CARENITY
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I. Cardiovascular

MYOCARDIAL INFARCTION

[POSTER – ISPOR EUROPE 2024] Understanding the Patient Perspectives of Post-Discharge Care and Impact of Treatment in the First Year Post-AMI

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2024)

Patients have a high risk of recurrent cardiovascular events post-acute myocardial infarction (AMI) and require long-term guideline-directed secondary prevention medical therapy.
Understanding treatment experiences post-AMI from patients' perspective is important for optimizing care.

Collaborator: CSL Behring
Authors: M. Cecilia Bahit, Serge Korjian, Gerald Chi, Yazan Daaboul, Ginger Jiang, Deepak L. Bhatt, Roxana Mehran, Paul Nara, Alka Shaunik, C. Michael Gibson

[POSTER – ISPOR EUROPE 2024] Digital Engagement to Capture Insights Into Patient Perspectives on Care and Quality-of-Life: Utilizing an Online Survey to Understand the Burden on Patients Post-Acute Myocardial Infarction

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2024)

The importance of tailored care to address patient preferences has been increasingly recognized
in recent years. Here, we evaluate an online survey designed to gather patient perspectives post-
acute myocardial infarction (AMI) and identify their treatment preferences/goals.

Collaborator: CSL Behring
Authors: M. Cecilia Bahit, Serge Korjian, Gerald Chi, Yazan Daaboul, Ginger Jiang, Deepak L. Bhatt, Roxana Mehran, Paul Nara, Alka Shaunik, C. Michael Gibson

[POSTER – ESH 2019] 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

[POSTER – ISPOR Europe 2018] 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) Europe (2018)

More than1 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

II. Dermatology

PSORIASIS

[ARTICLE – European Journal of Dermatology 2024] The patient's perspective on the burden of psoriasis: findings based on the ROCQ, an online survey

Published in European Journal of Dermatology (2024)

Psoriasis is a common chronic skin disease, with well-characterised impact on quality-of life, however, no information is available on the lifetime impact of psoriasis on patients' lives. This descriptive cross-sectional web-based survey of patients with psoriasis, recruited from an online patient community, was conducted in France in 2021. Established questionnaires (Major Life-Changing Decision Profile-MLCDP, Dermatology Life Quality Index-DLQI, Hospital Anxiety and Depression Scale [HADS]), CAGE and BRIEF-COPE) were administered together with specially created questions.

Collaborator: UCB
Authors: Nathalie Quiles-Tsimaratos, Alexandre Gherardi, Anne Crochard, Mélanie Hueber, Emilie Pain, Alizé Vives, Axel P Villani

[ARTICLE – Journal of Dermatology 2020] Perception of therapeutic inertia by patients with psoriasis in France

Published in Journal of Dermatology (2020)

Therapeutic inertia (TI), the failure of health-care providersto initiate or intensify therapy when indicated, is caused by theattitude of health-care providers, unlike the concept of poor therapeutic compliance, which is generally attributed to the attitude ofthe 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

[POSTER – EADV 2020] 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

[POSTER – EADV 2019] 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.

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

[POSTER – EADV 2019] 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 (TNFα), 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.

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

[POSTER – JDP 2019] 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.

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

[POSTER – JDP 2019] 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.

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

III. Endocrinology

ACROMEGALY

[ARTICLE – Annals of Endocrinology 2018] Daily life, needs and expectations of patients with acromegaly in France: An on-line survey

Published in Annals of Endocrinology (2018)

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 is annual incidence ranges between 2 and 11 cases per million inhabitants. To better understand the impact of acromegaly of 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

[POSTER – SFE 2016] L'acromégalie vue par le patient

Présenté au 33ème Congrès de la Société Française d'Endocrinologie (SFE) (2016)

L'acromégalie est une maladie rare, pour laquelle le parcours de soins, notamment en France, demeure mal compris, avec un délai diagnostic 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

DIABETES

[ARTICLE – Acta Diabetologica 2025] Perceptions of use and value for different types of digital health solutions among people with type 1 and 2 diabetes in France

Published in Acta Diabetologica (2025)

This study examines the use, perceptions, and inequalities in access to Digital Health Solutions (DHS) among people with diabetes (PwD). It aims to identify factors influencing adoption and explore perceived benefits and barriers to using DHS, focusing on person-important outcomes such as physical health, mental burden, and access to care.

Collaborator: Roche
Authors: Norbert Hermanns, Paco Cerletti, Julie Laurent, Renza Scibilia, Sören Skovlund

[ARTICLE – JMIR Diabetes 2025] Evaluating Digital Health Solutions in Diabetes and the Role of Patient-Reported Outcomes: Targeted Literature Review

Published in Journal of Medical Internet Research (JMIR) Diabetes (2025)

Digital health solutions (DHS) are technologies with the potential to improve patient outcomes as well as change the way care is delivered. The value of DHS for people with diabetes is not well understood, nor is it clear how to quantify this value.
We aimed to summarize current literature on the use of patient-reported outcome measures (PROMs) in diabetes as well as in selected guidelines for Health Technology Assessment (HTA) of DHS to highlight gaps, needs, and opportunities for the use of PROMs to evaluate DHS.

Collaborator: Roche
Authors: Paco Cerletti, Michael Joubert, Nick Oliver, Saira Ghafur, Pasquale Varriale, Ophélie Wilczynski, Marlene Gyldmark

[ARTICLE – Journal of Diabetes Science and Technology 2023] Identification of Core Outcome Domains and Design of a Survey Questionnaire to Evaluate Impacts of Digital Health Solutions That Matter to People With Diabetes

Published in Journal of Diabetes Science and Technology (2023)

Digital health solutions (DHS) are increasingly used to support people with diabetes (PwD) to help manage their diabetes and to gather and manage health and treatment data. There is a need for scientifically reliable and valid methods to measure the value and impact of DHS on outcomes that matter to PwD. Here, we describe the development of a survey questionnaire designed to assess the perceptions of PwD toward DHS and their prioritized outcomes for DHS evaluation.

Collaborator: Roche
Authors: Soren Eik Skovlund, Scibilia Renza, Julie Laurent, Paco Cerletti

[ARTICLE – Journal of Diabetes Science and Technology 2023] European Survey on Adult People With Type 1 Diabetes and Their Caregivers: Insights Into Perceptions of Technology

Published in Journal of Diabetes Science and Technology (2023)

Type 1 diabetes (T1D) is a complex condition requiring constant monitoring and self-management. The landscape of diabetes management is evolving with the development of new technologies. This survey aimed to gain insight into the perceptions and experiences of people with T1D (PWD) and their caregivers on the use of technology in diabetes care, and identify future needs for T1D management.

