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I. Articles

2023

[Cannabis-based products and multiple sclerosis-related pain: The role of routes of administration](#)

Published in Multiple Sclerosis and Related Disorders – 2023

Link et al. recently showed that among a US nationwide sample of people with multiple sclerosis (MS) and chronic pain, cannabis users reported higher levels of pain than non-users (Link et al., 2023). We found similar results in a sample of people with MS living in France and Spain (Barré et al., 2023). Moreover, the authors found that oil/tincture was the most common route of cannabis administration, followed by vaped products. However, while they acknowledged that different routes may be associated with different adverse effects and may be more effective in treating specific symptoms, they did not explore the relationship between route of administration and pain variables. We proposed to do so among our sample of MS patients.

Collaborator: Inserm

Authors: Tanguy Barré, Damien Testa, Clémence Ramier, Melina Santos, Fabienne Marcellin, Perrine Roux, Patrizia Carrieri, Lise Radoszycki, Camelia Protopopescu

[IDF2022-0874 Use of devices and digital tools for T1D management: insights from a survey of people with T1D and their caregivers](#)

Published in Clinical and Therapeutic Technology – 2023

T1D requires constant self-management and can substantially impact quality of life. We aimed to survey patient and caregiver experiences of T1D management.

Adult people with T1D (PwD) or their caregivers living in France, Germany, Italy, Spain, or the UK were invited to complete an online survey (July-August 2021).

Collaborator: Sanofi

Authors: Alfred Penfornis, Bernhard Kulzer, Su Down, Antoine Seigneux, Alize Vives, Mireille Bonnemaire

[Patient Perspectives on Value Dimensions of Lung Cancer Care: Cross-sectional Web-Based Survey](#)

Published in JMIR – 2023

While the lung cancer (LC) treatment landscape has rapidly evolved in recent years, easing symptom burden and treatment side effects remain central considerations in disease control. The aim of this study was to assess the relative importance of dimensions of LC care to patients, and to explore the disease burden, including socioeconomic aspects not commonly covered in patient-reported outcomes instruments.

Collaborator: Roche

Authors: Pasquale Varriale, Borna Müller, Grégory Katz, Lorraine Dallas, Alfonso Aguaron, Marion Azoulai, Nicolas Girard

[Symptom severity is a major determinant of cannabis-based products use among people with multiple sclerosis](#)

Published in Journal of Clinical Nursing – 2023

MS is responsible for a wide range of symptoms, including pain. Access to CBP differs according to local legislation. The French context is more restrictive than the Spanish one, and no data regarding cannabis use among MS patients has yet been published. Characterizing MS patients who use CBP constitutes a first step toward identifying persons most likely to benefit from them.

Collaborator: INSERM

Authors: Tangui Barré, Damien Testa, Melina Santos, Fabienne Marcellin, Perrine Roux, Patrizia Carrieri, Lise Radoszycki, Camelia Protopopescu

2022

[925-P: European Survey on Adults with Type 1 Diabetes \(T1D\) and Their Caregivers: Insights into Experience of T1D Management](#)

Published in Diabetes – 2022

T1D requires constant self-management and can substantially impact quality of life. We aimed to survey patient and caregiver experiences of T1D management.

Adult people with T1D (PwD) or their caregivers living in France, Germany, Italy, Spain, or the UK were invited to complete an online survey (July-August 2021).

Collaborator: Sanofi

Authors: Bernhard Kulzer, Su Down, Antoine Seigneux, Alize Vives, Mireille Bonnemaire, Alfred Penforinis

[Symptom improvements following therapeutic use of cannabis-based products in French people with multiple sclerosis](#)

Published in Science Direct – 2022

Lowering the effects of multiple sclerosis by using cannabis-based products has been under studies for several years. A recent article explored the extent of medical cannabis use in people with multiple sclerosis (MS) in Canada (Santarossa et al., 2022). However, THC-based substances are still criminalized in several countries such as France. There is therefore, a need to explore the therapeutic use of cannabis-based products (CBP) by people living with MS in this country. Through an online survey, participants completed a self-administered online questionnaire that collected data on socio-demographic characteristics, type of CBP, route of administration, self-reported motives to use CBP, and perceived effectiveness.

Collaborator: INSERM

Authors: Tangui Barré, Clémence Ramier, Camelia Protopopescu, Patrizia Carrieri, Lise Radoszycki

[The Burden of Cold Agglutinin Disease on Patients' Daily Life: Web-Based Cross-sectional Survey of 50 American Patients](#)

Published in JMIR Formative Research – 2022

Cold agglutinin disease (CAD) is a rare disorder, affecting 15% of patients with autoimmune hemolytic anemia. Few studies have assessed CAD symptoms and their impact on daily life, but these studies did not address the patients' perspectives. The aims of this study were to increase the knowledge about CAD through a patient-centric survey and to gain a better understanding of the burden of this disease. We conducted an internet-based survey in September 2020 among American patients registered on the CAD Unraveled website and members of the Cold Agglutinin Disease Foundation.

Collaborator: Sanofi

Authors: Florence Joly, Lisa Anne Schmitt, Patricia Ann McGee Watson, Emilie Pain, Damien Testa

[Patient perception of burden of disease and treatment preferences in non-small cell lung cancer: Results from a European survey](#)

Published in Lung Cancer Journal – 2022

To understand European non-small cell lung cancer (NSCLC) patients' perceptions of disease burden, treatment, and future expectations of treatment and care. A 32-item online survey was conducted on a sample of NSCLC patients across Europe. Descriptive statistics were used to analyze the data. Results were presented by disease stage (I–III vs. IV).

Collaborator: Amgen

Authors: Amanda Tufman, Kathy Redmond, Andromachi Giannopoulou, Sebastian Gonzalez-McQuire, Pasquale Varriale, Lena Geltenbort-Rost, Katarina Öhrling, Matthias Scheffler

[Patients' Perspectives About the Treatment They Receive for Cardiovascular Diseases and Mental Disorders: Web-Based Survey Study](#)

Published in JMIR Formative Research – 2022

Noncommunicable disease (NCD)-related deaths account for 71% of deaths worldwide. The World Health Organization recently developed a global action plan to address the impact of NCDs, with the goal of reducing the number of premature NCD-related deaths to 25% by the year 2025. Appropriate therapeutic adherence is critical for effective disease management; however, approximately 30%-50% of patients with an NCD do not comply with disease management activities as prescribed. This study aims to better understand patients' perspectives regarding therapeutic adherence and iatrogenic risk in 2 major groups of NCDs for which poor disease management can have fatal consequences: cardiovascular diseases and mental disorders.

Collaborator: Viatrix

Authors: Philippe Courtet, Jean-Jacques Mourad, Catherine Pecout, Anne-Felice Lainé-Pellet, Michael Checkroun, Charlotte Avril

[Patient Satisfaction with Once-Daily Single-Tablet Darunavir, Cobicistat, Emtricitabine, and Tenofovir Alafenamide \(DRV/c/FTC/TAF\): A RealWorld Study of Patient Self-Reported Outcomes in HIV-1-Diagnosed Adults](#)

Published in Patient Preference and Adherence – 2022

Human immunodeficiency virus (HIV)-1 infection remains a concern. As patient adherence to antiretroviral therapy is essential to avoid drug resistance and virologic failure, greater understanding of patient treatment satisfaction may help facilitate ongoing medication use. This descriptive study assessed patient satisfaction with DRV/c/FTC/TAF and HIV-related symptoms at baseline and follow-up (4– 6 weeks).

Collaborator: Janssen Global

Authors: Joyce LaMori, Antoine Seignez, Lise Radoszycki

[A novel disease specific scale to characterize the symptoms and impacts of fatigue in US adults with relapsing multiple sclerosis: A real-world study](#)

Published in Multiple Sclerosis and Related Disorders – 2022

Fatigue is among the most frequent and disabling symptoms in patients with relapsing multiple sclerosis (RMS). To measure MS fatigue and its impact on daily life in a real-world US population using an MS-specific patient-reported outcome (PRO) instrument, the Fatigue Symptoms and Impacts Questionnaire-RMS (FSIQ-RMS).

Collaborator: Janssen Global

Authors: Marion Azoulai, Tiphaine Lévy-Heidmann, Valentin Morisseau, Ophélie Wilczynski, Hoa H Le, Carol Jamieson, Leigh E. Charvet, Lauren B Krupp, Lindsey Lair

[Integrating Quality of Life in the Care Pathway of Cancer Patients Undergoing Immunotherapy Treatment: Descriptive, Cross-sectional Survey of an Online Patient Community's Experiences and Expectations](#)

Published in Journal of Medical Internet Research – 2022

New cancer treatments, such as immune checkpoint inhibitors (ICIs), can improve survival and health-related quality of life (HRQoL) in patients with cancer. Although long-term monitoring of HRQoL has been shown to improve survival, integration of HRQoL into everyday practice remains poorly documented. This study describes experiences and expectations of patients treated with ICIs regarding a discussion of HRQoL with health care professionals (HCPs) in cancer management.

Collaborator: Bristol-Myers Squibb France

Authors: Ophélie Wilczynski, Anthony Boisbouvier, Lise Radoszycki, François-Emerly Cotté, Anne-Françoise Gaudin, Hervé Lemasson

[Patients with Severe Uncontrolled Asthma: Perception of Asthma Control and its Management](#)

Published in Pulmonary Therapy - 2022

We conducted a study to understand the level of disease control and management, to discover new perspectives on severe asthma control experiences (or the lack of control), to understand the motivations for better disease control among people with uncontrolled severe asthma, and to gain insights into the behavioral changes that patients undergo when taking steps towards better asthma control.

Collaborator: Sanofi and Regeneron

Authors: Maureen George, Camille Graff, Alexis Bombezin-Domino, Emilie Pain

[Physical activity and quality of life of patients with rheumatoid arthritis at the time of COVID-19 lockdown: results from Carenity, an online patient community](#)

Published in Joint Bone Spine – 2021

It has been well established that physical activity (PA) has a positive impact on patients affected by rheumatoid arthritis (RA) [1]. However, the prolonged lockdown triggered by COVID-19 from March to May 2020 has dramatically decreased opportunities for PA in France. This study aimed to describe and measure the impact of this lockdown on PA practice, quality of life, and relationships with rheumatologists of patients affected by RA.

Collaborator: Sanofi Genzyme

Authors: Florence E Lévy-Weil, Sandrine Jousse-Joulin, Vincent Tiffreau, Raymond Perez, Valentin Morisseau, Alexis Bombezin--Domino, René-Marc Flipo

[Impact of the COVID-19 pandemic on patients affected by non-communicable diseases in Europe and in the USA](#)

Published in International Journal of Environmental Research and Public Health – 2021

Non-communicable diseases (NCDs), also known as chronic diseases, result from genetic, physiological, environmental, and behavioral factors. These long-term and sometimes life-long pathologies include cardiovascular diseases, cancers, chronic respiratory diseases, diabetes as well as mental health and neurological disorders. The objective of this study, performed in two independent waves, was to understand how patients with NCDs—a population that is particularly vulnerable in the context of the pandemic and lockdown—have been affected during the COVID-19 outbreak in Europe and in the USA.

Collaborator: Viatrix

Authors: Catherine Pécout, Emilie Pain, Michael Chekroun, Claire Champeix, Claudie Kulak, Rita Prieto, Joris van Vugt, Kim Gilchrist, Anne-Félice Lainé-Pellet

[Physical activity and rheumatoid arthritis: Need for practical, precise, and personalized support-Results from an online survey](#)

Published in Joint Bone Spine- 2021

Patients with rheumatoid arthritis (RA) frequently experience chronic joint pain, swelling, stiffness and fatigue. These symptoms may significantly impair patient daily physical activity (PA). Indeed, RA patients practice less exercise and exert lower levels of PA than their healthy counterparts. Health-enhancing PA together with specific exercises decreases the overall risk of morbidity and premature mortality in RA patients. The objective of this study was to describe the practice of PA in RA patients, in particular their perception of rheumatologist recommendations to engage in PA.

Collaborator: Sanofi Genzyme

Authors: Anne-Christine Rat, Arnaud Constantin, Catherine Beauvais, Yannick Guillodo, Valérie Guay, Emilie Pain, Lise Radoszycki, Florence Levy-Weil

[Patient Perspectives on the Therapeutic Profile of Botulinum Neurotoxin Type A in cervical dystonia](#)

Published in Journal of Neurology – 2021

Botulinum neurotoxin type A (BoNT-A) is an effective pharmacological treatment for the management of cervical dystonia (CD) that requires repeated administration at variable intervals. We explored patient perceptions of the impact of CD and the waning of BoNT-A therapeutic effects.

