, >10 000) were assessed using the χ^2 test for independence for categorical variables. All statistical analyses were performed using Stata[®] software (version 17.0; Stata Corporation, College Station, TX, USA).

Ethics approval and informed consent

The CoRIS cohort was approved by the Clinical Research Ethics Committee of the Gregorio Marañón General

University Hospital. All patients provided their consent to join CoRIS by signing an informed consent form. This particular study received approval from the Clinical Research Ethics Committee Carlos III Health Institute, Madrid, Spain (CEI PI 52 _2020-v2_Enmienda 2020-v2).

RESULTS

Of 225 physicians included in the study, 131 (58.2%) completed the questionnaire, of whom 61 (46.6%) were female. The median age of respondents was 52 years (IQR: 42–60), with 89 (67.9%) working in hospitals that followed up more than 1000 PWH, and they had been treating PWH for a median of 20 years (IQR: 12–30).

A total of 119 (90.9%) and 116 (88.6%) physicians agreed that measuring HRQoL is beneficial for both patients and medical decision-making, respectively. Furthermore, between 94 and 106 (72%–81%) stated that measuring HRQoL would encourage patients to engage in self-care, enhance the physician–patient relationship, and contribute to holistic patient-centred care. Additionally, 99 (75.6%) considered HRQoL measurement meaningless unless repeated over time. However, 56 (42.7%) physicians found measuring quality of life to be not useful due to a lack of resources needed to support individuals who report poor quality of life (Figure 1).

Regarding the need for information, training and resources, 88 (67.2%) physicians expressed a need for

