



## BIBLIOGRAPHY OF CARENITY

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## I. Articles

### 2020

#### [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 glycaemic 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 glycaemic 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 on-line 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

### [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, Guérault-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

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 FE, Gaudin AF, 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 $\alpha$ ), 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: Raïs 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

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<sup>ème</sup> 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<sup>ème</sup> colloque de données de santé en vie réelle organisé par l'AFCROs

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<sup>ème</sup> colloque de données de santé en vie réelle organisé par l'AFCROs

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<sup>ème</sup> 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<sup>ème</sup> 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 atteints 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<sup>ème</sup> 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, afpb

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<sup>ème</sup> 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<sup>ème</sup> 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