Collaborator: Sanofi
Authors: Alfred Penfornis, Su Down, Antoine Seignez, Alizé Vives, Mireille Bonnemaire, Bernhard Kulzer

[ARTICLE – Clinical and Therapeutic Technology 2023] 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 Seignez, Alize Vives, Mireille Bonnemaire

[ARTICLE – Diabetes 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 Seignez, Alize Vives, Mireille Bonnemaire, Alfred Penfornis

[ARTICLE – Diabetes Therapy 2020] 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

[ARTICLE – Patient preference and adherence 2019] 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 (2019)

This study aimed to assess awareness of glycated 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

[POSTER – DSVR 2023] Evaluation of healthcare products in diabetes: what are the most important domains for patients?

Presented: Colloque données de santé en vie réelle (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, patient’s 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 Fougeres, Cynthia Lesbros, Lise Radoszycki

[POSTER – ISPOR 2023] Self-reported health status and its predictors among people with diabetes in France

Presented: International Society for Pharmacoeconomics and Outcomes Research (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

[POSTER – ISPOR 2023] Prevalence and predictive factors of psychological distress among people with diabetes in France

Presented: International Society for Pharmacoeconomics and Outcomes Research (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

[POSTER – SFD 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

[POSTER – ISPOR 2021] 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

[POSTER – ISPOR Europe 2018] 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) Europe (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

[POSTER – Société Francophone du Diabète 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 plébiscités, notamment sur les résultats d'un essai déjà réalisé.

Collaborateur : Hôpital Européen de Marseille
Auteurs : Chiche L, Guillaume A, Verjus T, Chekroun M

[POSTER – Société Francophone du Diabète 2015] Informations et conseils : les préférences des patients diabétiques leurs attentes et le rôle des professionnels de santé

Présenté au Congrès de la Société Francophone du Diabète (2015)

Ce poster explore les préférences des patients diabétiques en matière d'informations et de conseils, ainsi que leurs attentes vis-à-vis des différents canaux d'information et du rôle des professionnels de santé dans leur prise en charge. L'étude documente les sources d'informations que les patients privilégient (consultations médicales, brochures, internet, etc.), les types de conseils qu'ils jugent les plus utiles pour gérer leur diabète au quotidien, et comment ils perçoivent l'implication des professionnels de santé (médecins, infirmiers, diététiciens…) dans l'éducation thérapeutique. L'objectif est d'identifier ce que les patients attendent réellement en termes de communication et de soutien, afin d'optimiser l'accompagnement, renforcer la satisfaction des patients et améliorer les pratiques d'information fournies par les soignants.

Collaborateur : Roche Diabetes Care
Auteurs : Boizel R, Badel R, Peylin E

[POSTER – Société Francophone du Diabète 2015] Modalités de recherche d'informations et de conseils par les patients diabétiques, améliorations

Présenté au Congrès de la Société Francophone du Diabète (2015)

Ce poster présente les résultats d'une étude descriptive réalisée auprès de patients diabétiques afin de comprendre comment ils recherchent des informations et des conseils sur leur maladie, ainsi que leurs attentes en matière de ressources et de soutien. L'analyse porte sur les sources d'information utilisées (documents, professionnels de santé, internet, etc.), la fréquence de leur consultation, et les types de conseils recherchés selon les profils des patients (type de diabète, traitement). L'objectif est d'identifier les modalités de recherche d'information les plus courantes, leurs limites perçues par les patients, et les améliorations souhaitées pour mieux accompagner les personnes vivant avec un diabète dans leur quotidien.

Collaborateur : Roche Diabetes Care
Auteurs : Boizel R, Badel R, Peylin E

[POSTER – Société Francophone du Diabète 2015] Evaluation des sources d'information et des outils d'autogestion du diabète par des patients type 1 et type 2, principales évolutions souhaitées

Présenté au Congrès de la Société Francophone du Diabète (2015)

Ce poster présente une analyse centrée sur les évaluations des patients diabétiques concernant leur prise en charge et leur qualité de vie liée au diabète. L'étude décrit comment les patients évaluent différents aspects de la gestion de leur diabète, y compris l'accès aux soins, la compréhension de leur traitement, la communication avec les professionnels de santé, et leur niveau de satisfaction vis-à-vis des informations reçues. Il met en lumière les points forts perçus par les patients ainsi que les domaines où ils ressentent des lacunes ou des besoins non satisfaits. L'objectif est de mieux comprendre les perceptions et les attentes des patients afin d'identifier des pistes d'amélioration pour optimiser le soutien et l'accompagnement des personnes vivant avec un diabète.

Collaborateur : Roche Diabetes Care
Auteurs : Boizel R, Badel R, Peylin E

OBESITY

[POSTER – ISPOR Europe 2018] 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) Europe (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

IV. Gastrointestinal

INFLAMMATORY BOWEL DISEASES (IBD)

[ARTICLE – Advances in Therapy 2025] Patient Preferences for Treatment Attributes in Inflammatory Bowel Disease: A Discrete Choice Experiment Among Patients in Five Non-Western Countries

Published in Advances in Therapy (2025)

Understanding patient preferences is important for facilitating informed decision-making in managing patients with inflammatory bowel disease (IBD). This study explored the preferences of patients with Crohn's disease (CD) and ulcerative colitis (UC) regarding advanced therapy treatment attributes in five non-Western countries: Argentina, Australia, Brazil, Saudi Arabia and Taiwan.

Collaborator: Takeda
Authors: Marjorie Argollo, Yoon K. An, Nahla Azzam, Domingo C. Balderramo, Olga Fadeeva, Chia-Jung Kuo, Julie Laurent, Elenore Uy

[ARTICLE – Inflammatory Bowel Diseases 2024] Patient Preferences for Treatment Attributes in Inflammatory Bowel Disease: Results From a Large Survey Across Seven European Countries Using a Discrete Choice Experiment

Published in Inflammatory Bowel Diseases (2024)

This study explored patients' preferences for treatment attributes in Crohn's disease or ulcerative colitis, such as subcutaneous/intravenous drug administration and adverse effects. Patients' preferences highlighted the importance of personalized care and shared decision making to maximize treatment benefits.