Collaborator: Ipsen

Authors: Comella C, Ferreira JJ, Pain E, Azoulai M, Om S.

[Immune-mediated inflammatory diseases and nutrition: results from an online survey on patients’ practices and perceptions](#)

Published in BMC Nutrition – 2021

The central role of microbiota and the contribution of diet in immune-mediated inflammatory diseases (IMID) are increasingly examined. However, patients’ perspectives on nutrition and its impact on their disease has not received a lot of attention. We aimed to directly collect information from patients with IMID about their dietary behaviors and their perceptions of the influence of nutrition on their disease.

Collaborator: Fresenius Kabi

Authors: Pham T, Sokol H, Halioua B, Pourcel G, Brun M, Pain E, Testa D

[Unsupervised clustering analysis of data from an online community to identify lupus patient profiles with regards to treatment preferences](#)

Published in Lupus – 2021

Lupus is a chronic complex autoimmune disease and non-adherence to treatment can deeply affect patient outcomes. The PREFERLUP study used unsupervised clustering analysis to identify profiles of patients with similar treatment preferences in an online community of French lupus patients, using Multiple Correspondence Analysis (MCA) with three unsupervised clustering methods.

Collaborator: Carenity Scientific Committee

Authors: Testa D, Jourde-Chiche N, Mancini J, Varriale P, Radoszycki L, Chiche L

[Impact of the COVID-19 Pandemic on Patients Affected by Non-Communicable Diseases in Europe and in the USA](#)

Published in the International Journal of Environmental Research and Public Health – 2021

Carenity, an international online patient community, conducted a patient study in two independent waves among adults affected by non-communicable diseases (NCDs) in Europe and in the United States of America (USA). The study aimed to assess the real time impact of the coronavirus disease 2019 (COVID-19) on the medical conditions of patients with NCDs, their access to health care, and their adaptation to daily life as well as to describe their sources of information on COVID-19 and their needs for specific information and support.

Collaborator: Viatrix

Authors: Pecout C, Pain E, Chekroun M, Champeix C, Kulak C, Prieto R, Van Vugt J, Gilchrist K, Lainé-Pellet AF

[Psychological distress during the first COVID-19 lockdown: vulnerability factors specific to people living with a chronic illness or disability](#)

Published in Issues in Health Economics n°255 – 2021

The impact of the crisis and of the first COVID-19 lockdown in France on mental health has been substantiated by surveys in the general population, which have highlighted the excessive risk of psychological distress among people living with a chronic illness or disability. However, the data from these surveys does not allow the situation of these specific populations to be studied precisely, due to their small number of respondents. To make up for this lack of information and to better understand the mechanisms involved, the choice was made to use an online survey distributed by a social network and by associations for people living with chronic illness or disability.

Collaborator: the Institute for Research and Information in Health Economics (IRDES)

Authors: Gandré C, Espagnacq M, Coldefy M, Radoszycki L, Testa D

2020

[Impact du confinement sur l'activité physique et la qualité de vie dans la polyarthrite rhumatoïde : résultats d'une étude chez 204 patients en France](#)

Publié à la Revue du Rhumatisme – 2020

Il est bien démontré que l'activité physique (AP) a un impact positif sur les patients atteints de polyarthrite rhumatoïde (PR). Or, le confinement prolongé dû au COVID-19 a considérablement limité les possibilités de pratique d'une AP en France. L'objectif principal de cette étude était de décrire et mesurer l'impact du confinement chez les patients atteints de PR sur leur pratique de l'AP et de leur qualité de vie. Un objectif secondaire était d'étudier la prise en charge par le rhumatologue en cette période de confinement.

Collaborateurs : Sanofi Genzyme

Authors: Florence E Lévy-Weil, Sandrine Jousse-Joulin, Vincent Tiffreau, Raymond Perez, Valentin Morisseau, Alexis Bombezin--Domino, René-Marc Flipo

[Perspective of an International Online Patient and Caregiver Community on the Burden of Spasticity and Impact of Botulinum Neurotoxin Therapy: Survey Study](#)

Published in JMIR Public Health and Surveillance – 2020

Patient- and caregiver-reported data are lacking on the burden of spasticity, and the impact of botulinum neurotoxin type A (BoNT-A) treatment for this condition, on patients' daily lives. As recommended in recent guidance from the US Food and Drug Administration, online patient communities can represent a platform from which to gather specific information outside of a clinical trial setting on the burden of conditions experienced by patients and caregivers and their views on treatment options in order to inform evidence-based medicine and drug development. The objective of our study is to characterize spasticity symptoms and their associated burdens on Western European and US patients and caregivers in the realms of work, daily activities, quality of life (QoL), as well as the positive and negative impacts of treatment with BoNT-A (cost, time, QoL) using Carenity, an international online community for people with chronic health conditions.

Collaborator: Ipsen

Authors: Atul T Patel, Theodore Wein, Laxman B Bahroo, Ophélie Wilczynski, Carl D Rios, Manuel Murie-Fernández.

[Understanding Reasons for Treatment Discontinuation, Attitudes and Education Needs Among People Who Discontinue Type 2 Diabetes Treatment: Results from an Online Patient Survey in the USA and UK](#)

Published in Diabetes Therapy – 2020

Type 2 diabetes mellitus (T2DM) requires long-term treatment to achieve and maintain glycaemic control; however, up to 50% of people with T2DM discontinue treatment by 1 year. It is therefore important to understand the patient perspective of therapeutic adherence and persistence. For that we use an online questionnaire was presented to people with T2DM in the USA and UK on PatientLive, a platform of Carenity, an online patient community. Those who discontinued at least one T2DM treatment within the last 6 months answered open-ended questions aimed to assess the reasons for discontinuation, how discontinuation could have been prevented, and what would have improved the experience with the discontinued treatment. Thematic qualitative analysis was performed on respondents' answers to these questions.

Collaborator: Sanofi

Authors: Aude Roborel de Climens, Emilie Pain, Anders Boss and Alka Shaunik.

[Chronic patients' satisfaction and priorities regarding medical care, information and services and quality of life: a French online patient community survey](#)

Published in BMC Health Services Research – 2020

The French healthcare system is evolving to meet the challenges of an aging population, the growing prevalence of chronic diseases, the development of new technologies and the increasing involvement of patients in the management of their disease. The aim of this study is to assess the satisfaction and priorities of chronic patients regarding medical care, information and services and their quality of life.

Collaborator: Medtronic France

Authors: Apolline Adé, Frédérique Debroucker, Laura Delporte, Cécile De Monclin, Emmanuel Fayet, Pierre Legendre, Lise Radoszycki, Michael Chekroun.

[Patient Perspectives on the Therapeutic Profile of Botulinum Neurotoxin Type A in Spasticity](#)

Published in Frontiers in Neurology – 2020

Botulinum toxin-A (BoNT-A) injections are first-line treatment for adult spasticity. Prior patient surveys have reported that BoNT-A treatment improves quality of life but that symptoms usually recur before the next injection. We aimed to explore, in-depth, patient perceptions of the impact of spasticity and the waning of BoNT-A therapeutic effects.

Collaborator: Ipsen

Authors: Jorge Jacinto, Pasquale Varriale, Emilie Pain, Andreas Lysandropoulos and Alberto Esquenazi

[Perception of therapeutic inertia by patients with psoriasis in France](#)

Published in Journal of Dermatology – 2020

Therapeutic inertia (TI), the failure of health-care providers to initiate or intensify therapy when indicated, is caused by the attitude of health-care providers, unlike the concept of poor therapeutic compliance, which is generally attributed to the attitude of the patient who does not follow the proposed prescriptions.

Collaborator: Dr Halioua of the scientific committee

Authors: Bruno Halioua, Jean Zetlaoui, Emilie Pain, Damien Testa, Lise Radoszycki

[Perception of oral corticosteroids in adult patients with asthma in France](#)

Published in Journal of Asthma – 2020

Oral corticosteroids (OCS) are frequently used as relievers for acute asthma and controllers for severe asthma. However, the relief offered by OCS is counterbalanced by adverse effects. We aimed to describe how patients perceive OCS treatment benefits and risks, and how this could affect their adherence to the treatment.

Collaborator: AstraZeneca

Authors: Dany Jaffuel, Caroline Fabry-Vendrand, Elsa Darnal, Ophélie Wilczynski, Emilie Pain & Arnaud Bourdin

[Economic Burden of the Out-of-Pocket Expenses for People with Multiple Sclerosis in France](#)

Published in PharmacoEconomics – Open 2020

People with chronic diseases in France frequently incur out-of-pocket expenses (OOPE) related to their medical care.

Objective: The objective of this study was to evaluate OOPE incurred by people with multiple sclerosis (MS) with respect to direct non-medical and medical expenditure.

Collaborator: Merck

Authors: Heinzlef O, Molinier G, Van Hille B, Radoszycki L, Dourgnon P, Longin J

2019

[Cutaneous neurofibromas: patients' medical burden, current management and therapeutic expectations: results from an online European patient community survey](#)

Published in the Orphanet Journal of Rare Diseases (OJRD) 2019

Neurofibromatosis type 1 is an inherited condition with variable phenotypic expression and a high medical and social burden.

Objectives: The objectives of this patient survey were to better understand the real-world experiences of patients living with cutaneous neurofibromas (cNF), to perceive their satisfaction and feelings about cNF current management (only laser and surgery are currently available), and to highlight their expectations of new therapeutic modalities.

Authors: Guiraud M, Bouroubi A, Beauchamp R, Bocquet A, Grégoire JM, Raully-Lestienne I, Blanco I, Wolkenstein P, Schmitt AM

[Risk behaviour and patient preferences for an improved non-melanoma skin cancer prevention modality for organ-transplanted patients; a European, multi-country, online patient community study](#)

Published in the European Journal of Dermatology (Eur J Dermatol) 2019

Immunosuppressants used in organ transplant patients increase the risk of non-melanoma skin cancer. This study aimed to evaluate patient behaviours towards skin cancer prevention methods and to understand characteristics of a future prevention strategy based on patients' perspective.

Authors: Basset Seguin N, Malveyh J, Nadal F, Creancier L, Raully-Lestienne I, Beauchamp R, Hezareh M, Schmitt AM, Ulianov L

[Patient perceptions of their glycemic control and its influence on type 2 diabetes outcomes: an international survey of online communities](#)

Published in Patient preference and adherence

This study aimed to assess awareness of glycosylated hemoglobin (A1C) testing and targets, perceived level of glycemic control and risk of complications, attitudes toward medications and self-management, and regimen-related distress in an international sample of patients with type 2 diabetes (T2D).

Collaborator: AstraZeneca

Authors: Simacek K, Curran C, Fenici P, Garcia-Sanchez R

[Daily life, needs and expectations of patients with acromegaly in France: An online survey](#)

Published in Annals of Endocrinology

Acromegaly is a chronic acquired disorder characterized by excessive secretion of growth hormone (GH) and increased insulin-like growth factor 1 (IGF-1) level, caused in most cases by a benign pituitary adenoma. Nowadays, its prevalence may vary between 28 to 137 per million people, while its annual incidence ranges between 2 and 11 cases per million inhabitants. To better understand the impact of acromegaly on patients' daily life and evaluate the needs and expectations of patients in terms of services and information, a survey was carried out online in patients or relatives who were registered in a social network of individuals with acromegaly?

Collaborator: IPSEN

Authors: Albarel F, Elaraki F, Delemer B

2018

[Patients' perception of privacy of personal data, shared in online communities: are we in presence of a paradox?](#)

Presented: International Conference on Informatics, Management and Technology in Healthcare (ICIMTH) 2018

Virtual online communities help people in coping with complex health issues, such as those present in patients suffering chronic diseases. Further research is required in order to clarify the impact of sharing of personal experiences on the perception of privacy and confidentiality by patients. We studied the case of Carenity an online social network created in France in 2011 bringing together 300,000 patients across Europe, and selected patients suffering Multiple Sclerosis. We conducted an exploratory-descriptive survey, and 253 patients completed an online questionnaire. Most participants did not consider that their privacy was threatened when sharing their personal experiences and data associated with their health condition. As common sense prevents one to share information to strangers to ensure privacy, such paradox may be explained by new strategies to face challenges imposed by chronic conditions disease, where sharing personal experiences may be considered as a complementary source of social support by patients.