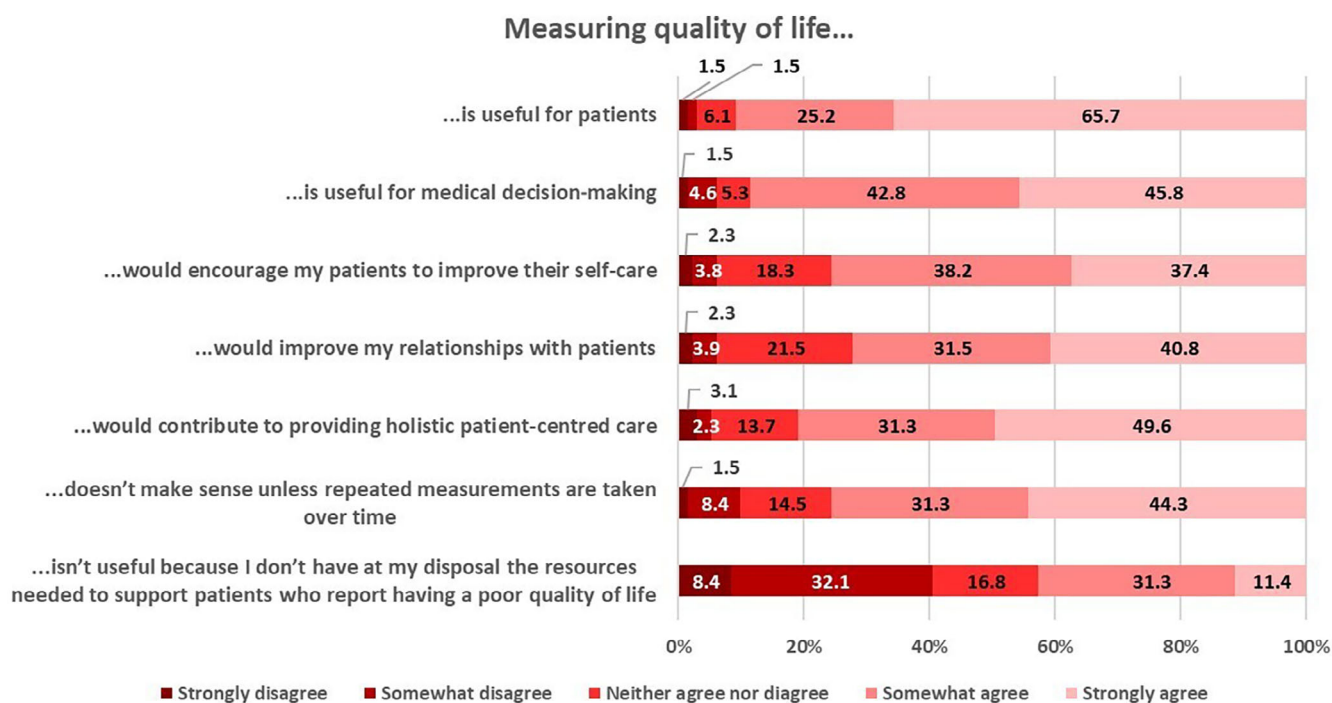


FIGURE 1 Physicians' opinion about the usefulness of measuring health-related quality of life (HRQoL).

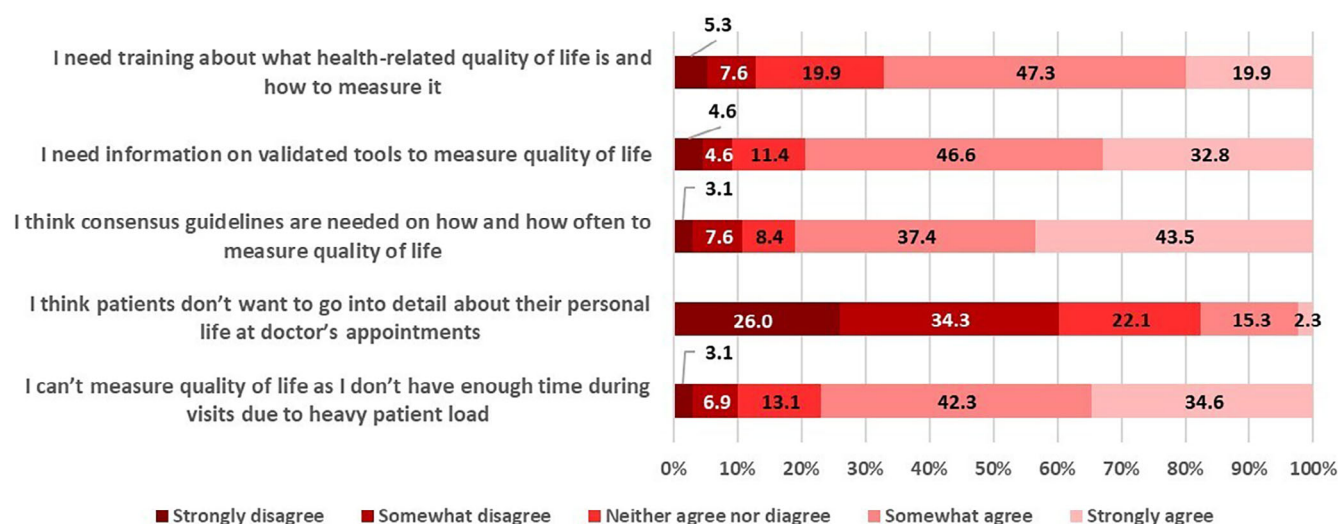


FIGURE 2 Physicians' opinion about the need for information, training and resources to measure health-related quality of life (HRQoL).

training on what HRQoL is and how to measure it, while 104 (79.4%) required information on validated tools. Additionally, 106 (80.9%) agreed that clinical guidelines are necessary to establish a consensus on how, and how often, to measure HRQoL. Furthermore, 100 (76.9%) physicians stated that they were unable to measure HRQoL due to insufficient time during visits, attributed to heavy patient loads (Figure 2).

