



Medical analysis of social networks

Infodemiological studies

Infodemiology was defined by Gunther Eysenbach in the early 2000s as information epidemiology. It is an area of science research focused on scanning the internet for user-contributed health-related content, with the ultimate goal of improving public health.

Kap•Code
FROM DATA TO HEALTH

What happens in 1 MINUTE around the world?



1 million

Are connected*



347 222

Browse Instagram*



87 500

Tweet*



4,5 millions

Watch a video*



Social networks and health



3 out of 10 French people and more than 50% of American have already talked about their health or the health of others on the web



The use of social media has increased with the **health crisis**

WHAT CAN WE DO

with this abundance of data in the **health sector**?



How does social media influence health?



**Treatment/medication
intake**



Healthcare pathway



Misinformation

How does social media influence health?

Life 24/08/2017 19:07

La grogne monte chez les patients sous **Levothyrox**: "le numéro vert mis en place n'est qu'une illusion"

Face au manque d'informations et d'écoute, ils sont nombreux à s'être tournés vers **Facebook**.

Par Sandra Lorenzo

Signalements d'effets indésirables, pétitions, témoignages de personnalités comme Anny Duperey... La machine s'emballe autour du **Levothyrox**.

La polémique autour de la nouvelle formule du Lévothyrox, un médicament utilisé par les patients souffrant de troubles de la thyroïde, ne cesse de croître. "Le 'vent de panique' provoqué et relayé sur les **réseaux sociaux** et certains médias **n'est pas légitime**", s'est ainsi inquiété mercredi le Collège de la médecine générale dans un communiqué.

Covid long : le cri d'alarme de patients

Par La Provence Priscilla Ribeiro, Covid Long Solidarité



Sur les **réseaux sociaux**, les malades du covid long affichent des photos d'eux en noir et blanc réalisant une activité qu'ils ne sont désormais plus capables de faire. Tous ces témoignages sont regroupés sous le #LongCovidAwarenessDay.
PHOTOS TWITTER

Le Pr Salmon-Ceron, a fait partie des premiers spécialistes à "croire" les patients atteints de **Covid long**. Ils se sont tout d'abord heurtés à un grand scepticisme de la part du corps médical, puis retrouvés sur les **réseaux sociaux** en créant l'association AprèsJ20.

L'**Ozempic** est devenu une denrée rare au niveau mondial depuis que les réseaux sociaux, à commencer par le préféré des adolescents, **TikTok**, ont vanté ses vertus. « Des remontées de terrain ont fait état d'un usage parfois détourné, dit hors Autorisation de Mise sur le Marché (AMM), chez des personnes non diabétiques ni malades, dans une volonté de perte de poids », explique l'agence nationale du médicament (ANSM), qui a **lancé l'alerte en France en septembre**.

Société, Santé

Ozempic: l'inquiétante promotion d'un antidiabétique comme coupe-faim sur les **réseaux sociaux**

En France, les autorités s'inquiètent de l'utilisation de cet antidiabétique que beaucoup s'injectent pour perdre du poids. Carine a accepté de nous raconter comment elle s'en est procuré.

What Kap Code offers



01

OBSERVE

- + Infodemiological studies to understand patient behavior
- + Extraction of data on health-related quality of life
- + Identification of needs and difficulties encountered
- + Analysis of healthcare pathways

02

ENGAGE

- + Recruiting patients and caregivers via social networks
- + Applied to observational studies, focus groups and clinical trials

03

MONITOR & ALERT

- + Early detection of pharmacovigilance signals
- + Early detection of fake news
- + Detection of weak signals

Our vision for the past 10 years



SOCIAL MEDIA

A reliable medical source

PATIENT

Whistleblower

SOCIAL NETWORKS

Source of RWE

JMIR CANCER

Original Paper

Patient and Caregiver Perceptions of Advanced Bladder Systemic Treatments: Infodemiology Study Based on Social Media

Simone KANAR¹, PharmD; Paul Lousakakis¹, MS; I. MSc; Ada Mohamdi¹, MSc; Stéphane Schick¹, PhD

Corresponding Author:
Mariusz Blumel, BPharm, MS, PhD
EMD Serono
1 Technology Place
Rockland, MA, 02370
United States
Phone: 1 781 681 2051
Email: mariusz.blumel@emdserrono.com

Abstract

Background: In 2022, it was estimated that more than 8 million people in the United States have been diagnosed with bladder cancer, with a 5-year survival rate of 77%. For most patients, the diagnosis is made after the onset of symptoms, which are often nonspecific and can be mistaken for other conditions. The aim of this study was to assess patient and caregiver perceptions of advanced bladder cancer treatments using social media posts.