Collaborator: INSERM

Authors: Lamas E, Coquedano C, Bousquet C, Ferrer M, Chekroun M, Zorrilla S, Salinas R

[Adverse Drug Reactions detection on social media: bias and limitation](#)

Presented: PhUSE 2018 – The clinical data science conference

Social media are computer-mediated technologies that facilitate the creation & sharing of information and are an important source for Adverse Drug Reaction (ADR) collection. This can help to reduce under-reporting in postmarketing phase products or monitor drug-specific trends.

In the paper “Patient-generated Health Data (Social Media) is a Potential Source for ADR Reporting” we concluded that the application of social media is subject to challenges because the data are inconsistent, unstructured and region-specific.

In an attempt to solve these challenges, the current paper will focus on the following topics:

- Increasing the number of sources and languages;
- Diversifying and comparing data sources (general social media vs specialized media such as the online patient community Carenity®).

This analysis will provide a better understanding of the collected data, allowing us to estimate biases when working with social media, and will lead to a new field of application: the pharmaco-epidemiology.

Collaborator: Keyrus Biopharma

Authors: Le Covec E, Radoszycki L, Chollet S

[Assessing patients' acceptance of their medication to reveal unmet needs: results from a large multi-diseases study using a patient online community](#)

Published in Health and Quality of Life Outcomes

Patient with chronic conditions are required to take long-term treatments for their disease itself or to prevent any potential health risks. Measuring patient acceptance of their medication should help to better understand and predict patients' behavior toward treatment. This study aimed to describe the level of patient acceptance toward various long-term treatments in real life using an online patient community.

Collaborator: Mapi

Authors: Lambert J, Chekroun M, Gilet H, Acquadro C, Arnould B

2017

[The Meaning of Patient Empowerment in the Digital Age: The Role of Online Patient-Communities](#)

Published in Studies in Health Technology and Informatics

Traditionally, patient empowerment has been used as a strategy for health promotion. The rise of online communities of patients represents a good example of how patient empowerment occurs, independently of the intervention of existing healthcare providers and insurers, allowing thus a more accurate definition of meaning of this concept. We describe two situations related with the development of health-related social networks: (1) The emergence of a new biomedical research model in which patients lead research, shifting the equilibrium of power from the professionals to research subjects themselves, and (2) The emergence of Lay Crowd-Sourced Expertise in these communities, arising from the daily exchange among patients affected by chronic conditions and their relatives, giving place to a new era of bottom-up data generation, previously unknown in biomedical sciences. We enrich these descriptions by analyzing interviews to key actors of these "on line" communities.

Collaborator: Inserm

Authors: Eugenia Lamas, Rodrigo Salinas, Carla Coquedano, Marie-Pierre Simon, Cedric Bousquet, Marcela Ferrer, Sergio Zorrilla

[Defining patient centricity with patients for patients and caregivers: a collaborative endeavour](#)

Published in BMJ Innovations

Patient engagement is an essential aspect in the research/development of biopharmaceutical products and disease management. Patient centricity should be defined as 'Putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome for that person and their family'. Important principles for patients focused on education/information, cocreation, access and transparency. The development of a consistent definition of patient centricity and its associated principles provides an opportunity for biopharmaceutical companies to adopt and use these as a reference point for consistent patient engagement throughout the product life cycle.

Collaborator: AstraZeneca

Authors: Yeoman G, Furlong P, Seres M, Binder H, Chung H, Garzya V, Jones R

[Advantages and limitations of online communities of patients for research on health products](#)

Published by Elsevier Masson

The way patients and their caregivers share information on various online platforms about health topics and their own experiential knowledge presents new potential environments for research, particularly as concerns health products. How patients freely express their experiences and feelings and the reality of what they share also opens the way for societal research into health products, a field that is still under-explored. The round table on this topic endeavoured to: explore these issues and develop a better understanding of the phenomenon and the different varieties of online communities and networks for patients; identify possible advantages, special features, and methodological, regulatory, and ethical limitations that researchers currently face; and finally, to put forward the first recommendations in this growing field of research.

Authors: Ravoire S, Lang M, Perrin E, the participants of Giens XXXII Round Table No. 6, Audry A, Bilbault P, Chekroun M, Demerville L, Escudier T, Guérout-Accolas L, Guillot C, Malbezin M, Maugendre P, Micallef J, Molimard M, Montastruc F, Pierron E, Reichardt L, Thiessard F

2015

[Characteristics and information searched for by French patients with systemic lupus erythematosus: A web-community data-driven online survey](#)

Published in Lupus: SAGE Journals

The aim of this study is to provide information about the needs of patients with systemic lupus erythematosus (SLE) using Carenity, the first European online platform for patients with chronic diseases. At one year after its creation, all posts from the Carenity SLE community were collected and analysed. A focused cross-sectional online survey was performed. This study shows, for the first time, the feasibility of using data from a community of French patients to obtain insights into the needs and sources of information searched for in the context of a specific disease.

Authors: Meunier B, Jourde N, Mancini J, Chekroun M, Retornaz F, Chiche L

Collaborator: Aix Marseille Université, Assistance Publique – Hôpitaux de Marseille, Hôpital Européen Marseille

II. Posters

2023

[Self-reported health status and its predictors among people with diabetes in France](#)

Presented: ISPOR (2023)

In this study, we aimed at measuring self-reported health status in people with diabetes in France and analysed independent risk factors for lower self-reported health status.

Collaborator: Roche Diagnostics International AG

Authors: T. Arnaut, P. Cerletti, J. Laurent, N. Hermanns

[Prevalence and predictive factors of psychological distress among people with diabetes in France](#)

Presented: ISPOR (2023)

High levels of diabetes distress can lead to reduced quality of life and increased likelihood of incident depression. Therefore, relevant factors regarding diabetes distress should be examined explicitly. The aim of this study was to measure the level of diabetes distress in France and analyze potential independent risk factors for elevated diabetes distress. The insights in significant factors can lead to effective treatment approaches and a reduction of diabetes distress and its consequences.

Collaborator: Roche Diagnostics International AG

Authors: P. Cerletti, T. Arnaut, J. Laurent, N. Hermanns

[Patient-Driven Outcome Selection \(PDOS\): a patient-focused approach for selecting outcomes using patient-generated data](#)

Presented: ISPOR (2023)

Patient-Reported Outcomes (PROs) are increasingly used to support the development and the evaluation of health products and services. Due to the wide variety of instruments available, identifying the most suitable Patient-Reported Outcome Measures (PROMs) to use in a specific context might be complex. There is no consensus on a standardized method to choose PROs considering the scientific context and the regulatory recommendations. This research aimed at developing a patient-centric, structured, replicable and generalizable method for PROs selection and development using patient-generated data.

Authors: Lise Radoszycki, Emilie Pain, Cynthia Lesbros, Luis-Alejandro Gonzalez

[Evaluation of healthcare products in diabetes: what are the most important domains for patients?](#)

Presented: DSVR (2023)

Patients' perspectives (quality of life and unmet needs) are more and more considered to evaluate new drugs, medical devices and digital health solutions. In clinical and medical researches, patients' experiences are collected using dedicated instruments (PROs: Patient-Reported-Outcomes).

This research aimed at identifying the most important domains for people with diabetes to optimise and facilitate the selection and development of PROs used for healthcare product evaluation.

Authors: Emilie Pain, Arnaud Fougères, Cynthia Lesbros, Lise Radoszycki

[An innovative patient-centric approach to integrate patients' perspectives in the selection of Patient-Reported Outcomes](#)

Presented: ISPOR (2023)

Patient-Reported Outcomes (PROs) are more and more used to support health products and services development and their evaluation by health authorities. Their identification and selection is thus a critical step in medical research to assess the medical conditions from the patients' perspectives during clinical trials and clinical practices. Nevertheless, due to the wide variety of instruments available, identifying the most suitable PROs to use in a specific context might be complex.

There is no consensus on a standardized method to select PROs considering the medical and scientific context and the regulatory recommendations. Patients' perspectives being and more considered in medical product development and in healthcare decision-making, it appears valuable to take into account their preferences during the PRO selection and development process.

This research thus aimed at developing a patient-centric method for PROs selection and applied it in a pilot study on lung cancer.

Authors: Lise Radoszycki, Emilie Pain, Carine Odouard

2022

[The Lung Cancer Patient Experience and Care Pathway: A Multi-Country Survey](#)

Presented: World Conference on Lung Cancer (2022)

Lung cancer is the second most common malignancy that affects men and women and it is the leading cause of cancer related deaths. Globally in 2020, there were ~2 million new cases of lung cancer and ~1.8 million deaths. Approximately 10-15% of lung cancer cases are classified as small cell lung cancer (SCLC) while the majority of all cases (80-85%) are classified as non-small cell lung cancer (NSCLC). Factors commonly considered (among others) in the determination of NSCLC prognosis include age, performance status, weight loss, and tumor-node-metastasis staging. The 5-year overall survival rate of people living with lung cancer is up to ~90% for those diagnosed with early-stage vs ~63% with localized and ~7% with metastatic disease.

Objective: There is growing evidence that experiences and outcomes of people with lung cancer are impacted not only by treatments, but also by quality of clinical care and supportive resources. For a better understanding of the care pathway differences in people living with cancer and their unmet support needs, we conducted a global survey of people with lung cancer.

Collaborator: Novartis

Authors: Pauline Frank, Andrew Ciupek, Pasquale Varriale, Julie Laurent, Ortal Bar Ziv

[A Real World Study Characterizing Impact of Fatigue and Patient Symptom Recall in Adults with Relapsing Multiple Sclerosis](#)

Presented: Americas Committee for Treatment and Research in Multiple Sclerosis (2022)

Fatigue is among the most frequent and disabling symptoms in patients with relapsing multiple sclerosis (RMS). Patient reported outcomes (PROs) are fundamental to studying fatigue. Questions remain regarding MS fatigue and their impacts, and determining the best time frame for data collection e.g., daily assessments versus recall of fatigue as experienced over a 1- or 2-week interval.

Objective: The study aims to use the FSIQ-RMS in order to measure MS fatigue symptoms and their impact on daily life in a real-world population and to compare fatigue symptom data collected daily for 7 days versus a 7-day recall.

Collaborator: Janssen Global

Authors: Lauren B. Krupp, Thomas Zwingers, Maria Ait-Tihyaty, Gabriela Kanevsky, Ophélie Wilczynski, Eva Katz, Leigh E. Charvet

2021

[Results from a large survey exploring patient preferences for treatment attributes in inflammatory bowel disease across 7 countries in Europe](#)

Presented: UEG Week (2021)

Inflammatory bowel disease, comprising Crohn's disease and ulcerative colitis poses a substantial burden on patient and healthcare systems. Understanding patient preferences through shared decision-making optimizes treatment acceptance and adherence. Discrete choice experiments (DCEs) elicit multi-attribute preferences, thereby quantifying the strength of each preference for healthcare interventions.

Objective: The present study aims to explore patients' preferences for treatment attributes of the currently available advanced therapies.

Collaborator: Takeda

Authors: Gionata Fiorino, Nawal Bent-Ennakhil, Pasquale Varriale, Fiona Braegger, Eveline Hoefkens

[Impact of Cold Agglutinin Disease and its related Fatigue on Patients' Daily Life: an Online Survey among 50 US Patients](#)

Presented: Rare Patient Advocacy Summit (2021)

Cold Agglutinin Disease (CAD) is a rare disease and type of autoimmune hemolytic anemia characterized by autoantibodies that bind to red blood cells at below core body temperature. In addition to cold-induced symptoms, the anemia and hemolysis observed in CAD causes numerous symptoms including fatigue, dizziness, shortness of breath, headaches; reported in very few publications. Disease severity may fluctuate. There is no approved drug for the treatment of CAD.

Objective: The present study aims to assess the impact of CAD and its related effects on patients' daily life..

Collaborator: Sanofi Genzyme

Authors: Patricia Ann McGee Watson, Florence Joly, Lisa Anne Schmitt, Emilie Pain, Damien Testa

[Post-lockdown impact of the COVID-19 pandemic on patients affected by chronic diseases in Europe](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2021)

Patients with Chronic Medical Conditions (CMC) require regular access to healthcare professionals and have to take long-term treatments. The COVID-19 pandemic may affect their clinical outcomes.