A total of 118 (90.1%) physicians concurred that HRQoL should be measured. Most (96; 82.7%) agreed that specific scales for PWH should be used, recommending an annual assessment frequency (74.1%). They suggested that HRQoL measurement be conducted by nurses from HIV units (49.1%), through personal interviews during medical visits (43.1%) or via mobile apps (32.8%). However, 97.4% believed that the patient's profile should guide the method selection for measuring HRQoL. At the time of the survey, 63 (55.3%) physicians did not assess HRQoL in any patients, primarily due to time or resource constraints (75.8%). Among the 51 physicians who evaluated HRQoL in some of their patients, 35.3% used personal interviews, and only 15.7% used validated scales for PWH (data not shown).

No significant differences were found in physicians' opinions by sex, age, years of experience in caring for PWH, or the number of PWH followed at their hospitals. However, a majority of physicians aged >55 years (56.8%) and/or those with ≥25 years of experience (60.0%) preferred personal interviews to measure HRQoL, while most physicians aged 40–55 years (44.9%) or with 15–24 years' experience (45.7%) favoured mobile apps. Additionally, the percentage of physicians who evaluated the quality of life in any of their patients at the time of the survey was higher among older individuals (58.1%, 32.7% and 45.5%

among physicians aged >55, 40–55 and <40 years, respectively) and among those with more years of experience (64.1%, 28.6% and 40.0% for ≥25, 15–24 and <15 years' experience, respectively) (data not shown).

DISCUSSION

In this study, we examined physicians' opinions on measuring HRQoL among PWH. Clinicians generally concurred that assessing HRQoL could positively impact patient's overall well-being, both clinically and personally. They emphasized the importance of training, resources and consensus among healthcare professionals regarding HRQoL assessment. However, more than half of the physicians reported not measuring HRQoL in any patients mainly due to time and resource constraints.

The majority of physicians agreed on the benefits of measuring HRQoL for patients and its utility in medical decision-making. They also recognized its potential to promote patient self-care, enhance the physician–patient relationship and contribute to holistic patient-centred care. These findings align with prior research on the benefits of using PROMs in clinical practice, both generally [12] and specifically for HIV infection [13]. However, more than half of the physicians reported not integrating HRQoL measures into their routine medical care, mainly due to time constraints, heavy patient loads and inadequate support and resources. These barriers at the health provider level have also been identified in studies on integrating PROMs into routine general clinical practice [14], including contexts specific to HIV care [15]. However, the impact of measuring HRQoL on consultation times and physician

workload may vary depending on the specific tool used. Previous studies suggest that integrating PROM feedback into clinical visits could streamline healthcare provider efforts, reduce workloads and improve efficiency by addressing patient concerns during consultations [16]. Nearly half of the physicians in our study indicated that HRQoL assessments could be conducted by nurses. This finding is consistent with a recent study in Spain, where a significant percentage of HIV-specialized physicians proposed that PROM questionnaires could be administered by nursing staff or other trained healthcare personnel in facilities [17].

Physicians in our study expressed the need for training on HRQoL and its measurement methods. These findings highlight the necessity for professional training and are consistent with prior research, wherein healthcare professionals expressed concerns about the need for knowledge and skills regarding the appropriate implementation of PROMs, both in general practice [14] and in the care of PWH [13, 17]. A recent meta-analysis revealed that the most commonly used instruments for assessing HRQoL in PWH are the WHO Quality of Life HIV Brief (WHOQOL-HIV BREF) and the Medical Outcomes Study HIV (MOS-HIV) [18]. As expressed in our survey, developing clinical practice guidelines on HRQoL measurement and using scales specifically designed for PWH could facilitate the integration of HRQoL assessments into clinical practice.

Most physicians agreed that HRQoL measurements are meaningful only when conducted with repeated assessments over time, and an annual assessment was their preferred option. In France, HIV healthcare providers suggested completing PROMs minimally before medical consultations and receiving alerts under specific conditions when problematic scores were detected [15]. Considering that Spanish guidelines recommend a hospital visit at least once a year [19], annual HRQoL assessments could be a suitable option that would balance current clinical routine care, resource availability and patient well-being. This is consistent with the EACS guidelines, which advocate for the annual use of PROM tools for all individuals to facilitate dialogue between care providers and patients, enhance both patient and physician awareness of health status, promote patient-centred care and empower patients in the decision-making process [8].