Collaborator: Takeda Pharmaceuticals International AG
Authors: Gionata Fiorino, Nawal Bent-Ennakhil, Pasquale Varriale, Fiona Braegger, Eveline Hoefkens

[POSTER – European Crohn's and Colitis Organisation 2024] Preferences towards treatment attributes among patients with Crohn's disease and ulcerative colitis in Argentina, Australia, Brazil, Saudi Arabia and Taiwan: a discrete choice experiment

Presented: 19th Congress of the European Crohn's and Colitis Organisation (2024)

Immunosuppressants and biologics are the mainstay of treatment in patients with inflammatory bowel disease (IBD). Understanding patient preferences informs treatment decision-making and may optimize treatment acceptance and adherence. There is a lack of evidence regarding preferences towards treatment attributes among patients with IBD from non-Western countries.

This study aims to describe the preferences of patients with Crohn's disease (CD) and ulcerative colitis (UC) towards the attributes of treatment with advanced therapies for IBD, including safety and efficacy profiles, frequency and route of administration (RoA) in a real-world setting from 5 countries – Argentina, Australia, Brazil, Saudi Arabia and Taiwan.

Collaborator: Takeda
Authors: Marjorie Argollo, Yoon-KyoAn, Domingo C. Balderramo, Nahla Azzam, Chia-Jung Kuo, Olga Fadeeva, Elenore Uy

[POSTER – UEG Week 2021] Results from a large survey exploring patient preferences for treatment attributes in inflammatory bowel disease across 7 countries in Europe

Presented: United European Gastroenterology (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

[POSTER – ECCO 2021] 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-Ennakhil N, Varriale P, Braegger F, Hoefkens E

[POSTER – DSVR 2018] Vécu des patients sous biothérapies et biosimilaires dans la maladie de Crohn – Enquête européenne auprès d'une communauté de patients

Présenté au 10ème colloque de données de santé en vie réelle (DSVR) (2018)

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

[POSTER – JFHOD 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'Hépato-gastroentérologie & d'Oncologie Digestive (JFHOD) (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

V. Infectious

HUMAN IMMUNODEFICIENCY VIRUS (HIV)

[ARTICLE – Patient Preference and Adherence 2022] 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

VI. Inflammatory diseases

[ARTICLE – BMC Nutrition 2021] 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

[POSTER – ISPOR 2020] 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 shrone 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

[POSTER – DSVR 2020] Impact de la pandémie de COVID-19 sur les patients atteints de maladies inflammatoires à médiation immunitaire et prenant une biothérapie

Présenté au colloque données de santé en vie réelle (DSVR) (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

[POSTER – SFR 2019] 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

[POSTER – JFN 2019] 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

VII. Mental health

[POSTER – Psych Congress 2024] Treating insomnia symptoms as part of major depressive disorder: a cross-sectional survey on patient needs in the US

Presented: Psych Congress (2024)

Major Depressive Disorder (MDD) is a common mental health condition characterized by a prolonged depressed mood, as well as a loss of pleasure or interest in activities. Approximately 280 million people are affected by it worldwide. In the US, it is estimated that 21.0 million adults experienced at least one major depressive episode in their life. It represents 8.3% of all US adults. Around 70% of patients with MDD also suffer from insomnia. When treated for depression, patients' related insomnia is often noted, but neither addressed nor treated. This study aimed to evaluate needs of patients with MDD for adjunctive treatment for insomnia symptoms in the US.

Collaborator: J&J
Authors: Geoffroy P.A, Riise J, Dwibedi N, Sellem L, Zhiheng Z

[POSTER – ENCP 2024] Treating insomnia symptoms as part of major depressive disorder: a cross-sectional survey on patient needs in EU5 countries

Presented: ENCP (2024)

Major Depressive Disorder (MDD) is a common mental health condition worldwide, with more than 280 million people affected by it. In Europe, it is estimated to affect 6.4% of adults. Around 70% of patients with MDD also suffer from insomnia. When treated for depression, patients' related insomnia is often noted, but treated as a separate treatment. This study aimed to evaluate needs of patients with MDD for adjunctive treatment for insomnia symptoms in the EU5 countries (France, Germany, Italy, Spain, UK).

Collaborator: J&J
Authors: Geoffroy P.A, Riise J, Dwibedi N, Sellem L, Zhiheng Z

[POSTER – Encéphale 2021] 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 : Viatris
Auteurs : Courtet P, Azoulai M, Morisseau V, Levy-Heidmann T, Pecout C

[POSTER – DSVR 2020] Dépression résistante, impact social et professionnel : la voix des patients

Présenté au colloque données de santé en vie réelle (DSVR) (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

[POSTER – Encéphale 2019] Dépression résistante, impact social et professionnel : la voix des patients

Presenté au congrès “Encéphale” (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

[POSTER – Congrès Français de Psychiatrie 2016] Que pensent les patients souffrant de trouble de l’humeur ? Enquête auprès d’une communauté de patients (carenity.com)

Présenté au 9ème Congrès Français de Psychiatrie (2016)

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

VIII. Neurology

CERVICAL DYSTONIA

[ARTICLE – Journal of Neurology 2021] 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

[POSTER – IAPRD 2020] 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. Azoulai, E. Pain, S. Om

MULTIPLE SCLEROSIS

[ARTICLE – Multiple Sclerosis and Related Disorders 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 (Barr´e 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: Tangui Barré, Damien Testa, Clémence Ramier, Melina Santos, Fabienne Marcellin, Perrine Roux, Patrizia Carrieri, Lise Radoszycki, Camelia Protopopescu

[ARTICLE – Journal of Clinical Nursing 2023] 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

[ARTICLE – Science Direct 2022] 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 canabis-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

[ARTICLE – Multiple Sclerosis and Related Disorders 2022] 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

[ARTICLE – PharmacoEconomics 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

[POSTER – ISPOR Europe 2024] Worldwide longitudinal observational study of fatigue-related symptoms in patients with relapsing multiple sclerosis, daily assessment and 7-day lookback

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2024)

Fatigue is one of the most common symptoms of multiple sclerosis (MS). Using MS-specific patient reported outcomes to characterize it would grant a better understanding of its impact on patients' quality of life (QoL).
This observational longitudinal study aimed to measure fatigue in Relapsing MS (RMS) patients from multiple countries using the Fatigue Symptoms and its Impacts Questionnaire-RMS (FSIQ-RMS).