Objective: Evaluate the impact of the COVID-19 epidemic on patients with CMC in Europe.

Authors: Alexis Astruc, Bruno Halioua, Jean Zetlaoui, Meryem Harrizi, Alexis Bombezin--Domino, Lise Radoszycki

[Integration of Patient-Reported Outcome Measures in the Evaluation of Digital Health Solutions- Research in Diabetes](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2021)

Although the field of Digital Health Solutions (DHS) for improving outcomes in diabetes has evolved rapidly over the last 20 years, there are still significant challenges in generating relevant evidence and demonstrating the value such solutions bring to patients and the overall health-care value chain.

Objective: This research was conducted to review guidelines from national health authorities regarding patient outcomes to consider in the evaluation of DHS and to determine if existing Patient-Reported Outcome Measures (PROMs) are adequate tools for assessing the value of DHS.

Collaborator: Roche Diabetes Care

Authors: Cerletti P, Van Haelst P, Gyldmark M, Varriale P, Wilczynski O

[Post-Lockdown Impact of the COVID-19 Pandemic on Patients Affected By Chronic Diseases in the United States](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2021)

Patients with Chronic Medical Conditions (CMC) require regular access to healthcare professionals and have to take long-term treatments. The COVID-19 pandemic may affect their clinical outcomes

Objective: The present study aims to assess the first post-lockdown impact of the COVID-19 outbreak on CMC patients living in the United States.

Collaborators: GEM Resopso, Université Sorbonne Paris Nord

Authors: Halioua B, Zetlaoui J, Astruc A, Harrizi M, Bombezin--Domino A, Radoszycki L

[Impact of Cold Agglutinin Disease and Its Related Fatigue on Patients' Daily Life- An Online Survey Among 50 US Patients](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2021)

Cold agglutinin disease is a rare and poorly understood disorder affecting 15% of patients with autoimmune hemolytic anemia. Few studies have assessed CAD symptoms, and its impact on daily life, but they did not address the patients' perspective. To get real-world evidence of the impact that CAD has on the patient's daily life, Carenity conducted an Internet-based survey in September 2020 among patients registered on the CAD Unraveled website and members from the Cold Agglutinin Disease Foundation.

Objective: To assess the impact of Cold Agglutinin Disease (CAD) and its related effects on patients' daily life.

Collaborator: Sanofi Global, Cold Agglutinin Disease Foundation (CADF)

Authors: Schmitt LA, McGee Watson PA, Pain E, Testa D

[Survey to identify patient characteristics, treatment preferences and impact of inflammatory bowel disease \(IBD\) on quality of life across 7 countries in Europe](#)

Presented: 16th European Crohn's and Colitis Organisation (ECCO) Virtual Meeting (2021)

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is characterized by chronic inflammation of the gastrointestinal tract, with no cure currently available. The increasingly complex and diverse treatment paradigm for IBD suggests that along with clinical guidelines, patient engagement through shared decision-making engages patients in treatment decisions and optimizes the chance of a chosen therapy matching their personal preferences. Adequate information and fair presentation of the trade-off between the risks and benefits of treatment are critical for patients' participation in medical decisions.

Objective: This patient survey aimed to describe the demographics and clinical characteristics of respondents and patient-rated preferences towards existing treatment options and impact on quality of life (QoL); here, we present patient demographics, clinical characteristics, and impact of IBD on QoL.

Collaborators: Takeda Pharmaceuticals International, Humanitas University, Imelda Hospital

Authors: Fiorino G, Bent-Enakhil N, Varriale P, Braegger F, Hoefkens E

[Measuring the symptoms and impacts of fatigue in adults with relapsing multiple sclerosis using a novel disease specific scale](#)

Presented: European Academy of Neurology (EAN) Congress Virtual Meeting (2021)

Fatigue is among the most frequent and disabling symptoms in patients with relapsing multiple sclerosis (RMS) and a main cause of impaired health-related quality of life. Fatigue is defined by subjective experience and measured via patient reported outcome (PRO) instruments. However, previously available PROs that assess MS-related fatigue do not meet instrument development and psychometric property requirements based on current guidelines. PRO tools that are MS-specific can improve understanding of MS fatigue and its impact, improving its clinical management. Fatigue Symptoms and Impacts Questionnaire - Relapsing Multiple Sclerosis (FSIQ-RMS), a novel MS-specific PRO instrument, was developed to assess both fatigue in patients with RMS and its impacts on physical activity, cognitive and emotional function and coping mechanisms.

Objective: The study was aimed at measuring MS fatigue symptoms and their impact on daily life in a real-world population using a self-administered online questionnaire including the RMS-specific FSIQ-RMS

Collaborators: Janssen Global, NYU Langone Health

Authors: Wilczynski O, Katz E, Charvet L, Krupp L, Schuier M, Lair L

[Measuring the symptoms and impacts of fatigue in adults with relapsing multiple sclerosis using a novel disease specific scale: A real-world study in US population](#)

Presented: Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) 2021

Multiple Sclerosis (MS) is a chronic autoimmune inflammatory disease of the central nervous system. It affects more than 700,000 people in Europe, and is one of the most common causes of neurological disability in young and middle-aged adults, with females up to three times more frequently impacted than males. While prevalence varies worldwide, it is highest in Europe and North America. The disease is characterized by demyelination and axonal loss leading to neurological impairment and severe disability. Relapsing forms of MS include clinically isolated syndrome, relapsing-remitting MS (which makes up 85 percent of all MS cases), and secondary progressive MS. In addition to the debilitating neurological symptoms of the disease, patients often also suffer from “hidden symptoms,” namely fatigue and depression, both of which are major contributors to reduced quality of life. Fatigue is one of the most common symptoms of MS, occurring in about 80 percent of patients.

Objective: To measure multiple sclerosis (MS) fatigue and its impact on daily life in a real-world population using a survey including the relapsing MS (RMS)-specific Fatigue Symptoms and Impacts Questionnaire-Relapsing Multiple Sclerosis (FSIQ-RMS).

Collaborators: Janssen Global, NYU Langone Health

Authors: Lair L, Tiphaine Lévy-Heidmann T, Morisseau V, Jamieson C, Charvet L, Krupp L, Azoulay M

2020

[Concordance between Patient and Clinician Perspectives of Health-Related Quality of Life \(HRQoL\) Management in Clinical Practice in France](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2020

Although long-term monitoring of symptoms and HRQoL is associated with survival in cancer patients, HRQoL assessment in clinical practice is suffering from a lack of a standardised approach and from logistical constraints.

Objective: This post-hoc analysis compared patient and clinician perspectives of HRQoL management among cancer patients.

Collaborator: Bristol-Myers Squibb

Authors: V. Westeel, M. Bourdon, A.B. Cortot, D. Debieuvre, A.C. Toffart, M. Acquadro, B. Arnould, J. Lambert, A. Boisbouvier, L. Radoszycki, O. Wilczynski, F.E. Cotte, A.F. Gaudin, H. Lemasson

[Impact of botulinum toxin A 'wearing-off' on quality of life in patients with cervical dystonia](#)

Presented: International Association of Parkinsonism and Related Disorders (IAPRD) 2020

Botulinum neurotoxin type A (BoNT-A) is an effective pharmacological treatment for the management of cervical dystonia (CD) that requires repeated administration at variable intervals.

Objective: Understand the patient perspective on the impacts of botulinum neurotoxin-A (BoNT-A) 'wearing-off' (waning of therapeutic effect) on daily function and quality of life (QoL).

Collaborator: Ipsen

Authors: J. Ferreira, C. Comella, M. Azoulay, E. Pain, S. Om

[Using unsupervised clustering analysis of real life data from an online community to identify lupus patients' profiles regards to their treatment preferences](#)

Presented: European Alliance of Associations for Rheumatology (EULAR) 2020

Lupus is a prototype of a chronic complex autoimmune disease. Non-adherence rate to treatment is surprisingly high and impairs its management. Adherence to drug treatment is a complicated and multifactorial phenomenon, including characteristics of treatment.

Objective: This study used unsupervised clustering analysis to identify profiles among lupus patients with regards to their treatment preferences (apart from efficiency).

Authors: D. Testa, V. Morisseau, L. Radoszycki, I. Anfray, L. Chiche

[Patients knowledge on microbiota and acceptability of fecal microbiota transplantation in various chronic diseases](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR US) 2020

Gut microbiota is now considered a key player in human health. Despite increasing media exposure, patients' knowledge on microbiota has never been assessed.

Objective: We evaluated, in various chronic diseases, patient knowledge of microbiota and the acceptability of fecal microbiota transplantation (FMT) via an online patient community using an established approach.

Authors: N. Benech, L. Radoszycki, C. Fidyk, P. Varriale, H. Sokol

[Patient treatments preferences: how to identify patient profiles directly from online real-life data? Application to lupus.](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR US) 2020

A patient's view on and subsequent compliance may vary depending on the pathology, treatment constraints, and patient profile. Thus, selecting a treatment that best fits a patient's profile and preferences could encourage better compliance.

Objective: To identify patient profiles sharing similar expectations through a Multiple Correspondence Analysis (MCA) associated with unsupervised clustering methods.

Authors: Testa D, Morisseau V, Radoszycki L, Fidyk C, Chiche L

[Impact of spasticity and waning of effect of botulinum toxin A \(BoNT-A\) treatment on patients' employment and quality of life: results of a multinational online survey](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR US) 2020

Botulinum toxin-A (BoNT-A) injections are first-line treatment for adult spasticity. Prior patient surveys have reported that BoNT-A treatment improves quality of life but that symptoms usually recur before the next injection.

Objective: Present the self-reported impact of spasticity and waning of effect of Botulinum Toxin A (BoNT-A) treatment on patients' quality of life (QoL) and employment status.

Collaborator: Ipsen

Authors: A. Esquenazi, J. Jorge, P. Varriale, E. Pain, A. Lysandropoulos

[The Role of Real World Evidence in Health Technology Assessment over Time: A Research on the French Situation](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2020

Real-World Evidence (RWE) is more and more recognized as a valuable source of evidence and has been a growing focus of Health Technology Assessment (HTA) in the past few years. The HTA body in France is called the Haute Autorité de Santé (HAS) (National Authority for Health) and commissions the Transparency Committee to evaluate post-registration studies.

Objective: The ongoing research aims at describing the current role of post-registration studies in the HTA process and the evaluation of those studies in France.

Authors: Radoszycki L, Wilczynski O, Avril C

[Impact of the COVID-19 Pandemic on Patients with Immune-Mediated Inflammatory Diseases Taking a Biologic Therapy](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2020

The COVID-19 pandemic has shone a light on the vulnerability of people living with pre-existing immune-mediated inflammatory diseases (IMID) and taking a biologic therapy.

Objective: The present study aims to evaluate the impact of the COVID-19 outbreak on the medical consultations, biologic treatment modifications and access to treatment-specific information of IMID patient taking a biologic therapy.

Collaborator: Dermatology Center, GEM Resopso, University Sorbonne Paris Nord

Authors: Halioua B, Zetlaoui J, Astruc A, Testa D, Bombezin-Domino A, Radoszycki L

[Impact of the COVID-19 Pandemic on Patients Affected By Chronic Diseases in Europe](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2020

Patients with chronic medical conditions (CMC) require regular access to healthcare professionals and have to take long-term treatments. The coronavirus (COVID-19) may affect their clinical outcomes.

Objective: The present study aims to assess the impact of the COVID-19 outbreak on adult patients with CMC living in Europe.

Collaborator: Dermatology Center, GEM Resopso, University Sorbonne Paris Nord

Authors: Halioua B, Zetlaoui J, Astruc A, Lévy-Heidmann T, Testa D, Bombezin-Domino A, Radoszycki L

[Patient Perceptions and Expectations Towards the Role of Rheumatologists in the Recommendations of Physical Activity Practice – A Cross-sectional Study Involving 308 Patients Living with Rheumatoid Arthritis in France](#)

Presented: American College of Rheumatology (ACR) Convergence 2020

Rheumatologists consider physical activity (PA) to be an important goal of the care of patients with rheumatoid arthritis (RA). However, there are very few studies on patients' perceptions of and expectations on the rheumatologist's role in PA participation counselling.