In our study, no significant differences by sex, age or years of experience were observed in physicians' perspectives on the usefulness of measuring HRQoL and the need for information, training and resources. Among physicians who monitored HRQoL in their patients, the most frequently used tool was personal interviews. Younger physicians preferred mobile applications, consistent with prior studies highlighting the benefits of electronic systems for PROMs in both general healthcare settings [12] and HIV care specifically [13, 17]. The

authors advocate for the combined use of both methods for routine HRQoL measurement, a practice supported by a prior study in Spain's HIV healthcare, which suggested using paper-based PROMs for newly diagnosed cases to facilitate personalized conversations and electronic PROMs for PWH follow-up visits to monitor progress [17]. It is worth noting that almost all physicians in our study agreed that the method to measure HRQoL should be tailored to the patient's profile. These proposals align with the EACS guidelines, which recommend integrating PROMs into electronic patient records using digital tools and emphasize the importance of providing support for individuals facing technological or language barriers, as they often have higher unmet needs [8].

To the best of our knowledge, this study represents the first comprehensive exploration of physicians' opinions on HRQoL measurement within the HIV healthcare setting in Spain, which extends beyond specific measurement tools and involves a substantial number of participants. Additionally, it integrates a global perspective on physicians' perceptions of HRQoL, along with their viewpoints stratified by sex, age and years of experience in managing PWH. However, our findings could be limited by a 41.8% non-response rate. Also, we only assessed physicians' opinions and we did not include nurses or other healthcare workers, which in several settings can have an important role on the assessment of HRQoL. Moreover, we were unable to assess the perspectives of PWH regarding PROMs and HRQoL collection, which are crucial for developing effective, person-centred care strategies.

CONCLUSIONS

In conclusion, while most physicians in Spain recognize the importance of measuring HRQoL in PWH, many encounter challenges such as time constraints, limited resources and insufficient training, which hinder its routine implementation. From the physicians' perspective, establishing clear clinical guidelines and incorporating HRQoL scales specifically tailored for people living with HIV (PLWH) are essential for effectively measuring HRQoL. Additionally, involving other healthcare professionals, such as nurses, and utilizing digital tools can streamline the process, facilitating the integration of HRQoL assessments into routine care. This approach would ultimately improve patient outcomes and support holistic, patient-centred care.

AUTHOR CONTRIBUTIONS

All authors were involved in the setting up of the cohort and contributed to its design. All authors were involved in data collection. IJ and IS-G asked the research question presented in this paper and designed the study.

IJ and JP designed the questionnaire. JP and CM-S analysed the data. RI, IS-G, TG and IJ wrote the first draft of the paper. All authors were involved in interpretation of the data and commented on interim drafts. All authors read and approved the final draft.

AFFILIATIONS

¹National Centre for Epidemiology, Carlos III Health Institute, Madrid, Spain

²CIBERINFEC, Carlos III Health Institute, Madrid, Spain

³Infectious Diseases Group, Department of Internal Medicine, Infanta Sofia University Hospital, Infanta Sofia University Hospital and Henares University Hospital Foundation for Biomedical Research and Innovation (FIIB HUIS HHEN), Madrid, Spain

⁴European University of Madrid, Madrid, Spain

⁵Infectious Diseases Unit, Internal Medicine Department, San Carlos Clinical Hospital, Health Research Institute of the San Carlos Clinical Hospital (IdISSC), Madrid, Spain

⁶Complutense University of Madrid, Madrid, Spain

⁷Department of Infectious Diseases, San Cecilio Clinical University Hospital, Granada, Spain

⁸Department of Infectious Diseases, Clínic Barcelona hospital, August Pi i Sunyer Biomedical Research Institute (IDIBAPS), Barcelona, Spain

⁹Department of Infectious Diseases, San Pedro University Hospital, Logroño, Spain