Collaborator: Janssen
Authors: Emma Zylbermine, Julie Laurent, Lise Radoszycki

[POSTER – ISPOR Europe 2024] Characterizing fatigue in US, European and Latin-American adults with relapsing multiple sclerosis: a real-world study conducted using a novel disease specific scale

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2024)

Relapsing multiple sclerosis (RMS) is an inflammatory demyelinating disorder of the central nervous system and the most common progressive neurologic disease of young adults worldwide.
Fatigue is one of the most common symptoms of RMS and one of the main causes of patients' quality-of-life (QoL) impairment. Considering its subjective aspect, using MS-specific patient reported outcomes to characterize it would grant a better understanding of its impact on patients' QoL.

This study aimed to measure fatigue in RMS patients from multiple countries using the Fatigue Symptoms and its impact Questionnaire-Relapsing Multiple Sclerosis (FSIQ-RMS).

Collaborator: Janssen
Authors: Valentine Ficara, Julie Laurent, Lise Radoszycki

[POSTER – ISPOR Europe 2024] A real-world longitudinal study characterizing the impact of fatigue in adults with relapsing multiple sclerosis

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2024)

Around 900,000 adults in the United States (US) suffer from multiple sclerosis (MS), one of the most common progressive neurologic disease in young adults. Most MS patients suffer from fatigue, which is one of the main causes of their impacted quality of life. The Fatigue Symptoms and Impacts
Questionnaire – Relapsing Multiple Sclerosis (FSIQ-RMS) is a disease-specific tool designed to assesses its impact on quality of life from a patient perspective.
This study aimed to identify the factors impacting FSIQ-RMS scores over time in RMS patients from the US.

Collaborator: Janssen
Authors: Laury Sellem, Julie Laurent, Lise Radoszycki

[POSTER – ACTRIMS 2022] 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 (ACTRIMS) (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

[POSTER – EAN 2021] 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

[POSTER – ACTRIMS 2021] 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, Lévy-Heidmann T, Morisseau V, Jamieson C, Charvet L, Krupp L, Azoulai M

[POSTER – ACTRIMS and ECTRIMS 2020] A real-world study characterizing symptoms and impacts of fatigue in US adults with relapsing multiple sclerosis using a novel disease specific scale

Presented: Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) and European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) (2020)

Fatigue is among the most frequent and disabling symptoms in patients with relapsing multiple sclerosis (RMS) and is considered to be one of the main causes of impaired quality of life. Considering its subjective nature, fatigue is assessed most accurately via patient reported outcomes (PRO) instruments. However, the available PROs that assess MS-related fatigue have limitations such as not being subtype-specific or assessing only either symptoms or their impacts.

A greater understanding of MS fatigue and associated, MS-specific PRO tools to characterize fatigue and its impact would improve clinicians' decision making and patient care. FSIQ-RMS, a novel MS-specific tool was designed to assess both fatigue symptoms in patients with RMS and their impacts on physical activity, cognitive and emotional function and coping mechanisms.

Objective: The study was aimed at measuring MS fatigue and its impact on daily life in a real-world population using a survey including the RMS-specific FSIQ-RMS.

Collaborators: Janssen Global, NYU Langone Health

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

[POSTER – DSVR 2020] 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 Colloque données de santé en vie réelle (DSVR) (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, Tangui Barré, Perrine Roux, Patrizia Carrieri, Camelia Protopopescu

[POSTER –ECTRIMS 2019] 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

[POSTER – ISPOR Europe 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) Europe (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

[POSTER – ICIMTH 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

[POSTER – ISPOR Europe 2018] 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) Europe (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 aimof 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

[POSTER – ECTRIMS 2018] 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) (2018)

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

[POSTER – ISPOR Europe 2018] 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) Europe (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

[POSTER – ISPOR 2017] 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.

Collaborators: 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

PARKINSON'S DISEASE

[ARTICLE – Parkinson’s disease 2025] Patterns of Use and Patient-Reported Effects of Cannabinoids in People With PD: A Nationwide Survey

Published in Parkinson’s disease (2025)

People with Parkinson’s disease (PD) may use cannabis-based products for symptom management. In France, products containing tetrahydrocannabinol (THC) are prohibited, while cannabidiol (CBD)-products are readily available. However, data on cannabinoid use in French people with PD are lacking. To identify correlates of the use of cannabis-based products and to document their patterns of use and perceived effects.

Collaborator: Academics
Authors: Tangui Barré, Géraldine Cazorla, Vincent Di Beo, Fabienne Lopez, Lise Radoszycki, Gwenaëlle Maradan, Christelle Baunez, Patrizia Carrieri

[ARTICLE – Clinical Parkinsonism & Related Disorders 2024] Acceptability of and attitudes to the therapeutic use of cannabis and cannabidiol in people with Parkinson’s disease: A French survey

Published in Clinical Parkinsonism & Related Disorders (2024)

Cannabis and cannabidiol (CBD) may potentially alleviate symptoms and improve the quality of life of people with Parkinson’s disease (PD), although clinical results to date have provided conflicting evidence. In France cannabis use is illegal outside the current restricted medical cannabis experimental framework which does not include PD as an eligible condition. In contrast, CBD products are legal and are easily available. We aimed to evaluate the acceptability of therapeutic cannabis and CBD use, and to assess cannabinoid-related attitudes among people with PD in France, with a view to assessing the potential inclusion of medical cannabinoids in PD treatment options.

Collaborator: Academics
Authors: Tangui Barré, Géraldine Cazorla, Vincent Di Beo, Fabienne Lopez, Lise Radoszycki, Gwenaëlle Maradan, Christelle Baunez, Patrizia Carrieri

SPASTICITY

[ARTICLE – JMIR Public Health and Surveillance 2020] Perspective of an International Online Patient and Caregiver Community on the Burden of Spasticity and Impact of Botulinum Neurotoxin Therapy: Survey Study

Published in Journal of Medical Internet Research (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.

[ARTICLE – Frontiers in Neurology 2020] 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

[POSTER – ISPOR 2020] 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) (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

[POSTER – TOXINS 2019] 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

[POSTER – TOXINS 2019] 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

[POSTER – TOXINS 2019] 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

STROKE

[POSTER – ISPOR 2025] Factors Influencing the Quality of Life of Stroke Survivors – Results of an Online Survey in the US

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2025)

Globally, stroke and its sequelae, including hemiparesis and spasticity, are among the leading causes of disability. Stroke survivors are often challenged with long-term disabilities and complications, which often result in a poor health-related QoL. To gather real-world evidence on post-stroke spasticity (PSS) in a real-life treatment setting and identify key factors influencing patient QoL.