Methods: Public posts on social media in the United States, France, and the United Kingdom were collected. The posts included publicly available demographic data and were written in English. Posts mentioning any form of bladder cancer treatment were included in the analysis.

Results: A total of 40 posts by 40 patients and 142 caregivers were identified. The posts were categorized into 10 topics. The most common topics were related to the diagnosis, treatment, and side effects of bladder cancer. The posts also included information about the patient's quality of life, the caregiver's role, and the patient's experience with the healthcare system.

Conclusions: Despite chemotherapy being standard for bladder cancer, particularly among caregivers, additional support is needed for patients and caregivers. The study highlights the need for better communication and support for patients and caregivers.

Keywords: Content analysis, social media, fuzzy matching, symptoms, Covid-19

JOURNAL OF MEDICAL INTERNET RESEARCH

Original Paper

Social Media Platforms Listening Study on Atopic Dermatitis: Quantitative and Qualitative Findings

Paula Vulliamy¹, MSc; Engin Buzdal², MS; Mihal Penthos³, MS; Pami Fritouzi⁴, MSc; Anis Gadi⁵, MSc; Sebastian Boudreau⁶, MD; Laurence Misy⁷, PhD; Stéphane Hasi⁸, MS; Ada Mohamdi⁹, MSc; Nathalie Tesler¹⁰, PharmD; Stéphane Schick¹, MD

Corresponding Author:
Paula Vulliamy, MSc
Public Health and Informatics
J. Hassen et al. (Eds.)
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doi:10.3233/JMIR210308

Abstract

Background: Atopic dermatitis (AD) is a chronic inflammatory skin condition that affects approximately 15-20% of the population. The condition is characterized by intense itching, dry skin, and red, inflamed patches. The diagnosis is often made by a dermatologist, but patients may also seek information from social media. The aim of this study was to explore patient and caregiver perceptions of AD and its treatment using social media posts.

Methods: Public posts on social media in the United States, France, and the United Kingdom were collected. The posts included publicly available demographic data and were written in English. Posts mentioning any form of AD treatment were included in the analysis.

Results: A total of 40 posts by 40 patients and 142 caregivers were identified. The posts were categorized into 10 topics. The most common topics were related to the diagnosis, treatment, and side effects of AD. The posts also included information about the patient's quality of life, the caregiver's role, and the patient's experience with the healthcare system.

Conclusions: Despite the availability of various treatments, patients and caregivers still face challenges in managing AD. The study highlights the need for better communication and support for patients and caregivers.

Keywords: Content analysis, social media, fuzzy matching, symptoms, Covid-19

Covid long : le cri d'alarme de patients

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La grogne monte chez les patients sous Levothyrox: "le numéro vert mis en place n'est qu'une illusion"

Face au manque d'informations et d'écoute, ils sont nombreux à s'être tournés vers Facebook.

Par Sandra Lorenzo

Drug's Approval Widens Path for Rare-Disease Treatments

BY AMY DOCKRILL MARON

Federal regulators approved a drug to treat a debilitating disease using data collected about patients over decades, creating an opening for researchers of other rare conditions who often struggle to prove their treatments work. The Food and Drug Administration on Tuesday approved Neura Pharmaceuticals Inc.'s drug SkySclerax, or omanavone, for treating the neurological disorder Friedreich's ataxia in adults and adolescents age 16 and older.

The FDA last year said results from a single clinical trial didn't sufficiently demonstrate the drug slows the progression of a disease that causes progressive damage to the spinal cord, muscle weakness, and movement problems. Instead of running another trial, Neura submitted additional data including an analysis from a so-called natural history study that has continued to collect information about patients for more than two decades.

"Data created by patient

communities can be regulatory grade," said Annie Kennedy, chief of policy, advocacy and patient engagement at the Evelyn F McKnight Foundation for Rare Diseases, a nonprofit advocacy group. "This approval is proof of that principle."

Unlike clinical trials, natural history studies don't test a drug. Instead, patients every year undergo a battery of tests to track how a disease is progressing. For its omanavone analysis, the Neura investigators compared disease progression in patients who received the drug with people

in the natural history study who were close matches based on factors including gender and age of diagnosis but didn't take omanavone.

Neura's pivotal trial included 103 patients, drawn primarily from the approximately 25,000 people worldwide with the disorder, mainly in the U.S., Europe and Australia. Some traveled hundreds or more miles to reach trial sites. Not everyone interested in participating was eligible.