¹⁰Infectious Diseases Unit, Virgen de la Victoria University Hospital, Malaga Biomedical Research Institute and Nanomedicine Platform (IBIMA Plataforma-BIONAND), Málaga, Spain

¹¹Internal Medicine Department, Costa del Sol University Hospital, Marbella, Spain

¹²Infectious Diseases Unit, Internal Medicine Department, Son Espases University Hospital, Illes Balears Health Research Institute (IdISBa), Palma de Mallorca, Spain

¹³HIV Unit, Internal Medicine, Department, Hospital La Paz-Carlos III, Hospital La Paz Institute for Health Research (IdiPAZ), Madrid, Spain

¹⁴Department of Infectious Diseases, Gregorio Marañón General University Hospital, Madrid, Spain

¹⁵Department of Infectious Diseases, University Hospital Ramón y Cajal, Ramón y Cajal Health Research Institute (IRYCIS), Madrid, Spain

¹⁶Department of Medicine, Alcalá University, Madrid, Spain

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CoRIS Executive committee

Santiago Moreno, Inma Jarrín, David Dalmau, M Luisa Navarro, M Isabel González, Federico Garcia, Eva Poveda, Jose Antonio Iribarren, Félix Gutiérrez, Rafael Rubio, Francesc Vidal, Juan Berenguer, Juan González, M Ángeles Muñoz-Fernández.

CoRIS Coordination Unit

Inmaculada Jarrín, Cristina Moreno, Marta Rava, Rebeca Izquierdo, Cristina Marco, Teresa Gómez-García.

BioBank HIV Hospital General Universitario Gregorio Marañón

M Ángeles Muñoz-Fernández, Roxana Juárez.

Hospital General Universitario de Alicante (Alicante)

Joaquín Portilla, Irene Portilla, Esperanza Merino, Gema García, Iván Agea, José Sánchez-Payá, Juan Carlos Rodríguez, Livia Giner, Sergio Reus, Vicente Boix, Diego Torrus, Verónica Pérez, Julia Portilla, Héctor Pinargote.

Hospital Universitario de Canarias (San Cristóbal de la Laguna)

María Remedios Alemán, Ana López Lirola, Dácil García, Felicitas Díaz-Flores, M Mar Alonso, Ricardo Pelazas, María Inmaculada Hernández, Lucia Romero, Abraham Bethencourt, Daniel Rodríguez.

Hospital Universitario Central de Asturias (Oviedo)

Víctor Asensi, María Eugenia Rivas-Carmenado, Rebeca Cabo Magadan, Javier Díaz-Arias.

Hospital Universitario 12 de Octubre (Madrid)

Federico Pulido, Rafael Rubio, Otilia Bisbal, M Asunción Hernando, David Rial, María de Lagarde, Adriana Pinto,

Laura Bermejo, Mireia Santacreu, Roser Navarro, Juan Martín Torres.

Servicio de Enfermedades Infecciosas. Hospital Universitario Donostia. Instituto de Investigación BioDonostia (Donostia- San Sebastián)

José Antonio Iribarren, M José Aramburu, Xabier Camino, Miguel Ángel Goenaga, M Jesús Bustinduy, Harkaitz Azkune, Maialen Ibarguren, Xabier Kortajarena, Ignacio Álvarez-Rodríguez, Leire Gil, Francisco Carmona-Torre, Ana Bayona Carlos, Maialen Lekuona Sanz.

Hospital General Universitario De Elche (Elche)

Félix Gutiérrez, Catalina Robledano, Mar Masiá, Sergio Padilla, Araceli Adsuar, Rafael Pascual, Marta Fernández, Antonio Galiana, José Alberto García, Xavier Barber, Javier García Abellán, Guillermo Telementi, Lucía Guillén, Ángela Botella, Paula Mascarell, Mar Carvajal, Alba de la Rica, Carolina Ding, Lidia García-Sánchez, Nuria Ena, Leandro López, Jennifer Vallejo, Nieves Gonzalo-Jiménez, Montserrat Ruiz, Christian Ledesma, Santiago López, María Espinosa, Ana Quiles, María Andreo.