Collaborator: Ipsen
Authors: S. Haidar, E. Pain, L. Radoszycki, J. Bouchard

IX. Oncology

BREAST CANCER

[POSTER – Miami Breast Cancer Conference 2026] Real-World Patient and Caregiver Experiences With Breast Cancer Risk of Recurrence in the US: Results of an Online Survey and Social Media Analysis

Presented: 43rd Annual Miami Breast Cancer Conference (2026)

Patients with hormone receptor–positive (HR+)/human epidermal growth factor receptor 2–negative (HER2−) early breast cancer (EBC) remain at risk of early (≤5 years) and late (>5 years) disease recurrences despite standard-of-care adjuvant endocrine therapy. Up to 27% of all patients with BC will recur within 10 years of diagnosis, particularly if initially diagnosed at stage II or III where recurrence rates are 41% and 63%, respectively. Currently, there is little published evidence related to the concerns of patients and caregivers concerning risk of recurrence (ROR). Lack of awareness about ROR has considerable impact on patient and caregiver quality of life, which may result in emotional distress from being unprepared about the true ROR. Here, we present important insights on ROR through the combined results of an online patient survey and subsequent social media analysis (SMA) of patients and caregivers.

Collaborator: Novartis

Authors: Hope S. Rugo, Megan-Claire Chase, Megan Rutt, Mary Lou Smith, Sue Weldon, Emilie Pain, Gaurav Vadnerkar, Tamalika Sen, Shiva Padhi, Nimisha Nadimpalli, Liz Santarsiero, Corinth Auld, Nadia Harbeck, Anees B. Chagpar

[POSTER – SABCS 2025] Real-World Patient and Caregiver Experiences With Breast Cancer Risk of Recurrence in the US: Results of an Online Survey and Social Media Analysis

Presented: San Antonio Breast Cancer Symposium (SABCS) (2025)

Patients with hormone receptor–positive (HR+)/human epidermal growth factor receptor 2–negative (HER2−) early breast cancer (EBC) remain at risk of early (≤5 years) and late (>5 years) disease recurrences despite standard-of-care adjuvant endocrine therapy. Up to 27% of all patients with BC will recur within 10 years of diagnosis, particularly if initially diagnosed at stage II or III where recurrence rates are 41% and 63%, respectively. Currently, there is little published evidence related to the concerns of patients and caregivers concerning risk of recurrence (ROR). Lack of awareness about ROR has considerable impact on patient and caregiver quality of life, which may result in emotional distress from being unprepared about the true ROR.
Here, we present important insights on ROR through the combined results of an online patient survey and subsequent social media analysis (SMA) of patients and caregivers.

Collaborator: Novartis
Authors: Hope S. Rugo, Megan-Claire Chase, Megan Rutt, Mary Lou Smith, Sue Weldon, Emilie Pain, Gaurav Vadnerkar, Tamalika Sen, Shiva Padhi, Nimisha Nadimpalli, Liz Santarsiero, Corinth Auld, Nadia Harbeck, Anees B. Chagpar

COLORECTAL CANCER

[POSTER – ESMO 2023] P-102 Unmet needs of patients during colorectal cancer care and treatment – a qualitative study through an online patient community

Presented: European Society for Medical Oncology (ESMO) (2023)

Approximately 500,000 people are diagnosed with colorectal cancer (CRC) every year in Europe [1]. Approximately 15 to 30% of these patients are initially diagnosed at a metastatic stage (mCRC), and 20% to 50% of patients with initially localized disease will relapse and present metastasis [2]. The study objective is to better understand the unmet needs of mCRC patients' during their care and treatment pathway, especially for patients with genetic alterations.

Collaborator: Pierre Fabre
Authors: E. Samalin, L. Lorenzon, C. Sarrauste de Menthière, L. Guéroult-Accolas, R. Paixão, C. Chaves Almagro, E. Pain, E. Martinelli

LUNG CANCER

[ARTICLE – Oncology and Therapy 2024] Experience and Care Pathway of Patients with Lung Cancer: An Online International Survey

Published in Oncology and Therapy (2024)

In our global survey, we sought to expand this understanding to people living with LC in countries across different regions, and to bring a more comprehensive understanding of the care pathway experiences in terms of disease management and impact on their daily lives, treatment decision-making, stakeholder involvement, and gaps in information/support services. In light of COVID-19 and the mobilization of patients to engage more online, we also sought to leverage online patient communities as participants for our survey. This enabled access to additional "real-world" patient populations beyond traditional channels such as local recruitment agencies and patient organizations.

Collaborator: Novartis
Authors: Pauline Frank, Julie Laurent, Lorraine Dallas, Pasquale Varriale, Andrew Ciupek

[ARTICLE – JMIR 2023] Patient Perspectives on Value Dimensions of Lung Cancer Care: Cross-sectional Web-Based Survey

Published in Journal of Medical Internet Research (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

[ARTICLE – Lung Cancer Journal 2022] 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

[POSTER – ISPOR 2023] An innovative patient-centric approach to integrate patients' perspectives in the selection of Patient-Reported Outcomes

Presented: International Society for Pharmacoeconomics and Outcomes Research (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

[POSTER – World Conference on Lung Cancer 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

MULTIPLE MYELOMA

[ARTICLE – Frontiers in Oncology 2025] A discrete choice experiment analysis to understand patient preferences for multiple myeloma treatments

Published in Frontiers in Oncology (2025)

Multiple myeloma (MM) is a malignant plasma cell disorder characterized by the clonal expansion of abnormal plasma cells within the bone marrow. The management of relapsed/refractory multiple myeloma (RRMM) represents a significant challenge as the disease relapses or becomes refractory to previous treatments. Recent advances in therapy have expanded RRMM treatment options. This study aimed to gain a deeper understanding of patients' treatment preferences regarding available therapeutic options.