Objective: Describe RA patients participation in PA and their perception of rheumatologist recommendations to engage in PA

Collaborator: Sanofi Genzyme France

Authors: Anne-Christine Rat, Arnaud Constantin, Catherine Beauvais, Yannick Guillodo, Valérie Guay, Emilie Pain, Alexis Bombezin-Domino, Florence E Lévy Weil

[Real-world study of the impact of the Covid-19 pandemic on patients with psoriasis](#)

Presented: 29th European Academy of Dermatology and Venereology (EADV) Congress (2020)

This study was made during the outbreak of coronavirus disease 2019 (COVID19) pandemic known as COVID-19. The virus has spread over 200 countries, affecting more than 35 million people and causing over than 1 000 000 deaths. Consequences have arisen for the clinical outcomes of patients with psoriasis as well as obstacles to regular access to healthcare and taking long-term medications.

Objective: Evaluation of the impact of the COVID-19 outbreak on patients with psoriasis using an online patient community.

Collaborator: Scientific committee

Authors: B. HALIOUA, J. ZETLAOUI, R. KANENGIESER, E. PAIN, T. LÉVY-HEIDMANN, L. RADOSZYCKI

[Oncologists' consideration of Health related quality of life in clinical practice for Immune-Checkpoint Inhibitors-treated patients: an online patients community research](#)

Presented: European Society for Medical Oncology Immuno-Oncology Congress 2019

Preserving the health related quality of life (HRQoL) of cancer patients is a major goal of clinicians and health authorities. Routine monitoring of PROs in daily clinical practice has demonstrated improvements in symptom management, patient satisfaction with care, levels of supportive care use, clinician/patient communication, HRQoL and overall survival. The study objective was to describe patients' experience and expectations regarding HRQoL, in particular in their relationship with oncologists/radiotherapists.

Objective: The study objective was to describe patients' experience and expectations regarding HRQoL, in particular in their relationship with oncologists/radiotherapists

Collaborator: Bristol-Myers Squibb France

Authors: Wilczynski O, Boisbouvier A, Radoszycki L, Cotte F-E, Gaudin A-F, Lemasson H

2019

[Health-related quality of life \(HRQoL\) in clinical practice for immune-checkpoint inhibitors \(ICI\)-treated patients: what are French patients' experiences and expectations? Results from an online patient community research](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2019

Preserving the health related quality of life (HRQoL) of cancer patients is a major goal of clinicians and health authorities. By providing patients with a survival benefit and a better tolerance profile compared to therapeutic standards, immune-checkpoint inhibitors (ICI) treatment has become a therapeutic alternative in many tumor types. While the feasibility of collecting ICI-related symptom and HRQoL data is the subject of various studies, to understand patients' and HCPs' behaviors and expectations regarding HRQoL management in routine clinical practice becomes essential.

Objective: The study objective was to describe ICI-treated patients' experiences and expectations regarding HRQoL consideration in cancer management.

Collaborator: Bristol-Myers Squibb (BMS)

Authors: Wilczynski O, Boisbouvier A, Radoszycki L, Cotte F-E, Gaudin A-F, Lemasson H

[Study on the therapeutic adherence by patients with psoriasis in France: a study of 181 patients](#)

Presented: European Academy of Dermatology and Venereology (EADV) 2019

Medication adherence is an important challenge when treating psoriasis that requires a long-term management to induce and maintain clinical remission. Low adherence to therapies in psoriasis decreases treatment outcomes and increases the total healthcare costs. A majority of treatment failures may also be attributed to poor adherence to medications.

Objectives: The aim of this study was to determine the prevalence of adherence and to identify specific factors, which can impact medication adherence in patients with psoriasis.

Authors: Halioua B, Zetlaoui J, Pain E, Radoszycki L, Testa D

[Patients' perceptions and experiences of biologic therapies for psoriasis in France](#)

Presented: European Academy of Dermatology and Venereology (EADV) 2019

Some patients with moderate to severe psoriasis do not respond or cannot be treated with conventional systemic drugs. The development of biological agents targeting tumor necrosis factor alpha (TNF α), interleukin (IL)-17, IL-12 and IL-23 revolutionized the management of those patients. Yet, treatment dissatisfaction and non-adherence are common among patients with psoriasis. There is scarce data in France about patients' perceptions and experiences with biologic therapies for psoriasis.

Objectives: The objective of this study was to describe patients' perceptions and experiences with psoriasis in France, addressing communication with physicians, satisfaction with biologics and concerns regarding treatment options.

Authors: Halioua B, Zetlaoui J, Pain E, Radoszycki L, Testa D

[Use and impacts of cannabis for therapeutic purposes in patients with multiple sclerosis in France and Spain: results from an online patient community study](#)

Presented: European Committee for Treatment and Research In Multiple Sclerosis (ECTRIMS) 2019

In France, the possession and use of cannabis is a penal offence. In Spain, legislation allows the consumption and cultivation of cannabis in private. Some cannabis-based pharmaceutical products, such as Nabiximols, have marketing authorisation in both countries but are only available to patients in Spain. The objective of this study were (1) to better understand the use of cannabis for therapeutic purposes by patients with multiple sclerosis (MS), (2) to evaluate its impact on MS symptoms and (3) to compare the results in France and Spain, two countries with different legislations.

Authors: Legendre P, Testa D, Chatenet J, Radoszycki L, Verjus T

[Treatment acceptability and patients' expectations regarding arterial hypertension: results from an online European patient community pilot survey](#)

Presented: European Society of Hypertension (ESH) 2019

Arterial hypertension is highly prevalent in developed countries and it is a major cardiovascular risk factor and a major contributor to mortality. Patients are often required to take several antihypertensive medications and about half of patients have uncontrolled blood pressure. The aim of the study is to better understand patient's perception of arterial hypertension, difficulties regarding their treatment and expectations to improve their adherence.

Collaborator: Servier

Authors: Mourad J-J, Antakly Y, Wilczynski O

[Rheumatoid arthritis and ankylosing spondylitis clinical trials: how to encourage patient participation? Results from a real-world study conducted via Carenity, a worldwide online patient community.](#)

Presented: European League Against Rheumatism (EULAR) Congress 2019

Involving patients affected with rheumatoid arthritis (RA) or ankylosing spondylitis (AS) in clinical trials may be highly challenging: in a worldwide context of competitive clinical research, patient engagement is key to optimize medical research and increase participation rates. The objectives of the study is to identify patients' motivations for and hindrances to joining a trial in order to increase participation rate by implementing tailored services and information.

Authors: Gauchoux R, Boisbouvier A, Dos Santos R, Radoszycki L

[Burden of spasticity among patients and caregivers: results of a multinational survey](#)

Presented: TOXINS 2019

Spasticity is caused by an upper motor neuron lesion leading to intermittent or sustained involuntary activation of muscles, and is a symptom of various disorders, including multiple sclerosis (MS), stroke, traumatic brain or spinal cord injury and cerebral palsy. The aim of this study is to understand the burden of spasticity treatment from patient and caregivers perspectives, in terms of impact on employment status, activities of daily living and quality of life.

Collaborator: Ipsen

Authors: Patel A, Wein T, Bahroo L, Wilczynski O, Rios C, Murie-Fernandez M

[Fewer injections of botulinum toxin type A for treatment of spasticity are perceived as beneficial by both patients and caregivers.](#)

Presented: TOXINS 2019

Botulinum toxin type A (BoNT-A) is a recommended pharmacological option for patients with spasticity, and its anti-spastic effects have been demonstrated in stroke and central nervous system lesions, multiple sclerosis and cerebral palsy. The aim of this study is to understand the impact of fewer BoNT-A injections from patient and caregiver perspectives.

Collaborator: Ipsen

Authors: Wein T, Patel A, Bahroo L, Wilczynski O, Rios C, Murie-Fernandez M

[The patients' perspective on botulinum neurotoxin A treatment: results of a multinational survey for patients with spasticity.](#)

Presented: TOXINS 2019

Management strategies for adult spasticity include physical and pharmacological therapies, as well as surgery in severe or intractable cases. Botulinum toxin type A (BoNT-A) is a recommended pharmacological option for patients with spasticity, and its anti-spastic effects have been demonstrated in stroke and central nervous system lesions, multiple sclerosis and cerebral palsy. The aim of this study is to understand the burden of BoNT-A treatment from the patient perspective, in terms of impact on activities of daily living and quality of life.

Collaborator: Ipsen

Authors: Bahroo L, Patel A, Wein T, Wilczynski O, Rios C, Murie-Fernandez M

2018

[MS patients' perception of the effects of PR-fampridine on walking disorders and daily life: results from an observational study conducted via an online community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

Multiple Sclerosis (MS) is a neurodegenerative disease frequently causing walking impairment. Prolonged-release PR-fampridine (dalfampridine extended-release in US) is approved for the improvement of gait function in MS patients with walking disability (Expanded Disability Status Scale 4-7). Fampridine targets the underlying neurological causes of MS walking impairment through modification of neurotransmission in the CNS and can be used in patients with any subtype of MS. The study aims at observing how patients' daily life evolved following the prescription of PR-fampridine.

Collaborator: Biogen

Authors: Simon O, Wilczynski O, Khalil J

[Walking disorders in MS: how do they impact patients' quality of life? Results from an observational study conducted via an online patient community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

Multiple Sclerosis (MS) is a neurodegenerative disease, characterized by inflammation leading to demyelination and axonal loss. Symptoms of MS such as spasticity, loss of balance or muscle weakness may progressively lead to irreversible disabilities, greatly impacting patients' overall quality of life. Nearly half (45%) of patients reported experiencing mobility difficulties within a month of diagnosis and nearly all patients (93%) report difficulties within 10 years. The objectives are to assess the impact of walking disability on MS patients' quality of life and to identify patients' expectations regarding walking impairment.

Collaborator: Biogen

Authors: Simon O, Wilczynski O, Khalil J

[What are the most valued patient outcomes regarding medical care for French patients with type 1 diabetes? Results from an online patient community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

In 2015, there was approximately 370 000 type 1 diabetic patients in France. The ageing population and financial constraints have put a great strain on the French healthcare system. Value-based healthcare (VBHC) is emerging as a possible solution to build a more efficient healthcare system. The objectives are to define and rank the most valued outcomes in medical care for patients affected by type 1 diabetes (T1D) and to better understand patients' expectations for healthcare organizations and patient support services.

Collaborator: Medtronic

Authors: Debroucker F, Delporte L, Ullmann E

[What are the most valued patient outcomes regarding medical care for French patients with heart failure? Results from an online patient community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

More than 1 million people were suffering from heart failure (HF) in France in 2017. The ageing population and financial constraints have put a great strain on the French healthcare system. Value-based healthcare (VBHC) is emerging as a possible solution to build a more efficient healthcare system. The objectives are to define and rank the most valued outcomes in medical care for patients affected by heart failure and to better understand patients' expectations for healthcare organizations and patient support services.

Collaborator: Medtronic

Authors: de Monclin C, Debroucker F, Ullmann E

[What are the most valued patient outcomes regarding medical care for French patients with obesity? Results from an online patient community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

Obesity affected approximately 6.9 million of French adults in 2012. The ageing population and financial constraints have put a great strain on the French healthcare system. Value-based healthcare (VBHC) is emerging as a possible solution to build a more efficient healthcare system. The objectives are to define and rank the most valued outcomes in medical care for patients affected by obesity and to better understand patients' expectations for healthcare organizations and patient support services.

Collaborator: Medtronic

Authors: Debroucker F, Fayet E, Ullmann E

[Dramatic improvement in treatment acceptance observed in patients with Multiple Sclerosis switching treatment: a real-world study](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR EU) 2018

Most chronic conditions require the patients to take long-term treatments. Lack of adherence and persistence are major barriers to optimal treatment benefit. Patients' behaviour and attitude towards their treatment are hypothesised to result from their complex evaluation of the risk-benefit ratio of their treatment. Measuring patients' acceptance of their medication may help better understand and predict patients' behaviour towards treatment. Patients with Multiple Sclerosis (MS) are prescribed long-term treatments to slow the progression of their chronic disease. Important unmet needs are still voiced by patients. Frequent treatment discontinuation and switching are reported in studies as disease modified therapies in MS patients. In recent years, new MS and Central Nervous System (CNS) treatments have been put on the market with the aim of addressing unmet needs. The objective of this study is to evaluate the impact of treatment change on the level of acceptance of medication in patients with Multiple Sclerosis (MS), in real life.