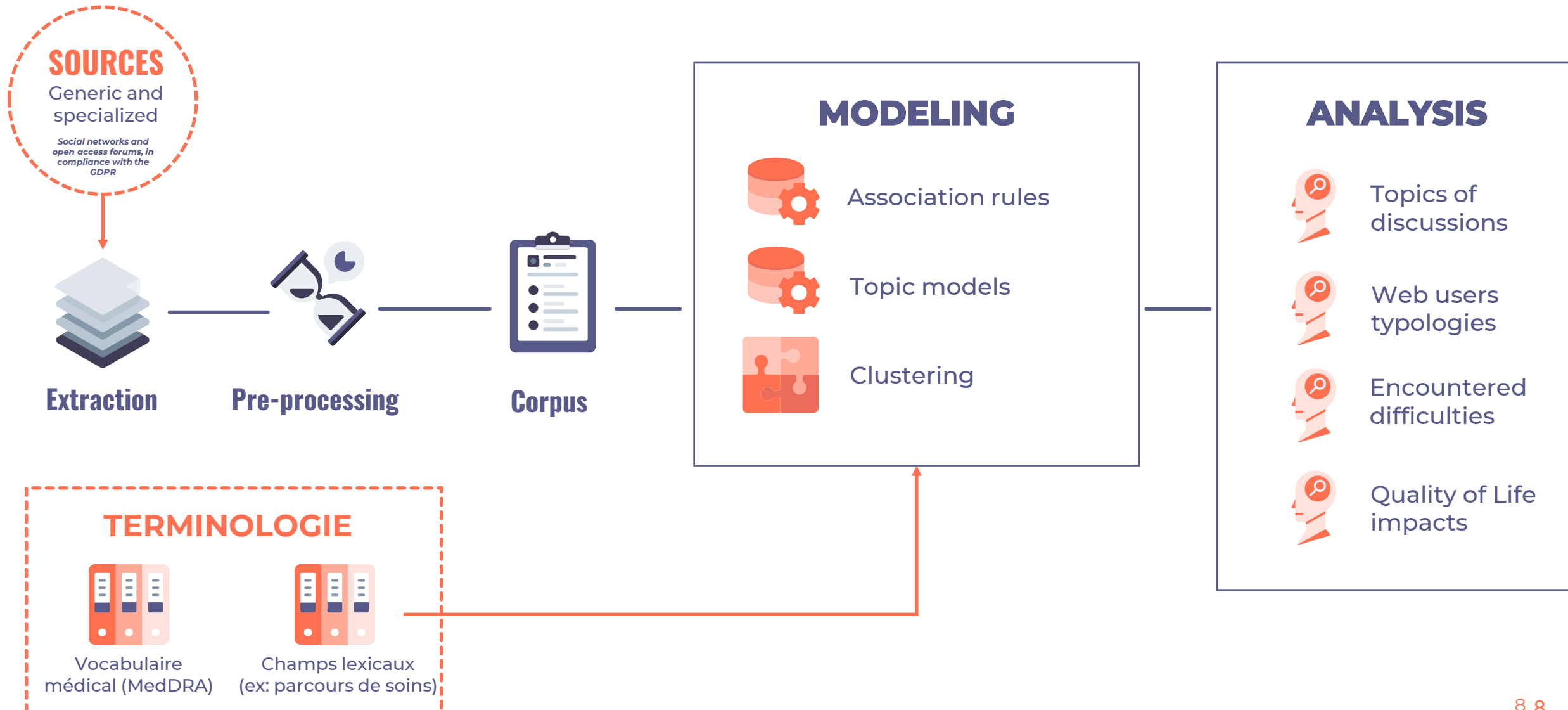
An analysis by Friedreich's ataxia clinicians and Neura determined that people who received the drug and continued

to take it over three years experienced an almost 55% reduction in the progression of the disease compared with people in the natural history study who didn't receive the drug.

"The data collected in the natural history study were critical to showing the drug's benefit," said Neura CEO J. Warren Luff.

The company said it plans to charge \$370,000 a year for the drug and that through insurance and a patient assistance program, patients should be able to gain access.

How does it work?