Collaborator: Johnson & Johnson

Authors: Beth Faiman, Hoa H. Le, Julie Laurent, Saurabh Patel, Agne Paner-Straseviciute, Xinke Zhang, Joseph Mikhael

[POSTER – Myeloma Society Annual Meeting 2024] A Discrete Choice Experiment analysis to understand Treatment Preferences of Patients with Relapsed or Refractory Multiple Myeloma (RRMM) in the United States

Presented: 21st International Myeloma Society Annual Meeting (2024)

The treatment landscape for patients with relapsed refractory multiple myeloma (RRMM) has witnessed remarkable advancements with the introduction of novel therapies as later line options in recent years. Gaining a deeper understanding of how various factors influence patients' treatment preferences is crucial. This study is designed to assess patient preferences between treatment characteristics that are consistent with the therapeutic options available to these patients.

Collaborator: Johnson and Johnson
Authors: Beth Faiman, Hoa Le, Julie Laurent, Saurabh Patel, Agne Paner-Straseviciute, Xinke Zhang, Joseph Mikhael

PROSTATE CANCER

[POSTER – ISPOR 2026] Importance of Intermediate Clinical Endpoints in Prostate Cancer for Patients: a Cluster Analysis

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (2026)

Overall survival (OS) is the standard endpoint in prostate cancer (PC). Because localized PC develops slowly, intermediate clinical endpoints (ICEs) are used as potential predictors of OS. Understanding the patient relevance of ICEs is crucial for patient-centered care and decision-making by Health Technology Assessment agencies. The study aims to assess the patient relevance of ICEs, identify distinct patient profiles, and determine which factors best explain differences in perceptions of ICEs.

Collaborator: Johnson & Johnson

Authors: Kate Dotsikas, James McCallion, Julie Laurent, Cynthia Lesbros, Lise Radoszycki

SKIN CANCER

[ARTICLE – Eur J Dermatol 2019] 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.

Collaborator: Pierre Fabre
Authors: Basset Seguin N, Malvehy J, Nadal F, Creancier L, Rauly-Lestienne I, Beauchamp R, Hezareh M, Schmitt AM, Ulianov L

[POSTER – EADO 2018] How do Transplanted Patients manage their risk of Non Melanoma Skin Cancer?

Presented: European Association of Dermato Oncology (EADO) (2018)

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, Malvehy J, Ulianov L, Condomines M, Beauchamp R, Dos Santos R

[POSTER – EADO 2018] 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) (2018)

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

CANCERS

[ARTICLE – JMIR 2022] 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 (JMIR) (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-Emery Cotté, Anne-Françoise Gaudin, Hervé Lemasson

[POSTER – ISPOR 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) Europe (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

[POSTER – ESMO 2019] 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 (ESMO) 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

[POSTER – ISPOR 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

[POSTER – SFFPO 2019] Intégration de la qualité de vie des patients atteints de cancer et traités par immunothérapie dans la pratique clinique

Présenté au 36ème 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

[POSTER – DSVR 2019] 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 11ème colloque de données de santé en vie réelle (DSVR) (2019)

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

X. Rare diseases

CDKL5 DEFICIENCY DISORDER (CDD)

[ARTICLE – JMIR Formative Research 2025] Caregivers' Perceptions of Clinical Symptoms, Disease Management, and Quality of Life Impact in Cases of Cyclin-Dependent Kinase-Like 5 Deficiency Disorder: Cross-Sectional Online Survey

Published in Journal of Medical Internet Research (JMIR) Formative Research (2025)

Cyclin-dependent kinase-like 5 (CDKL5) deficiency disorder (CDD) is an ultrarare genetic condition causing developmental epileptic encephalopathy characterized by seizures and motor and intellectual disabilities. No disease-modifying therapies are available, and treatments focus mainly on symptom management to improve quality of life.
The aim of this study was to better understand the burden of CDD based on family caregivers' perceptions.

Collaborator: Orion Pharma
Authors: Sam Amin, Carol-Anne Partridge, Helen Leonard, Jenny Downs, Helen Allvin, Valentine Ficara, Emilie Pain, Minna A Korolainen

[POSTER – CDKL5 Global Patient Conference 2025] Caregivers' Voice in Leveraging CDD Burden

Presented: CDKL5 Global Patient Conference (2025)

This study was designed to do something rare: let caregivers tell us the true story, not just through words, but through data that regulators, pharma, and policy makers will listen to.

Collaborator: Orion Pharma
Authors: Sam Amin, Carol-Anne Partridge, Helen Leonard, Jenny Downs, Helen Allvin, Valentine Ficara, Emilie Pain, Minna A Korolainen

[POSTER – ISPOR Europe 2025] CDKL5 deficiency disorder: caregiver’s perception of clinical symptoms, disease management and its impact on quality-of-life

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2025)

Cyclin-dependent kinase-like 5 (CDKL5) deficiency disorder (CDD) is an ultra-rare genetic condition marked by developmental epileptic encephalopathy causing early-onset seizures, severe motor and cognitive impairments. To this day, no disease-modifying treatments exist for this condition, and treatments focus mainly on symptoms management. This study aimed to assess the burden of CDD for patients and their families, from the perspective of caregivers.

Collaborator: Orion Pharma
Authors: Emilie Pain, Valentine Ficara, Cynthia Lesbros

[POSTER – DSVR 2025] CDKL5 deficiency disorder (CDD): caregiver's perception of clinical symptoms, disease management and its impact on quality-of-life

Presented: Colloque données de santé en vie réelle (DSVR) (2025)

CDD is a developmental epileptic encephalopathy condition causing severe developmental delay, epileptic seizures, important psychomotor impairment with limited communication skills from the first months of life. The objective was to better understand the burden of CDD on both patients and their family from the perspective of caregivers.

Collaborator: Orion Pharma
Authors: Cynthia Lesbros

COLD AGGLUTININ DISEASE (CAD)

[ARTICLE – JMIR Formative Research 2022] The Burden of Cold Agglutinin Disease on Patients' Daily Life: Web-Based Cross-sectional Survey of 50 American Patients

Published in Journal of Medical Internet Research (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

[POSTER – Rare Patient Advocacy Summit 2021] 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

[POSTER – ISPOR 2021] 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

IMMUNE THROMBOCYTOPENIA (ITP)

[ARTICLE – British Journal of Haematology 2025] Patient survey in immune thrombocytopenia (ITP): Identifying unmet needs related to treatment and disease control in patients living in the United States

Published in British Journal of Haematology (2025)

Immune thrombocytopenia (ITP) is a chronic disease with primary therapeutic goals of platelet count recovery to safe levels to minimize active/future bleeding, alongside easing additional symptoms negatively impacting overall patient well-being with consequent improvement in physical fatigue/energy levels, daily/work-related activities and social/emotional health. Documentation of this rare disease is important for evaluating real-world experiences in treatment satisfaction, expectations and unmet needs in disease management.
This study examined patient experiences and preferences, treatment satisfaction and expectations and unmet patient needs related to disease management and control based on the outcomes of a survey conducted in adults with ITP.