Collaborator: ICON

Authors: Vilcot T, de Bock E, Chekroun M, Arnould B

[How can Acceptance Measurement Help Understanding Patients' Concerns and Working on Solutions? \(Crohn's Disease, COPD, Osteoarthritis\)](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR US) 2018

Patients with chronic disease are generally required to take long-term treatments to treat their illness and avoid complications. However lack of adherence is very common and represents major barriers to treatment efficiency. The objectives of this study are to evaluate the level of acceptance to medication in chronic diseases patients (Crohn's disease, chronic obstructive pulmonary disease, Osteoarthritis) in real life; to identify issues and to define priorities for action. Treatment acceptance is not satisfactory in chronic disease patients. General acceptance is mainly driven by patients' perceived treatment effectiveness, side effects and long term use while socio-demographical and clinical characteristics have a minor contribution. These findings indicate patients' priorities and unmet needs; however, they must be confirmed using longitudinal data.

[Adherence issues in Crohn's Disease](#)

[Adherence issues in Chronic Obstructive Pulmonary Disease \(COPD\)](#)

[Adherence issues in Osteoarthritis](#)

Collaborator: Mapi

Authors: Wiederkehr S, de Bock E, Chekroun M, Arnould B

[How do Transplanted Patients manage their risk of Non Melanoma Skin Cancer?](#)

Presented: European Association of Dermato Oncology (EADO)

While organ transplants greatly improve patients' quality of life, transplant patients must nonetheless take immunosuppressive drugs to prevent organ rejection. Thus, new risks emerge, including a higher chance of developing non-melanoma skin cancer (NMSC). The objectives of the study were to describe characteristics of patients with and without skin lesions and to better understand the skin monitoring after organ transplant.

Collaborator: Pierre Fabre

Authors: Basset Seguin N, Malveyh J, Ulianov L, Condomines M, Beauchamp R, Dos Santos R

[Patients' behavior and risk perception of non-melanoma skin cancer after organ transplant: what are patients' expectations for new preventive treatments?](#)

Presented: European Association of Dermato Oncology (EADO)

While organ transplants greatly improve patients' quality of life, transplant patients must nonetheless take immunosuppressive drugs to prevent organ rejection. Thus, new risks emerge, including a higher chance of developing skin cancer. The objectives of the study were to better understand the organ transplant patients' behaviors regarding non-melanoma skin cancer (NMSC) risk and to define patients' expectations regarding a new treatment to prevent NMSC lesions.

Collaborator: Pierre Fabre

Authors: Malveyh J, Basset Seguin N, Ulianov L, Condomines M, Beauchamp R, Dos Santos R

[Multiple sclerosis clinical trials: how to encourage patient participation? Results from a patient study conducted by Carenity.com – A worldwide online patient community.](#)

Presented: European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS)

Multiple sclerosis (MS) clinical research is in a worldwide competition. Patient engagement is key to optimize medical research and increase participation rate. Identify levers to improve patients' motivations to join a clinical trial and identify hindrances to their enrolment in order to better communicate and increase participation rate.

Authors: Dos Santos R, Radoszycki L, Chekroun M

2017

[How can Acceptance Measurement Help Understanding Patients' Concerns and Working on Solutions? \(Diabetes Treatment, Multiple Sclerosis, Rheumatoid Arthritis\)](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2017

Patients with chronic disease are generally required to take long-term treatments to treat their illness and avoid complications. However lack of adherence is very common and represents major barriers to treatment efficiency. The objectives of this study are to evaluate the level of acceptance to medication in chronic diseases patients (Multiple Sclerosis, Diabetes and Rheumatoid Arthritis) in real life; to identify issues and to define priorities for action. Treatment acceptance is not satisfactory in chronic disease patients. General acceptance is mainly driven by patients' perceived treatment effectiveness, side effects and long term use while socio-demographical and clinical characteristics have a minor contribution. These findings indicate patients' priorities and unmet needs; however, they must be confirmed using longitudinal data.

[Adherence issues in Diabetes Treatment](#)

[Adherence issues in Multiple Sclerosis](#)

[Adherence issues in Rheumatoid Arthritis](#)

Collaborator: Mapi

Authors: Wiederkehr S, de Bock E, Chekroun M, Arnould B

[French patients with MS and their caregivers have to financially support direct non-medical costs linked to their disease](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2017

The objectives of this study were to assess the out of pocket for MS patients and to measure the impact of MS on the patient quality of life. This survey presents the perception by patients with MS and their relatives of the indirect costs of the disease. The results indicate that, although MS is a long-term condition supported by health insurance, this pathology generates significant indirect costs for patients and their relatives every month. MS also has an impact on the daily lives of patients and caregivers, which involves indirect costs.

Collaborator: Merck, Hôpital de Poissy, IRDES, Ligue Française contre la Sclérose en Plaques

Authors: Van Hille B, Heinzlef O, Dourgnon P, Molinier G, Chekroun M, Longin J

[Accurate representation of patients' opinions for decision making: are online health communities good candidates?](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2017

The development of online patient communities worldwide has prompted questions about their ability to collect reliable information for a deeper understanding of patients' health experiences and unmet needs. The goal of this research is to analyse the key socio-economic characteristics of patient communities' users, examine their correspondence with national patients' demographics and provide guidance on whether or not weighting schemes should be considered for patients' communities' samples of users. Health communities provide a new service for a swift collection and analysis of patient-reported outcomes in a real-world setting.

Collaborator: Hospinnomics (Paris School of Economics and Assistance Publique – Hôpitaux de Paris)

Authors: Rais S, Radoszycki L, Dourgnon P, Rochaix L, Chekroun M

2016

[Patients' acceptance and adherence of their medication: results from a European multi-disease study with online patient community](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2016

This study aimed at evaluating the level of acceptance and adherence for various chronic diseases in real life using Carenity, a patient online community in five languages. Measuring patients' acceptance of their medication can help better understand and predict patients' behaviour towards treatment. All patients connecting to the Carenity platform were invited to complete an online questionnaire including: questions on demographics, chronic disease and medication, the ACCEPT® questionnaire and the MMAS-8® Questionnaire. Acceptance and adherence are two different but related constructs. While adherence assesses behaviour toward treatment, acceptance explains and partially predicts behaviour. This relationship is complex and varies across diseases.

Collaborator: Mapi, UCLA Fielding School of Public Health (Department of Community Health Sciences)

Authors: Elodie de Bock, Michael Chekroun, Donald E. Morisky, Benoit Arnould

2014

[Patients' acceptance of their medication: Results from a French multi-diseases study with patient online community using the ACCEptance by the Patients of their Treatment \(ACCEPT©\) questionnaire](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2014

According to the World Health Organization, about 50% of patients with chronic diseases do not strictly follow their prescriptions of long-term treatments in developed countries. These lacks of adherence and persistence can be major barriers to treatment efficiency in real world, for many chronic diseases. The generic ACCEptance by the Patients of their Treatment (ACCEPT) questionnaire was developed to measure patients' acceptance of their medication. The objective of this study was to evaluate for a variety of chronic diseases the level of patients' acceptance of their medication in real life using Carenity, a patient online community.

Collaborator: Mapi

Authors: Gilet H, Chekroun M, Arnould B

2013

[Patient network as a data-source for pro research. Carenity experience](#)

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2013

To explore the potential of online patient networks (PN) as a viable source of PRO data for clinical research. Several PNs have emerged in the last few years in different European countries, and as a natural meeting point for chronic patients they represent a promising source of patient reported data. In this poster, the experience with the French PN "carenity.com" is described. Results show differences in the expected direction, backing the validity of the data collected from this source.

Collaborator: Laser Analytica

Authors: Nacho Castejón, Chekroun M, Martínez García J, Gay CH, Rebollo P

III. Posters in French

2023

[Patients ayant un diabète type 1 : données sur l'organisation et le vécu de la transition de la pédiatrie à la diabétologie d'adultes : Observatoire Transition 1](#)

Présenté au congrès de de la Société Francophone du Diabète (SFD) (2023)

Le diabète est devenu un problème de santé publique important qui touche 60 millions de personnes en Europe, dont 10% sont touchées par le DT1, et la moitié de ces cas surviennent avant l'âge de 20 ans. Actuellement, en France, l'incidence du diabète de type 1 est d'environ 19 cas pour 100 000 enfants de moins de 15 ans. Pour les adolescents et les jeunes adultes, la transition de la pédiatrie à la diabétologie d'adultes constitue une étape importante où il faut maîtriser le risque de rupture de suivi. Il s'agit notamment d'assumer la prise en charge autonome du diabète, de travailler avec les nouveaux professionnels de santé (PDS) de soins adultes et tout en gérant les problématiques psychosociales concomitantes.

Objectifs : Cette étude vise à décrire le processus de la transition de la pédiatrie à la diabétologie d'adultes du point de vue du patient et à mesurer/comprendre le vécu des patients (difficultés personnelles et satisfaction liées à leur expérience pendant la transition).

Collaborateur: Sanofi/Alcimed

Auteurs : Eroukhmanoff J, Ballot Schmit C, Baron S, Bahloul A, Beltrand J, Borot S, Dalla Vale F, Mosnier Pudar H, Nicolino M, Ammar H, Salame Z, Penfornis A, Renard E

2021

[Étude en vie réelle de l'impact de l'épidémie de COVID 19 sur les patients atteints de maladies chroniques](#)

Présenté au: Collège national des généralistes enseignants (CNGE) 2021

La pandémie de coronavirus (COVID 19) est l'une plus grandes crises sanitaires mondiales depuis près d'un siècle. Celle-ci a eu des conséquences majeures sur l'état de santé des patients, plus à risque de développer des formes graves ou de décéder du COVID 19 que la population générale.

Objectifs: Évaluer l'impact de l'épidémie de COVID 19 sur les patients chroniques à l'aide d'une communauté de patients en ligne.

Collaborateur : Université Sorbonne Paris Nord

Auteurs : Alexis Astruc, Bruno Halioua, Jean Zetlaoui, Ophélie Wilczynski, Tiphaine Lévy Heidmann, Lise Radoszycki

[Impact post déconfinement de la pandémie de COVID 19 sur les patients chroniques en Europe](#)

Présenté au : Présenté au Journées Nationales d'Infectiologie (JNI) 2021

L'ampleur de la pandémie de COVID 19 et l'isolement qui en a résulté pourraient avoir des conséquences majeures sur l'état de santé des patients atteints de maladies chroniques. Ces patients particulièrement à risque ont besoin de contacts réguliers avec les professionnels de santé et doivent prendre des traitements au long cours. La pandémie peut perturber leurs soins.

Objectifs : Cette étude vise à évaluer l'impact de la pandémie de COVID 19 sur les patients atteints de maladie chronique vivant en Europe, à la fin du 1er confinement.

Auteurs : Astruc A, Halioua B, Zetlaoui J, Harrizi M, Bombezin Domino A, Radoszycki L

[Impact post déconfinement de la pandémie de COVID 19 sur les patients chroniques en France](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2021)

L'ampleur de la pandémie de COVID 19 et l'isolement qui en a résulté pourraient avoir des conséquences majeures sur l'état de santé des patients atteints de maladies chroniques. Ces patients particulièrement à risque ont besoin de contacts réguliers avec les professionnels de santé et doivent prendre des traitements au long cours. La pandémie peut perturber leurs soins.

Objectifs : Cette étude vise à évaluer l'impact de la pandémie de COVID 19 sur les patients atteints de maladie chronique vivant en France, à la fin du 1er confinement.

Auteurs : Astruc A, Halioua B, Armand L, Danès L, Bombezin Domino A, Radoszycki L

[La prise en compte des données de vie réelle dans l'évaluation des technologies de santé : analyse des études post inscription en France](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2021)

Les données de vie réelle sont de plus en plus reconnues comme une source d'information essentielle et complémentaire aux études cliniques et ont fait l'objet d'une attention croissante dans l'évaluation des technologies de la santé (ETS) au cours des dernières années.

Objectifs : Décrire le rôle des études post inscription dans le processus d'ETS et décrire l'évolution des études post-inscription en France.

Auteurs : Wilczynski O, Radoszycki L, Avril C

Observance et iatrogénie: expérience des patients atteints de troubles psychiques

Présenté au congrès de l'Encéphale (2021)

Les troubles psychiatriques occupant une place majeure au sein des Maladies Non Transmissibles (MNT), leur prévention et la diminution de leur progression sont des défis majeurs. Environ 14% de la charge de morbidité mondiale a été attribuée aux troubles psychiatriques, principalement en raison de leur nature chroniquement invalidante. Les traitements pharmacologiques sont une stratégie coût efficace majeure pour aller vers la guérison ou la restauration fonctionnelle des pathologies psychiatriques.