Detec't methodology



EXTRACTION

Yesterday I had an appointment at the hospital with my OBGYN et and it seems that my pregnancy get complicated, due to my medications ... #FML

ENTITY DETECTION

Yesterday *Pronoun* **I** *Verb* **had** an *Event* **appointment** at the *Medical centre* **hospital** with my *Pregnancy* **OBGYN** et and it seems that my *Healthcare practitioner* **pregnancy** get *Problematic* **complicated**, due to my *Therapeutics* **medications** ... #FML

STEMMING

«Yesterday I had an appointment at the hospital with my OBGYN et and it seems that my pregnancy get complicated, due to my medications ... #FML »

MESSAGE CLASSIFICATION

1st category

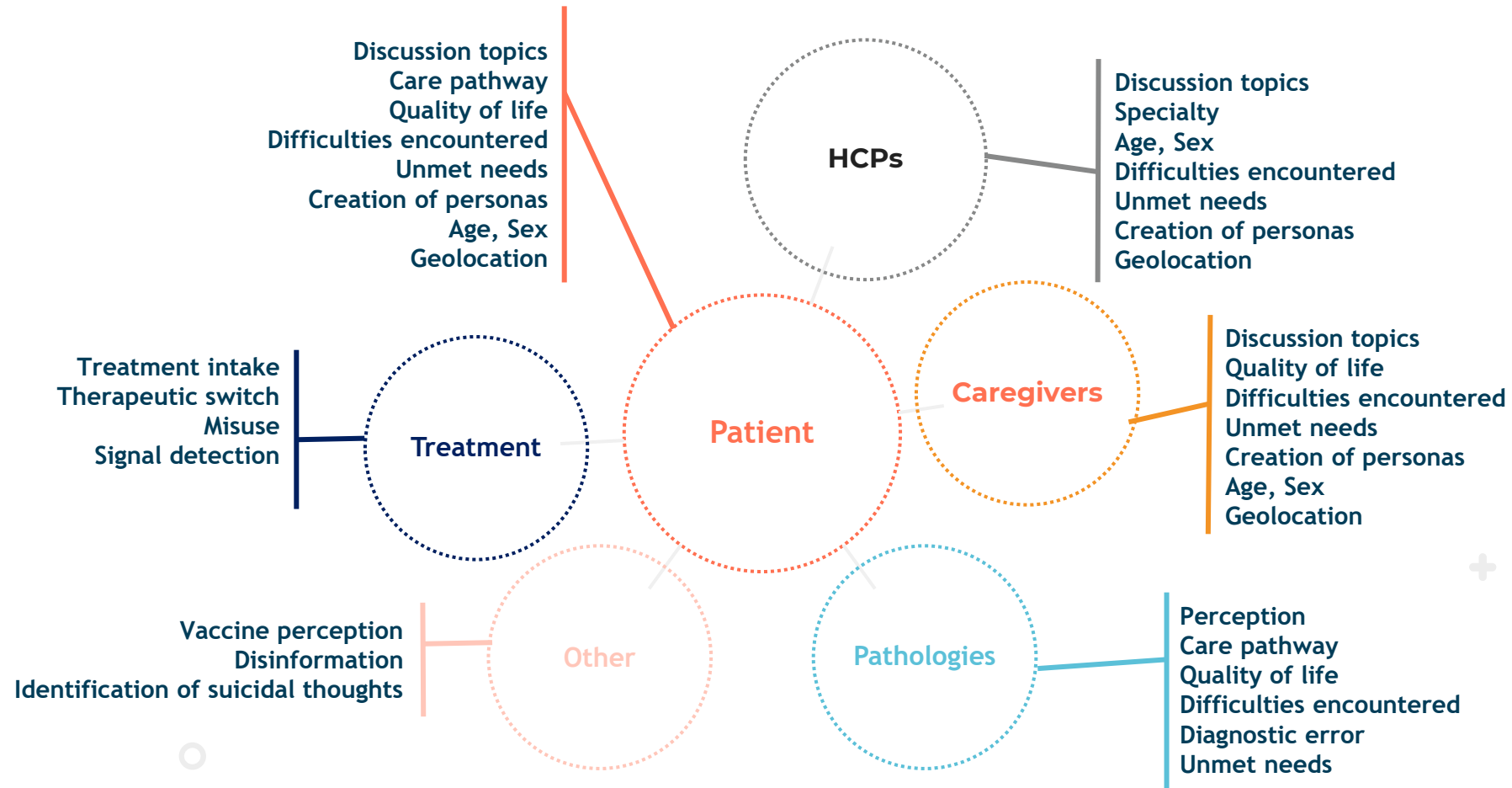
2nd category

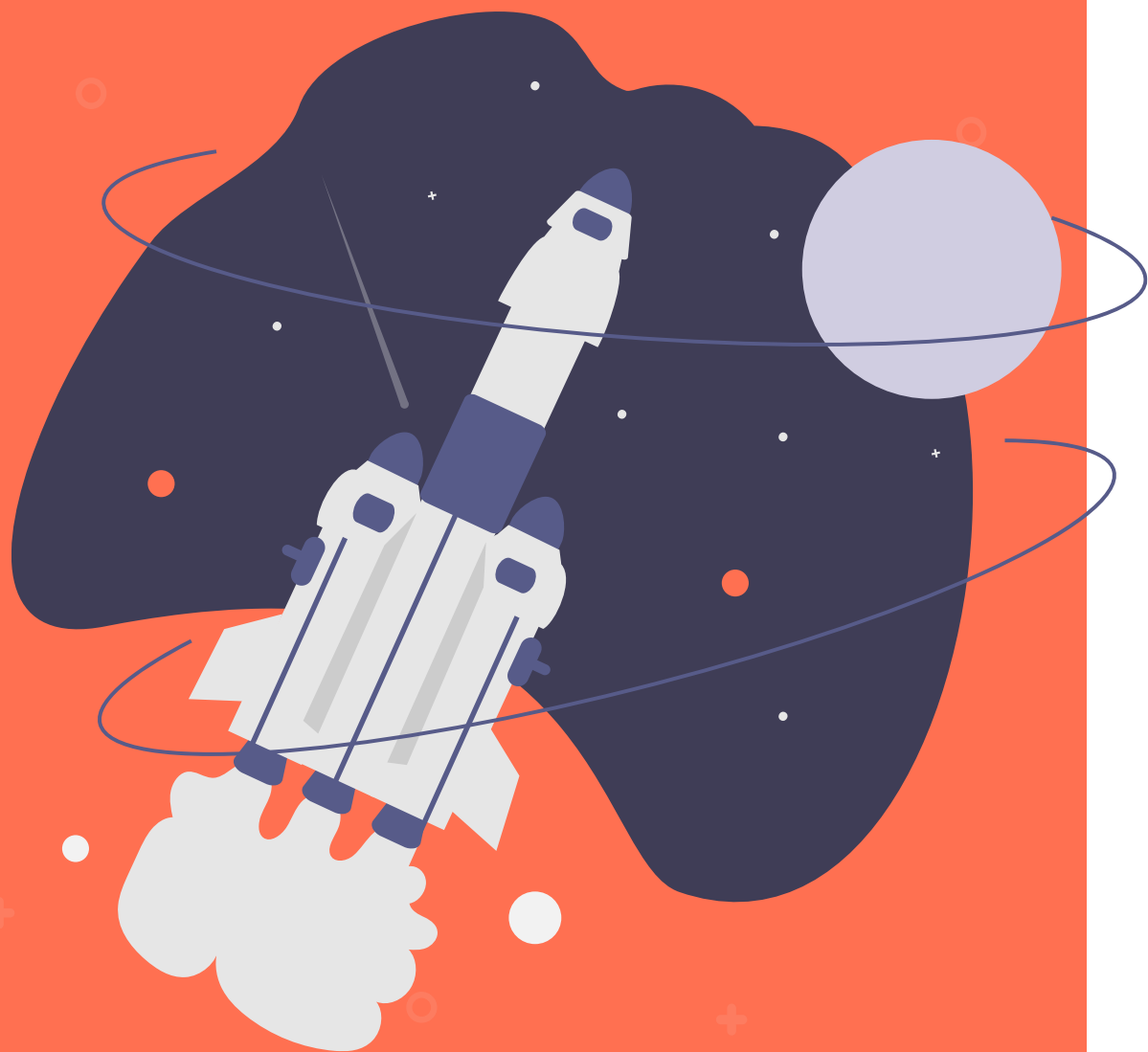
3rd category

Detec't is an **automated** social network analysis based on **methods** of artificial intelligence and text mining