Hospital Universitari Germans Trias i Pujol (Can Ruti) (Badalona)

Roberto Muga, Arantza Sanvisens, Daniel Fuster.

Hospital General Universitario Gregorio Marañón (Madrid)

Juan Carlos López Bernaldo de Quirós, Isabel Gutiérrez, Juan Berenguer, Margarita Ramírez, Paloma Gijón, Teresa Aldamiz-Echevarría, Francisco Tejerina, Cristina Díez, Leire Pérez, Chiara Fanciulli, Saray Corral.

Hospital Universitari de Tarragona Joan XXIII (Tarragona)

Joaquín Peraire, Anna Rull, Anna Martí, Consuelo Viladés, Beatriz Villar, Lluïsa Guillem, Montserrat Olona, Graciano García-Pardo, Frederic Gómez-Bertomeu, Verónica Alba, Silvia Chafino, Alba Sánchez.

Hospital Universitario y Politécnico de La Fe (Valencia)

Marta Montero, María Tasias, Eva Calabuig, Miguel Salavert, Juan Fernández, Rosa Blanes.

Hospital Universitario La Paz/IdiPAZ (Madrid)

Juan González-García, Ana Delgado-Hierro, José Ramón Arribas, Víctor Arribas, José Ignacio Bernardino, Carmen Busca, Joanna Cano-Smith, Julen Cadiñanos, Juan Miguel Castro, Luis Escosa, Iker Falces, Pedro Herranz, Víctor Hontañón, Alicia González-Baeza, M Luz Martín-Carbonero, Mario Mayoral, Rafael Micán, Rosa de Miguel, Rocío Montejano, M^a Luisa Montes, Luis Ramos-Ruperto, Berta Rodés, Talía Sainz, Elena Sendagorta, Eulalia Valencia, M del Mar Arcos, Alejandro de Gea Grela, Carlos Oñoro López.

Hospital San Pedro Centro de Investigación Biomédica de La Rioja (CIBIR) (Logroño)

José Ramón Blanco, Laura Pérez-Martínez, José Antonio Oteo, Valvanera Ibarra, Luis Metola, Mercedes Sanz.

Hospital Universitario Miguel Servet (Zaragoza)

Rosa Martínez, Desiré Gil, Álvaro Cecilio, Ruth Caballero, María Aranzazu Caudevilla.

Hospital Universitari Mutua Terrassa (Terrassa)

David Dalmau, Marina Martinez, Angels Jaén, Mireia Cairó, Javier Martinez-Lacasa, Roser Font, Laura Gisbert.

Hospital Universitario de Navarra (Pamplona)

María Rivero, Maider Goikoetxea, María Gracia, Carlos Ibero, Estela Moreno, Jesús Repáraz, Fernando Baigorria.

Parc Taulí Hospital Universitari (Sabadell)

Gemma Navarro, Manel Cervantes Garcia, Sonia Calzado Isbert, Marta Navarro Vilasaro.

Hospital Universitario de La Princesa (Madrid)

Ignacio de los Santos, Alejandro de los Santos, Lucio García-Fraile, Enrique Martín, Ildefonso Sánchez-Cerrillo, Marta Calvet, Ana Barrios, Azucena Bautista, Carmen Sáez, Marianela Ciudad, Ángela Gutiérrez, María Aguilera García.

Hospital Universitario Ramón y Cajal (Madrid)

Santiago Moreno, Santos del Campo, José Luis Casado, Fernando Dronda, Ana Moreno, M Jesús Pérez, Sergio Serrano-Villar, M^a Jesús Vivancos, Javier Martínez-Sanz, Alejandro Vallejo, Matilde Sánchez-Conde, José Antonio Pérez-Molina, José Manuel Hermida, Erick De La Torre Tarazona, Elena Moreno, Laura Martín Pedraza, Claudio Díaz García, Jorge Díaz, Alejandro García, Raquel Ron.