Collaborator: Sanofi
Authors: Nichola Cooper, Caroline Kruse, Sharon Deneen Morgan, Julie Laurent, Marleni Arvelo-Saillant, Jean-Pascal Roussy, Matias Cordoba, Imene Gouia, Lisa-Anne Schmitt, Erin Reineke, Terry Gernsheimer

LUPUS

[ARTICLE – Lupus 2021] 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

[ARTICLE – Lupus 2015] Characteristics and information searched for by French patients with systemic lupus erythematosus: A web-community data-driven online survey

Published in Lupus (2015)

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

[POSTER – EULAR 2020] 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).

Collaborator: Carenity Scientific Committee
Authors: D. Testa, V. Morisseau, L. Radoszycki, I. Anfray, L. Chiche

[POSTER – ISPOR 2020] 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) (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.

Collaborator: Carenity Scientific Committee
Authors: Testa D, Morisseau V, Radoszycki L, Fidyk C, Chiche L

[POSTER – DSVR 2020] 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 colloque données de santé en vie réelle (DSVR) (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

[POSTER – DSVR 2019] 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 11ème colloque de données de santé en vie réelle (DSVR) (2019)

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

[POSTER – Rencontre Eurobiomed des maladies rares 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 3ème Rencontre Eurobiomed des maladies rares (2013)

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

NEUROFIBROMATOSIS TYPE 1

[ARTICLE – Orphanet Journal of Rare Diseases 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.

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

THYROID EYE DISEASE

[POSTER – SECOP 2026] Burden of Thyroid Eye Disease for caregivers: results from a survey in Spain and Germany

Presented: Congress of the Sociedad Española de Cirugía Oculoplástica (2020)

Thyroid eye disease (TED) is a progressive autoimmune disorder characterized by inflammation and expansion of orbital tissues. This study describes the multifaceted impact of moderate-to-severe TED on caregivers and the burden they experience.

Collaborators: Amgen
Authors: Antonio Manuel Garrido-Hermosilla, Fernando Heredia-Sánchez, Mariola Méndez Muros, Christina Giannopoulou, Berta Jover, Florian Siegmeier, Emilie Pain, Julie Laurent, Alex Eddy

XI. Respiratory

ASTHMA

[ARTICLE – Pulmonary Therapy 2022] 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

[ARTICLE – Journal of Asthma 2020] 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

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

[POSTER – CPLF 2019] 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) (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 connaitre 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

RESPIRATORY SYNCYTIAL VIRUS (RSV)

[ARTICLE – Pediatric Allergy and Immunology 2024] Parent's perception of respiratory syncytial virus and subsequent wheezing burden: A multi-country cross-sectional survey

Published in Pediatric Allergy and Immunology – 2024

Respiratory Syncytial Virus (RSV) is the leading cause of hospitalization in infants. RSV bronchiolitis is associated with an increased risk of subsequent wheezing. We aimed to document the parents' perception of the link between RSV infection and subsequent wheezing, wheezing-related healthcare and family resources use, and its impact on family daily life.

Collaborator: Sanofi
Authors: Adnan Custovic, Jorge Mestre-Ferrandiz, Leyla Kragten-Tabatabaie, Julie Laurent, Laury Sellem, Mary Koslap-Petraco, Chiara Cadeddu

[POSTER – ISPOR, EIP, and ERS 2025] Describing the burden of RSV infection and subsequent wheezing in toddlers: an international cross-sectional study

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2025), Excellence in Pediatrics (EIP) conference (2025), European Respiratory Society (ERS) congress (2025)

Respiratory syncytial virus (RSV) is one of the most common viral respiratory infections globally, with a rising incidence among children under five years of age. This study aimed to describe RSV and subsequent wheezing burden in toddlers infected between the ages of 6 and 24 months and their parents.

Collaborator: Sanofi
Authors: Julie Laurent, Valentine Ficara, and Sahar Haidar

[POSTER – ESPID and EAACI 2024] Increased risk of wheezing associated with respiratory syncytial virus (RSV) in a multi-country cross-sectional survey of parent's perception

Presented: 42nd Annual meeting of the European Society for Paediatric Infectious (ESPID) (2024), European Academy of Allergy & Clinical Immunology (EAACI) congress (2024)

RSV is a common and contagious seasonal virus. By two years of age, >90% of children will have had at least one RSV infection. Among infants under one year old, RSV is a leading cause of hospitalization for acute lower respiratory tract diseases such as bronchiolitis and pneumonia. Some studies suggest RSV bronchiolitis may be associated with an increased risk of subsequent wheezing in infants and children. With the upcoming arrival of new immunization solutions, it is important to document the full burden of RSV including its short/medium term complications.

Collaborator: Sanofi
Authors: Adnan Custovic, Jorge Mestre-Ferrandiz, Leyla Kragten-Tabatabaie, Julie Laurent, Laury Sellem, Mary Koslap-Petraco, Chiara Cadeddu

[POSTER – Cogent Public Health 2023] Burden of respiratory syncytial virus (RSV) infection and subsequent wheezing on infants and children: a multi-country parent's perception cross-sectional survey

Presented: Cogent Public Health (2023)

Respiratory Syncytial Virus (RSV) is the leading cause of hospitalisation for acute lower respiratory tract infections in infants under 1yo. Epidemiological studies suggest RSV bronchiolitis is associated with an increased risk of subsequent wheezing in children. This survey aimed to document the parents' perception of the potential link between RSV infection and subsequent wheezing-related healthcare and family costs and parents' awareness about RSV preventative solutions.

Collaborator: Sanofi
Authors: Custovic Adnan, Mestre-Ferrandiz Jorge, Kragten-Tabatabaie Leyla, Laurent Julie, Sellem Laury, Koslap-Petraco Mary, Cadeddu Chiara

ALL RESPIRATORY DISEASES

[POSTER – ISPOR 2025] Patient Perspectives on the Lifelong Impact of Preterm Birth in Chronic Respiratory Disease Care

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe (2025)

Approximately 15 million infants are born prematurely each year, a status often associated with an increased risk of chronic respiratory conditions such as asthma and Chronic Obstructive Pulmonary Disease (COPD). Data on prematurity impact on respiratory disease progression and management in adulthood remain limited. This study aims to investigate patient awareness of their preterm status, its perceived impact on their respiratory health, and how healthcare professionals (HCPs) consider preterm status when managing these conditions.