The algorithms we develop

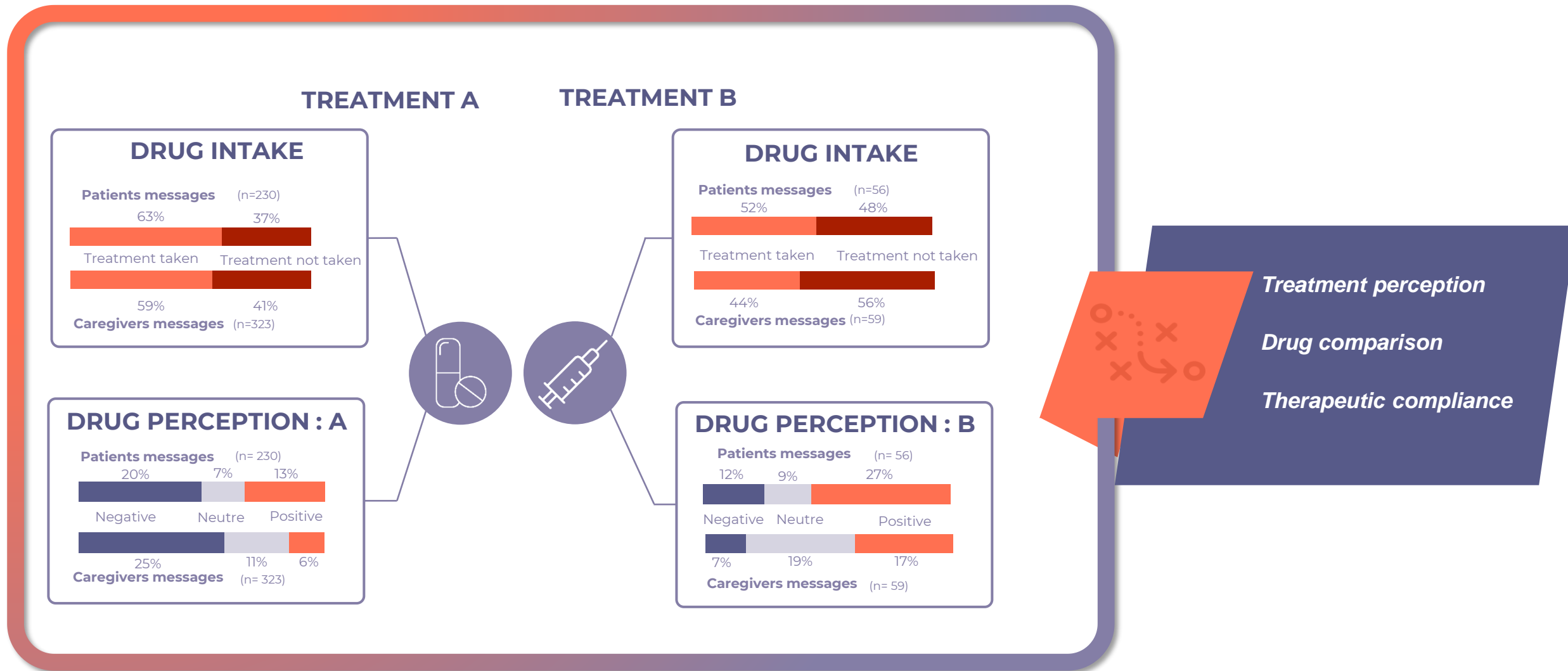
Addressable digital populations





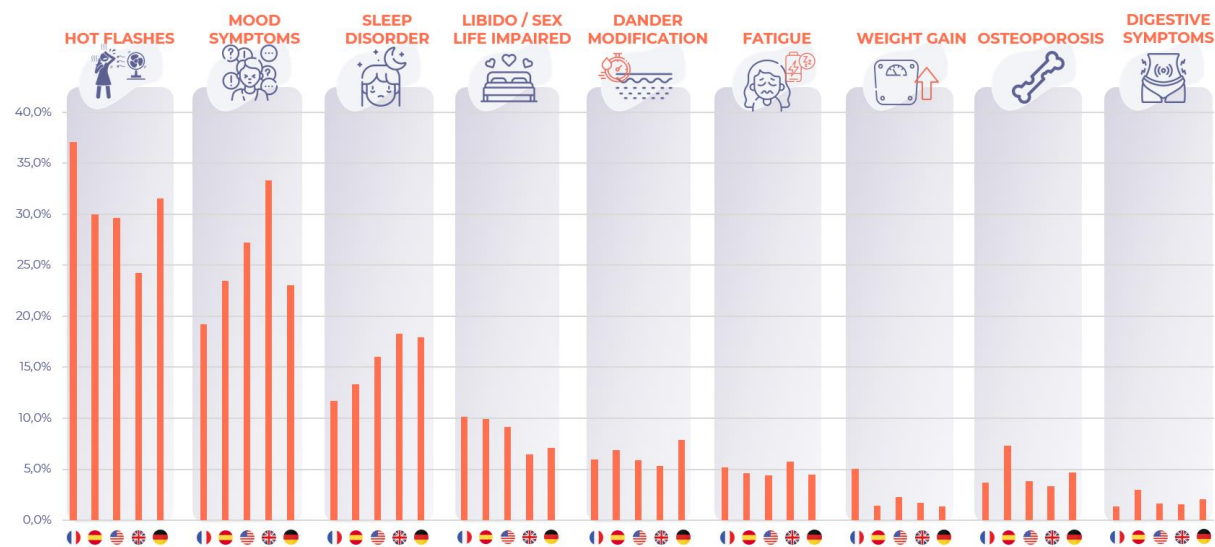
Some use cases

Use case : drug perception

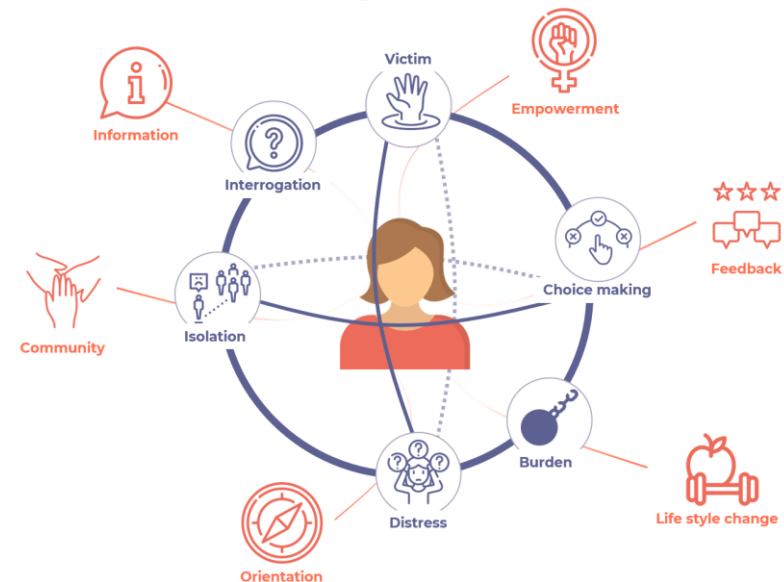


Use case : Woman health

Objectivation of clinical symptoms and everyday burden