Hospital General Universitario Reina Sofía (Murcia)

Enrique Bernal, Antonia Alcaraz, Joaquín Bravo, Ángeles Muñoz, Cristina Tomás, Eva Oliver, David Selva, Eva García, Román González, Elena Guijarro, Rodrigo Martínez, María Dolores Hernández.

Hospital Universitario Clínico San Cecilio (Granada)

Federico García, Clara Martínez, Leopoldo Muñoz Medina, Marta Álvarez, Natalia Chueca, David Vinuesa, Adolfo de Salazar, Ana Fuentes, Emilio Guirao, Laura Viñuela, Andrés Ruiz-Sancho, Francisco Anguita, Naya Faro, José Peregrina, Lucia Chaves, Marta Illescas, Valme Sánchez.

Centro Sanitario Sandoval (Madrid)

Jorge Del Romero, Montserrat Raposo, Carmen Rodríguez, Teresa Puerta, Juan Carlos Carrió, Mar Vera, Juan Ballesteros, Oskar Ayerdi, Begoña Baza, Eva Orviz.

Hospital Clínico Universitario de Santiago (Santiago de Compostela)

Antonio Antela, Elena Losada.

Hospital Universitario Son Espases (Palma de Mallorca)

Melchor Riera, María Peñaranda, M Angels Ribas, Antoni A. Campins, Mercedes Garcia-Gazalla, Francisco J Fanjul, Javier Murillas, Francisco Homar, Helem H Vilchez, Luisa Martin, Antoni Payeras.

Hospital Universitario Virgen de la Victoria (Málaga)

Jesús Santos, María López, Cristina Gómez, Isabel Vici-ana, Rosario Palacios.

Hospital Universitario Virgen del Rocío (Sevilla)

Luis Fernando López-Cortés, Nuria Espinosa, Cristina Roca, Silvia Llaves.

Hospital Universitario de Bellvitge (Hospitalet de Llobregat)

Juan Manuel Tiraboschi, Arkaitz Imaz, María Saumoy.

Hospital Universitario Valle de Hebrón (Barcelona)

Adrián Curran, Vicenç Falcó, Jordi Navarro, Joaquin Burgos, Paula Suanzes, Jorge García, Vicente Descalzo, Patricia Álvarez, Bibiana Planas, Marta Sanchíz, Lucía Rodríguez, Arnau Monforte, Paola Vidovic.

Hospital Costa del Sol (Marbella)

Julián Olalla, Javier Pérez, Alfonso del Arco, Javier de la Torre, José Luis Prada.

Hospital General Universitario Santa Lucía (Cartagena)

Onofre Juan Martínez, Lorena Martinez, Francisco Jesús Vera, Josefina García, Begoña Alcaraz, Antonio Jesús Sánchez Guirao.

Complejo Hospitalario Universitario a Coruña (CHUAC) (A Coruña)

Álvaro Mena, Berta Pernas, Pilar Vázquez, Soledad López, Brais Castelo.

Hospital Universitario Basurto (Bilbao)

Sofía Ibarra, Guillermo García, Josu Mirena, Oscar Luis Ferrero, Josefina López, Míreia de la Peña, Miriam López, Iñigo López, Itxaso Lombide, Víctor Polo, Joana de Miguel, Beatriz Ruiz Estevez, Maite Ganchegui Aguirre, María Jesús Barberá Gracia.

Hospital Universitario Virgen de la Arrixaca (El Palmar)

Carlos Galera, Marian Fernández, Helena Albendin, Antonia Castillo, Asunción Iborra, Antonio Moreno, M Angustias Merlos, Inmaculada Chiclano.

Hospital de la Marina Baixa (La Vila Joiosa)

Concha Amador, Francisco Pasquau, Concepción Gil, José Tomás Algado.

Hospital Universitario Infanta Sofía (San Sebastián de los Reyes)

Inés Suarez-García, Eduardo Malmierca, Patricia González-Ruano, M Pilar Ruiz, José Francisco Pascual, Luz Balsalobre, Ángela Somodevilla.