Collaborator: Chiesi
Authors: Valentine Ficara, Emilie Pain, Cynthia Lesbros, Bianca Frederico

[POSTER – DSVR 2025] Patient Perspectives on the Lifelong Impact of Preterm Birth in Chronic Respiratory Disease Care

Presented: colloque données de santé en vie réelle (DSVR) (2025)

Approximately 15 million infants are born prematurely each year. Preterm status is often associated with lifelong chronic respiratory conditions, such as asthma and Chronic Obstructive Pulmonary Disease (COPD) [2]. Data on prematurity impact on respiratory disease progression and management in adulthood remain limited. This study aims to investigate patient awareness of their preterm status, its perceived impact on their respiratory health, and how healthcare professionals (HCPs) consider preterm status when managing these conditions.

Collaborator: Chiesi
Authors: Valentine Ficara, Emilie Pain, Cynthia Lesbros

XII. Rheumatology

RHEUMATOID ARTHRITIS

[ARTICLE – Joint Bone Spine 2021] 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-19from 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 Flip

[ARTICLE – Joint Bone Spine 2021] 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 PAthan 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

[ARTICLE – Revue du Rhumatisme 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

[POSTER – ACR 2020] 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

[POSTER – SFR 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

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

[POSTER – Congrès Français de Rhumathologie 2014] Observance et Polyarthrite rhumatoïde : Quels sont les critères mis en avant par les patients ?

Présenté au 27ème Congrès Français de Rhumathologie (2014)

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

ALL RHEUMATOLOGIC DISEASES

[POSTER – EULAR 2019] 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

XIII. Multiple diseases

[ARTICLE – NEJM Catalyst Innovations in Care Delivery 2024] Outcomes or Experiences — What Do Patients Value More When Evaluating Medical Teams?

Published in NEJM Catalyst Innovations in Care Delivery (2024)

As quality-based payment proliferates worldwide, patient outcomes and patient experience measures are increasingly prioritized. However, little is known about whether patients value outcomes or experiences more when choosing a medical team. In a survey of patients across four European countries — France, Italy, Spain, and the United Kingdom — 998 patients with diagnoses of breast cancer, diabetes, inflammatory bowel disease, depression, or arthritis rated the importance of patient-reported outcome measures (PROMs) validated by the International Consortium of Health Outcomes Measurement relative to patient-reported experience measures (PREMs), which lack a standard instrument across Europe.

Collaborator: Academics
Authors: Gregory Katz, Rosalind Bell-Aldeghi, Lise Radoszycki, Damien Testa, Peter Pitts, Zirui Song

[ARTICLE – JMIR Formative Research 2022] Patients' Perspectives About the Treatment They Receive for Cardiovascular Diseases and Mental Disorders: Web-Based Survey Study

Published in Journal of Medical Internet Research (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: Viatris
Authors: Philippe Courtet, Jean-Jacques Mourad, Catherine Pecout, Anne-Felice Lainé-Pellet, Michael Checkroun, Charlotte Avril

[ARTICLE – International Journal of Environmental Research and Public Health 2021] 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: Viatris
Authors: Catherine Pecout, Emilie Pain, Michael Checkroun, Claire Champeix, Claudie Kulak, Rita Prieto, Joris van Vugt, Kim Gilchrist, Anne-Felice Lainé-Pellet

[ARTICLE – Issues in Health Economics 2021] 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

[ARTICLE – BMC Heath Services Research 2020] Chronic patients' satisfaction and priorities regarding medical care, information and services and quality of life: a French online patient community survey

Published in BMC Heath 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

[ARTICLE – Health and Quality of Life Outcomes 2018] 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 (2018)

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

[ARTICLE – PhUSE 2018] Adverse Drug Reactions detection on social media: bias and limitation

Presented: PhUSE – The clinical data science conference (2018)

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

[ARTICLE – Health Technology and Informatics 2017] The Meaning of Patient Empowerment in the Digital Age: The Role of Online Patient-Communities

Published in Studies in Health Technology and Informatics (2017)

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

[ARTICLE – BMJ Innovations 2017] Defining patient centricity with patients for patients and caregivers: a collaborative endeavour

Published in BMJ Innovations (2017)

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

[ARTICLE – Elsevier Masson 2017] Advantages and limitations of online communities of patients for research on health products

Published by Elsevier Masson (2017)

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, Guéroult-Accolas L, Guillot C, Malbezin M, Maugendre P, Micallef J, Molimard M, Montastruc F, Pierron E, Reichardt L, Thiessard F

[POSTER – ISPOR 2023] Patient-Driven Outcome Selection (PDOS): a patient-focused approach for selecting outcomes using patient-generated data

Presented: International Society for Pharmacoeconomics and Outcomes Research (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

[POSTER – ISPOR 2021] 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.

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

[POSTER – ISPOR 2021] 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

[POSTER – CNGE 2021] Étude en vie réelle de l'impact de l'épidémie de COVID 19 sur les patients atteints de maladies chroniques

Présenté : 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

[POSTER – JNI 2021] Impact post déconfinement de la pandémie de COVID 19 sur les patients chroniques en Europe

Présenté : 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.

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

[POSTER – DSVR 2021] Impact post déconfinement de la pandémie de COVID 19 sur les patients chroniques en France

Présenté au colloque données de santé en vie réelle (DSVR) (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 1 er confinement.

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

[POSTER – DSVR 2021] 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 colloque données de santé en vie réelle (DSVR) (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

[POSTER – ISPOR 2020] Patients knowledge on microbiota and acceptability of fecal microbiota transplantation in various chronic diseases

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

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

[POSTER – CMGF 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

[POSTER – DSVR 2020] 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 colloque données de santé en vie réelle (DSVR) (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

[POSTER – ISPOR 2020] 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

[POSTER – ISPOR 2020] 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

[POSTER – JFN 2019] 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

[POSTER – ISPOR 2018] 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) (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

[POSTER – ISPOR 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

[POSTER – ISPOR 2017] 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

[POSTER – ISPOR 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

[POSTER – ISPOR 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

[POSTER – ISPOR 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