Key levers to be a preferred partner for patients, according to their needs



5 countries analyzed

From clinical reality, to everyday burden

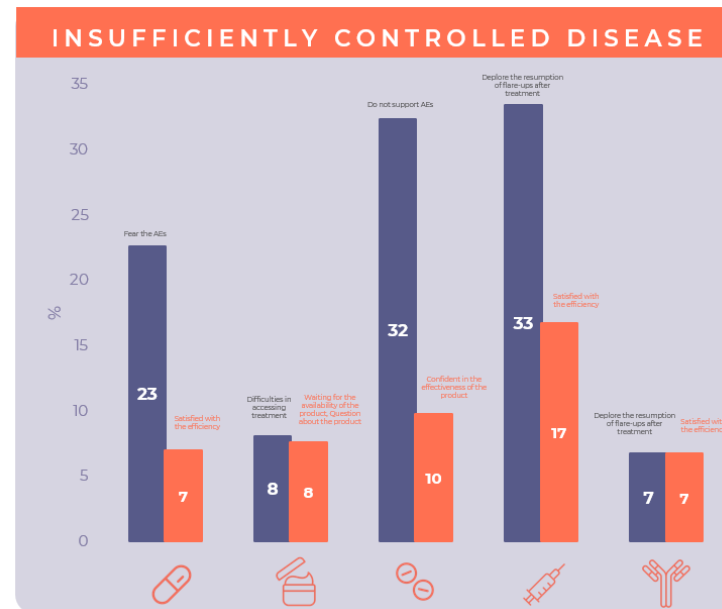
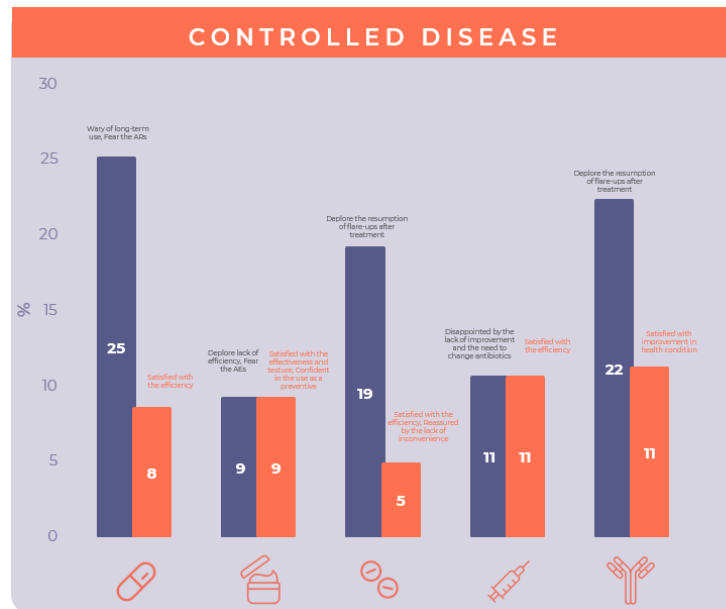
Solutions identified by patients