Objectifs : Mieux comprendre le vécu des patients présentant des troubles psychiques, notamment dans le domaine de leurs attitudes et leurs connaissances des risques et bénéfices de leur traitement afin de mieux appréhender leur perception de l'adhésion thérapeutique et du risque iatrogénique.

Collaborateur : Viatrix

Auteurs : Courtet P, Azoulay M, Morisseau V, Levy-Heidmann T, Pecout C

2020

Étude en vie réelle de l'impact de l'épidémie de COVID 19 sur les patients atteints de maladies chroniques

Présenté au : Congrès Médecine Générale France (CMGF) 2020

La pandémie de coronavirus (COVID 19) est l'une plus grandes crises sanitaires mondiales depuis près d'un siècle. Celle-ci a eu des conséquences majeures sur l'état de santé des patients, plus à risque de développer des formes graves ou de décéder du COVID 19 que la population générale.

Objectifs : Évaluer l'impact de l'épidémie de COVID 19 sur les patients chroniques à l'aide d'une communauté de patients en ligne.

Collaborateur : Université Sorbonne Paris Nord

Auteurs : Alexis Astruc, Bruno Halioua, Jean Zetlaoui, Ophélie Wilczynski, Tiphaine Lévy Heidmann, Lise Radoszycki

[Impact du confinement sur l'activité physique et la qualité de vie dans la polyarthrite rhumatoïde – Résultats d'une étude chez 204 patients en France](#)

Présenté au 33e congrès de la Société Française de Rhumatologie (SFR) 2020

Il est bien démontré que l'activité physique (AP) a un impact positif sur les patients atteints de polyarthrite rhumatoïde (PR). Or, le confinement prolongé dû au COVID-19 a considérablement limité les possibilités de pratique d'une AP en France. L'objectif principal de cette étude était de décrire et mesurer l'impact du confinement chez les patients atteints de PR sur leur pratique de l'AP et de leur qualité de vie. Un objectif secondaire était d'étudier la prise en charge par le rhumatologue en cette période de confinement.

Collaborateur: Sanofi Genzyme

Auteurs: F. Lévy-Weil, S. Jousse Joulin, V. Tiffreau, R. Perez, V. Morisseau, A. Bombezin—Domino, RM. Flipo

[Dépression résistante, impact social et professionnel : la voix des patients](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2020)

La dépression est la maladie psychique la plus répandue au monde. En France, on estime que près d'une personne sur cinq a souffert ou souffrira d'une dépression au cours de sa vie. En première intention, la prise en charge de la dépression implique une psychothérapie et le plus souvent un traitement antidépresseur (AD). Cependant, près d'un patient sur 3 ne répond pas correctement aux traitements AD actuels et est à risque d'évoluer vers une dépression résistante (DR). La DR se définit par l'échec à au moins deux traitements ATD successifs bien conduits (dose, durée, observance). La DR altère la qualité de vie sociale et familiale des patients. A notre connaissance, aucune étude évaluant la qualité de vie via une communauté de patients en ligne, source d'informations récente et originale n'a déjà été mise en place.

Objectif: L'objectif de cette étude était de caractériser l'impact de la dépression résistante au traitement (TRD) sur la qualité de vie des patients, y compris leur vie sociale, familiale et professionnelle.

Collaborateur: Janssen France

Auteurs: Véronique HUBER, Cécile DEAL, Valentin MORISSEAU, Pierre LEGENDRE, Anne SAUVAGET

[Facteurs associés à l'utilisation du cannabis à des fins thérapeutiques et évaluation de ses effets sur les symptômes de la sclérose en plaques en France et en Espagne - Résultats d'une enquête auprès d'une communauté de patients en ligne](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2020)

Alors qu'en France la possession et la consommation de cannabis est une infraction pénale, la législation espagnole autorise la consommation et la culture privée du cannabis. Même si certains produits pharmaceutiques à base de cannabis ont une autorisation de mise sur le marché dans les deux pays, seuls les patients en Espagne y ont accès. Malgré ces différentes législations, les patients atteints de maladies chroniques utilisent le cannabis sous différentes formes, « naturelle », transformée, autorisée ou non, à des fins thérapeutiques.

Objectifs : Identifier les caractéristiques des patients atteints de sclérose en plaques (SEP) qui utilisent déjà le cannabis pour des objectifs thérapeutiques ; évaluer l'effet du cannabis sur les symptômes de la SEP perçus par les patients ; identifier les facteurs associés à l'utilisation du cannabis, en comparant les résultats entre les deux pays ayant des législations différentes : France et Espagne.

Collaborateurs : INSERM, SESSTIM, IRD, ORS

Auteurs : Damien Testa, Lise Radoszycki, Tanguy Barré, Perrine Roux, Patrizia Carrieri, Camelia Protopopescu

[La classification non supervisée des données en vie réelle d'une communauté en ligne de patients permet l'identification de profils de patients lupiques concernant leurs préférences thérapeutiques](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2020)

L'adhésion d'un patient à son traitement et l'observance qui en découle peuvent varier selon la pathologie, les contraintes du traitement et le profil du patient. Ainsi, la sélection d'un traitement en adéquation avec le profil et donc les préférences du patient pourrait permettre une meilleure observance.

Objectifs : L'objectif de cette étude est d'identifier des profils de patients lupiques concernant leurs préférences thérapeutiques grâce à une analyse des correspondances multiples (ACM) associée à des méthodes de classification non supervisée.

Collaborateurs : Hôpital Européen de Marseille

Auteurs : Damien Testa, Valentin Morisseau, Lise Radoszycki, Laurent Chiche

[Étude en vie réelle de l'impact de l'épidémie de COVID-19, durant le confinement en France, sur les patients atteints de maladies chroniques](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2020)

La propagation de la pandémie de COVID-19 pourrait avoir des conséquences majeures sur l'état de santé des patients atteints de maladies chroniques. Ces patients sont particulièrement à risque, ils ont besoin de contacts réguliers avec les professionnels de santé et doivent prendre des traitements au long cours.

Objectifs : L'objectif de cette étude est d'évaluer l'impact de l'épidémie de COVID-19 sur les patients chroniques à l'aide d'une communauté de patients en ligne.

Collaborateurs : Comité scientifique de Carenity

Auteurs : Bruno Halioua, Jean Zetlaoui, Alexis Astruc, Alexis Bombezin-Domino, Damien Testa, Lise Radoszycki

[Impact de la pandémie de COVID-19 sur les patients atteints de maladies inflammatoires à médiation immunitaire et prenant une biothérapie](#)

Présenté au congrès de l'Association française des entreprises de la recherche clinique (AFCROs) (2020)

La pandémie de COVID-19 a mis en lumière la vulnérabilité des patients vivant avec une maladie inflammatoire à médiation immunitaire (IMID) et prenant une biothérapie. Ces patients, particulièrement à risque, ont besoin de contacts réguliers avec leurs professionnels de santé (PDS).

Objectifs : L'objectif de cette étude est d'évaluer l'impact de l'épidémie de COVID-19 sur la prise en charge des patients IMID prenant une biothérapie (modification des modalités de prise de la biothérapie, accompagnement par le corps médical, information reçue en lien avec la maladie et le traitement).

Collaborateurs : Comité scientifique de Carenity

Auteurs : Bruno Halioua, Alexis Astruc, Jean Zetlaoui, Damien Testa, Alexis Bombezin-Domino, Lise Radoszycki

2019

Dépression résistante, impact social et professionnel : la voix des patients

Présenté au congrès "Encéphale" de 2019.

La dépression est la maladie psychique la plus répandue au monde. En France, on estime que près d'une personne sur cinq a souffert ou souffrira d'une dépression au cours de sa vie. En première intention, la prise en charge de la dépression implique une psychothérapie et le plus souvent un traitement antidépresseur (AD). Cependant, près d'un patient sur 3 ne répond pas correctement aux traitements AD actuels et est à risque d'évoluer vers une **dépression résistante** (DR). La DR se définit par l'échec à au moins deux traitements ATD successifs bien conduits (dose, durée, observance). La DR altère la qualité de vie sociale et familiale des patients. A notre connaissance, aucune étude évaluant la qualité de vie via une communauté de patients en ligne, source d'informations récente et originale n'a déjà été mise en place.

Objectif: L'objectif de cette étude était de caractériser l'impact de la dépression résistante au traitement (TRD) sur la qualité de vie des patients, y compris leur vie sociale, familiale et professionnelle.

Collaborateur: Janssen France

Auteurs: Véronique HUBER, Cécile DEAL, Valentin MORISSEAU, Pierre LEGENDRE, Anne SAUVAGET

Considérations nutritionnelles dans les maladies inflammatoires chroniques : quels impacts sur la prise en charge des patients atteints de rhumatismes inflammatoires chroniques ?

Présenté au 32e congrès de la Société Française de Rhumatologie (SFR) 2019

Les facteurs environnementaux et génétiques ont un rôle primordial dans les maladies auto-immunes. Parmi les facteurs environnementaux, il a été démontré que la nutrition est considérée comme un facteur clé de la prise en charge et du contrôle des maladies inflammatoires chroniques par les patients. Ce rôle a été suggéré aussi bien dans les maladies inflammatoires de l'intestin (MICI) que dans les maladies liées à un rhumatisme.

Objectifs : L'objectif de cette étude est de décrire et comparer la prise en charge de la nutrition dans trois aires thérapeutiques (rhumatologie, gastro-entérologie et dermatologie) ainsi que de déterminer les attentes des patients en termes d'information et de services en lien avec ce sujet. Le cas des pathologies rhumatologiques a particulièrement été étudié.

Collaborateur : Fresenius Kabi

Auteurs : Pham T, Sokol H, Halioua B, Pourcel G, Brun M, Mary K, Pain E, Testa D

[Etude de l'observance thérapeutique chez 181 patients atteints de psoriasis en France](#)

Présenté aux Journées Dermatologiques de Paris (JDP) 2019

L'observance thérapeutique (OT) est définie par le degré de concordance entre le comportement du patient et les recommandations de son médecin. L'OT au cours du psoriasis varie de 21 à 66%. De multiples facteurs liés à la maladie, au traitement, à la relation médecin/patient, au médecin et au patient expliquent cette mauvaise observance. Une meilleure connaissance des éléments liés à la typologie des patients non-observants est susceptible d'améliorer l'observance, avec pour conséquence une meilleure efficacité thérapeutique.

Objectif : L'objectif de cette étude était de déterminer la prévalence de l'OT et d'analyser des facteurs susceptibles de l'influencer chez les patients souffrant de psoriasis.

Auteurs : Halioua B, Zetlaoui J, Pain E, Radoszycki L, Testa D

[Attentes des patients et perception du traitement par biothérapie chez 37 patients souffrant de psoriasis](#)

Présenté aux Journées Dermatologiques de Paris (JDP) 2019

Les biothérapies (BT) ont révolutionné la prise en charge des patients souffrant de formes modérées à sévères de psoriasis en cas d'échec, d'intolérance ou de contre-indication à deux traitements parmi : PUVAthérapie, acitrétine, méthotrexate et ciclosporine. Malgré des avantages reconnus des BT, il existe encore des réticences face à ces traitements, tant de la part de certains patients que de la part des professionnels de santé. Il existe peu de données en France sur les attentes et la perception du traitement par BT chez les patients souffrant de psoriasis.

Objectif : L'objectif de cette étude était de décrire les perceptions et les expériences des patients atteints de psoriasis en France, en abordant la communication avec les médecins, la satisfaction à l'égard des produits biologiques et les préoccupations concernant les options thérapeutiques.

Auteurs : Halioua B, Zetlaoui J, Pain E, Radoszycki L, Testa D

[Considérations nutritionnelles dans les maladies autoimmunes : quels impacts sur la prise en charge des patients ?](#)

Présenté aux Journées Francophones de Nutrition (JFN) 2019

Les facteurs environnementaux et génétiques ont un rôle primordial dans les maladies auto-immunes. Parmi les facteurs environnementaux, il a été démontré que la nutrition est un facteur clé de la prise en charge et du contrôle des maladies inflammatoires chroniques. Ce rôle a été démontré aussi bien dans les maladies inflammatoires de l'intestin (MICI) que dans les maladies liées à un rhumatisme.