Hospital Universitario de Jaén (Jaén)

María de la Villa López, Mohamed Omar, Carmen Herrero.

Hospital Universitario San Agustín (Avilés)

Miguel Alberto de Zárraga, Desirée Pérez.

Hospital Clínico San Carlos (Madrid)

Vicente Estrada, Noemí Cabello, M José Núñez, Iñigo Sagastagoitia, Reynaldo Homen, Ana Muñoz, Inés Armenteros Yeguas.

Hospital Universitario Fundación Jiménez Díaz (Madrid)

Miguel Górgolas, Alfonso Cabello, Beatriz Álvarez, Laura Prieto, Aws Al-Hayani, Irene Carrillo.

Hospital Universitario Príncipe de Asturias (Alcalá de Henares)

José Sanz, Alberto Arranz, Cristina Hernández, María Novella.

Hospital Clínico Universitario de Valencia (Valencia)

M José Galindo, Sandra Pérez Gómez, Ana Ferrer.

Hospital Reina Sofía (Córdoba)

Antonio Rivero Román, Inma Ruíz, Antonio Rivero Juárez, Pedro López, Isabel Machuca, Mario Frias, Ángela Camacho, Ignacio Pérez, Diana Corona, Javier Manuel Caballero.

Hospital Universitario Severo Ochoa (Leganés)

Rafael Rodríguez-Rosado Martínez-Echevarría, Rafael Torres.

Hospital Universitario Virgen de Valme (Sevilla)

Juan Macías Sánchez, Pilar Rincón, Luis Miguel Real, Anaís Corma, Alejandro González-Serna.

Hospital Álvaro Cunqueiro (Vigo)

Eva Poveda, Alexandre Pérez, Luis Morano, Celia Miralles, Antonio Ocampo, Guillermo Pousada, María Gallego, Jacobo Alonso, Inés Martínez.

Hospital Clínico Universitario de Valladolid (Valladolid)

Carlos Dueñas, Sara Gutiérrez, Marta de la Fuente López, Cristina Novoa, Xjoylin Egües, Pablo Tellería.

Hospital del Mar (Barcelona)

Carlos Güerri Fernández, Claudia Navarro Valls, Juan Du, Agustín Marcos Blanco, Itziar Arrieta Aldea, Esperanza Cañas Ruan, Cecilia Canepa, Natalia García Giralt.


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CONFLICT OF INTEREST STATEMENT

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ORCID

Rebeca Izquierdo  <https://orcid.org/0000-0001-5780-4462>

Inés Suárez-García  <https://orcid.org/0000-0002-7016-716X>

Teresa Gómez-García  <https://orcid.org/0000-0001-8871-8161>

Cristina Marco-Sánchez  <https://orcid.org/0009-0000-2799-0890>

Julián Puente-Ferreiro  <https://orcid.org/0000-0003-0664-925X>

Cristina Moreno  <https://orcid.org/0000-0002-3378-3158>

Asunción Díaz  <https://orcid.org/0000-0002-8309-4270>

Noemí Cabello-Clotet  <https://orcid.org/0000-0001-7259-554X>

David Vinuesa  <https://orcid.org/0000-0002-5663-8447>


José Luis Blanco  <https://orcid.org/0000-0003-2010-2744>

Cristina Gómez-Ayerbe  <https://orcid.org/0000-0001-6543-2355>

Julián Olalla  <https://orcid.org/0000-0002-8577-3891>

Melchor Riera  <https://orcid.org/0000-0002-0887-8710>

José Ignacio Bernardino  <https://orcid.org/0000-0003-3501-8529>

Juan Carlos de López Bernaldo de Quirós  <https://orcid.org/0000-0002-8989-9758>

Santiago Moreno  <https://orcid.org/0000-0002-2843-1094>

Inma Jarrín  <https://orcid.org/0000-0002-7485-2252>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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