Objectif : L'objectif de cette étude est de décrire et comparer la prise en charge de la nutrition dans trois aires thérapeutiques (rhumatologie, gastro-entérologie et dermatologie) ainsi que de déterminer les attentes des patients en termes d'information et de services en lien avec ce sujet.

Collaborateur : Fresenius Kabi

Auteurs : Halioua B, Pham T, Sokol H, Pourcel G, Brun M, Mary K, Pain E, Testa D

[Intégration de la qualité de vie des patients atteints de cancer et traités par immunothérapie dans la pratique clinique](#)

Présenté au 36^{ème} congrès de la Société Française et Francophone de Psycho-Oncologie (SFFPO) 2019

Préserver la qualité de vie (QdV) des patients atteints de cancer est un objectif majeur des cliniciens et des autorités de santé. En apportant aux patients un gain de survie et un meilleur profil de tolérance par rapport aux standards thérapeutiques, les traitements par Inhibiteurs de Checkpoints Immunologiques (ICI) sont devenus une alternative thérapeutique dans de nombreux types de tumeurs. Alors que la faisabilité de la collecte de données relatives aux symptômes et de données de QdV pour des patients traités par ICI font l'objet de diverses études, il devient essentiel de comprendre les attentes et les positions des patients et des professionnels de santé vis-à-vis de la gestion de la QdV en pratique clinique.

Objectif : L'objectif de l'étude était de décrire les expériences et les attentes des patients traités par ICI relatives à la prise en compte de la QdV dans la prise en charge du cancer.

Collaborateur : Bristol-Myers Squibb (BMS)

Auteurs : Wilczynski O, Boisbouvier A, Radoszycki L, Cotte FE, Gaudin AF, Lemasson H

[Place de la qualité de vie dans le parcours des patients atteints de cancer et traités par immunothérapie: enquête auprès d'une communauté de patients en ligne](#)

Présenté au 11^{ème} colloque de données de santé en vie réelle organisé par l'AFCCROs

En apportant aux patients un gain de survie et un meilleur profil de tolérance par rapport aux standards thérapeutiques, les traitements par Inhibiteurs de Checkpoints Immunologiques (ICI) sont devenus une alternative thérapeutique dans de nombreuses localisations tumorales. Il devient essentiel de comprendre la place accordée à la qualité de vie en pratique clinique pour les patients traités par ICI. Les objectifs de l'étude sont de décrire les pratiques actuelles des professionnels de santé concernant la prise en compte de la qualité de vie des patients traités ou ayant été traités par immunothérapie (ICI) tout au long de leur parcours de soins et d'évaluer le niveau de satisfaction des patients.

Collaborateur : Bristol-Myers Squibb (BMS)

Auteurs : Wilczynski O, Boisbouvier A, Radoszycki L, Cotté F-E, Gaudin A-F, Lemasson H

[Préférences des patients vis-à-vis des traitements : comment identifier des profils de patients à partir de données en vie réelle ? Application au cas du lupus.](#)

Présenté au 11^{ème} colloque de données de santé en vie réelle organisé par l'AFCCROs

L'adhésion d'un patient à son traitement et l'observance qui en découle peut varier selon la pathologie, les contraintes du traitement et le profil du patient. La mauvaise observance concernerait 50% des patients ce qui représente un problème de santé publique majeur. Les objectifs de cette étude sont de déterminer les attentes des patients atteints de lupus sur la forme galénique idéale et les caractéristiques du traitement, d'identifier des profils de patients partageant des attentes similaires grâce à une Analyse des Correspondances Multiples (ACM) et d'affiner ces profils en utilisant des techniques de classification non supervisée et réaliser une analyse comparative de ces méthodes.

Auteurs : Testa D, Legendre P, Radoszycki L, Gauchoux R

[Comprendre les symptômes des patients BPCO et leurs parcours de soins afin d'améliorer la prise en charge](#)

Présenté au Congrès de Pneumologie de Langue Française (CPLF) Marseille, 2019

La prévalence de la broncho-pneumopathie chronique obstructive (BPCO) dans la population des 40 ans et plus, non asthmatiques est estimée à 7,5%. Pour les individus atteints, la BPCO est une source majeure de handicap par la dyspnée, la limitation d'activité, les exacerbations, le risque d'insuffisance respiratoire chronique, les manifestations extra respiratoires qu'elle induit. L'évolution de la maladie peut aboutir à une insuffisance respiratoire chronique. Les objectifs de ce travail étaient de mieux connaître les signes avant-coureurs de la BPCO afin d'en accélérer le diagnostic et de mieux comprendre l'évolution des symptômes à la suite du diagnostic afin d'optimiser la prise en charge et le bien-être des patients.

Collaborateur : GSK

Auteurs : Jebrak G, Compagnon A, Chekroun M, Wilczynski O, Roche N

2018

[Impact des maladies inflammatoires chroniques de l'intestin et de leurs traitements sur le quotidien des patients – Enquête en vie réelle auprès d'une communauté de patients en ligne](#)

Présenté aux Journées Francophones d'Hépatogastroentérologie & d'Oncologie Digestive (JFHOD) Paris, 2018

Les maladies inflammatoires chroniques de l'intestin (MICI) telles que la maladie de Crohn et la rectocolite hémorragique se caractérisent par une inflammation de la paroi d'une partie du tube digestif. Les deux pathologies se distinguent notamment par le lieu de l'inflammation : la rectocolite hémorragique touche uniquement le rectum et une partie du côlon tandis que la maladie de Crohn peut affecter l'ensemble du tube digestif. Cette enquête menée en vie réelle porte sur une population relativement sévère de patients atteints de MICI. Elle met en exergue l'impact important de la maladie (particulièrement la maladie de Crohn) sur le quotidien des patients (notamment sur la vie professionnelle), ainsi que des problèmes d'errance diagnostique, d'observance et de gestion de la fatigue.

Collaborateur : Lilly

Auteurs : Sokol H, Hamidi K, Chartier F, Dos Santos R, Abitbol V

[Vécu des patients sous biothérapies et biosimilaires dans la maladie de Crohn – Enquête européenne auprès d’une communauté de patients](#)

Présenté au 10^{ème} colloque de données de santé en vie réelle organisé par l’AFCROs

Les biothérapies et leurs versions similaires, les biosimilaires, sont des traitements apportant des solutions thérapeutiques innovantes pour des maladies dépourvues de traitements satisfaisants tels que la maladie de Crohn (MC). L’avènement de ces traitements a bouleversé la prise en charge de ces patients. Si leur efficacité n’est plus à démontrer, leurs effets indésirables potentiels sont souvent redoutés. Peu de données existent sur la perception des patients face à ces traitements. Cette enquête a permis de mesurer la satisfaction des patients MC vis-à-vis de leur biothérapie/biosimilaire, de connaître la perception des patients MC vis-à-vis des biosimilaires et d’identifier les attentes des patients MC en termes d’accompagnement et d’informations.

Auteurs : Pain E, Chekroun M, Gauchoux R

2016

[Perception des Essais Cliniques par les Patients Diabétiques en France : Résultats de l’Etude 2000+ Carenity](#)

Présenté au Congrès de la Société Francophone du Diabète 2016

Depuis 10 ans, la place de la France dans la recherche clinique mondiale a reculé, une meilleure compréhension de la perception des essais cliniques par les patients pourrait permettre de dynamiser le recrutement. Cette enquête, la première menée en France directement auprès des patients via la plateforme Carenity, a permis d’identifier des axes d’amélioration pour favoriser le recrutement. Par exemple, des solutions « en ligne » pour mieux informer les patients sont plébiscitées, notamment sur les résultats d’un essai déjà réalisé.

Collaborateur : Hôpital Européen de Marseille

Auteurs : Chiche L, Guillaume A, Verjus T, Chekroun M

[L’acromégalie vue par le patient](#)

Présenté au 33^{ème} Congrès de la Société Française d’Endocrinologie

L’acromégalie est une maladie rare, pour laquelle le parcours de soins, notamment en France, demeure mal compris, avec un délai diagnostique conséquent. L’objectif de cette étude est de comprendre le parcours de soins et les attentes des patients atteint d’acromégalie grâce à un questionnaire en ligne diffusé sur la plateforme Carenity pendant 1 mois et demi. D’après cette étude, les patients acromégales abordent leurs symptômes « d’alerte » en premier lieu avec leur médecin généraliste. Il est donc essentiel de les informer et de les sensibiliser à cette pathologie rare.

Collaborateurs : IPSEN, Aix Marseille Université, Assistance Publique – Hôpitaux de Marseille, DEFHY

Auteurs : Albarel F, Duclos-Morlaes B, Brue T

[Que pensent les patients souffrant de trouble de l'humeur ? Enquête auprès d'une communauté de patients \(carenity.com\)](#)

Présenté au 9^{ème} Congrès Français de Psychiatrie

Les communautés de patients en ligne offrent une réelle innovation pour : l'accès à l'information, le suivi de la pathologie, les forums de discussions et la recherche médicale. Parmi les patients souffrant de maladies chroniques, ceux atteints de pathologies mentales sont particulièrement victimes de stigmatisation. Le but de cette étude est d'interroger les patients membres de la communauté Carenity.com, souffrant de trouble de l'humeur, sur le vécu de leur maladie, leurs liens avec l'entourage et les associations de patients afin d'améliorer le parcours de soins.

Collaborateurs : CHU Montpellier, afpbn

Auteurs : Crespe C, Molière F, Radoszycki L, Chekroun M, Courtet Ph

2015

[Posters présentés au congrès annuel de la Société Francophone du Diabète](#)

Présenté au Congrès de la Société Francophone du Diabète 2015

Quand elle est réalisée au niveau des principaux centres de diabétologie qui ont une grande expérience de l'éducation thérapeutique et de l'analyse de leurs activités, l'évaluation des pratiques liées au parcours de soins des patients diabétiques ne reflète pas celle de l'ensemble des patients. Le web social (communautés, forums en ligne et réseaux) est un nouveau moyen pour réaliser des enquêtes qui ont pour objectif de compléter la connaissance des attentes, des attitudes et des usages des patients, ainsi que du rôle des acteurs de santé. L'objectif des enquêtes est in fine d'améliorer l'offre de soins et de services à destination des patients.

[Informations et conseils : les préférences des patients diabétiques leurs attentes et le rôle des professionnels de santé](#)

[Modalités de recherche d'informations et de conseils par les patients diabétiques, améliorations](#)

[Evaluation des sources d'information et des outils d'autogestion du diabète par des patients type 1 et type 2, principales évolutions souhaitées](#)

Collaborateur : Roche Diabetes Care

Auteurs : Boizel R, Badel R, Peylin E

2014

[Observance et Polyarthrite rhumatoïde : Quels sont les critères mis en avant par les patients ?](#)

Présenté au 27^{ème} Congrès Français de Rhumatologie

L'observance est une préoccupation réelle dans une pathologie chronique telle que la Polyarthrite Rhumatoïde. L'objectif de cette étude est de mieux comprendre les différents critères d'acceptabilité et d'observance du traitement pour les patients et l'impact du traitement sur la qualité de vie du malade. Le second objectif est de préciser les besoins des patients en termes d'information sur les traitements et la pathologie, de suivi médical et de services (supports d'information, applications mobiles ...)

Collaborateurs : Pfizer, CHU de Lille

Auteurs : Flipo RM, Poupier-Chevrier C, Contré

2013

[Identification des Besoins et Sources d'Information des Patients « Maladies Rares » par Analyse des Données Issues de Communautés de Patients en Ligne en France : l'Étude Lupus-Carenity](#)

Présenté au 3^{ème} Rencontre Eurobiomed des maladies rares

Le Lupus érythémateux systémique est une maladie auto-immune rare touchant moins de 30 000 personnes en France et il n'existe que peu de données concernant les besoins et les sources d'informations des patients souffrant de cette pathologie. L'étude Lupus-Carenity combine les résultats de deux approches, une analyse de l'ensemble des verbatims de la communauté « Lupus » un an après sa création et une enquête en ligne auprès des membres de cette communauté. Ce travail confirme la faisabilité et l'intérêt de l'analyse des données provenant de communautés de patients en ligne en France dans le cadre des pathologies rares.

Collaborateurs : Aix Marseille Université, Assistance Publique – Hôpitaux de Marseille

Auteurs : Chiche L, Chekroun M