Omnichannels communication strategy

Positionning counselling

Use case: Skin disease control

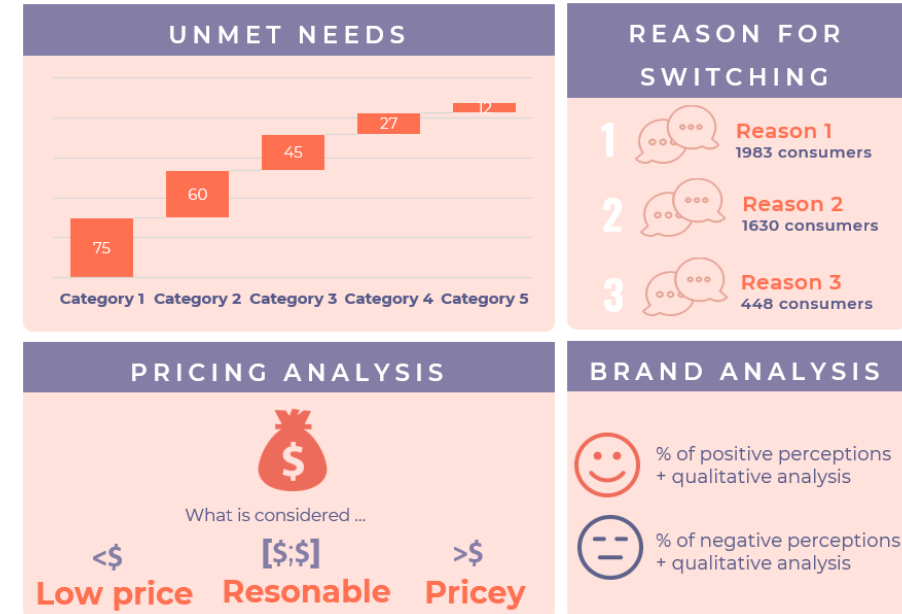
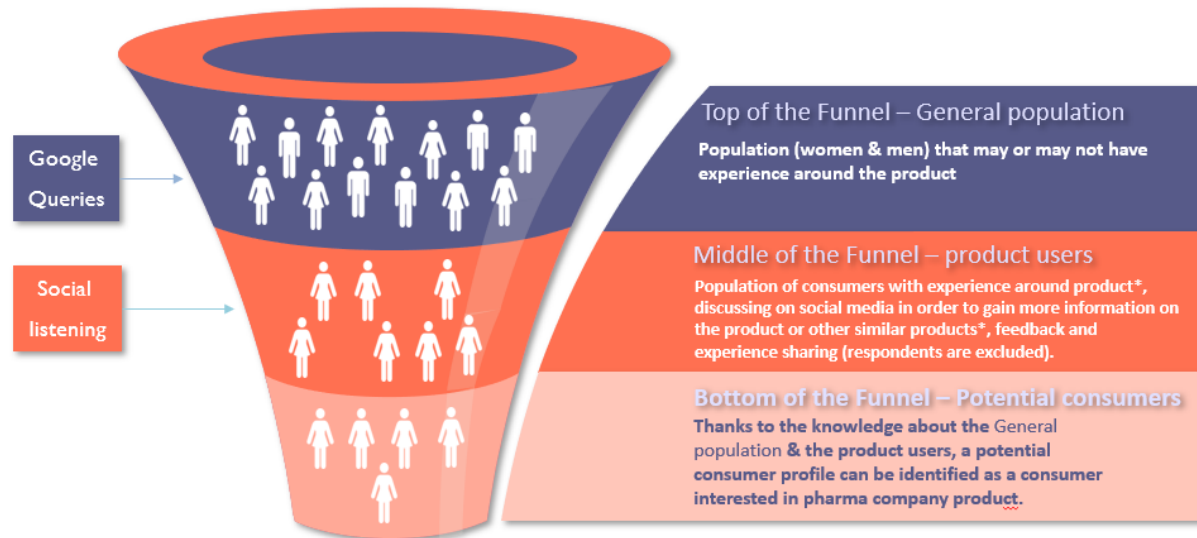
Medical service rendered, patients perception and satisfaction, according to therapeutic



Evaluation of symptoms control

Perceptions, fears and satisfaction associated with treatment

Use case : Market research – product launch



Over the counter medication market

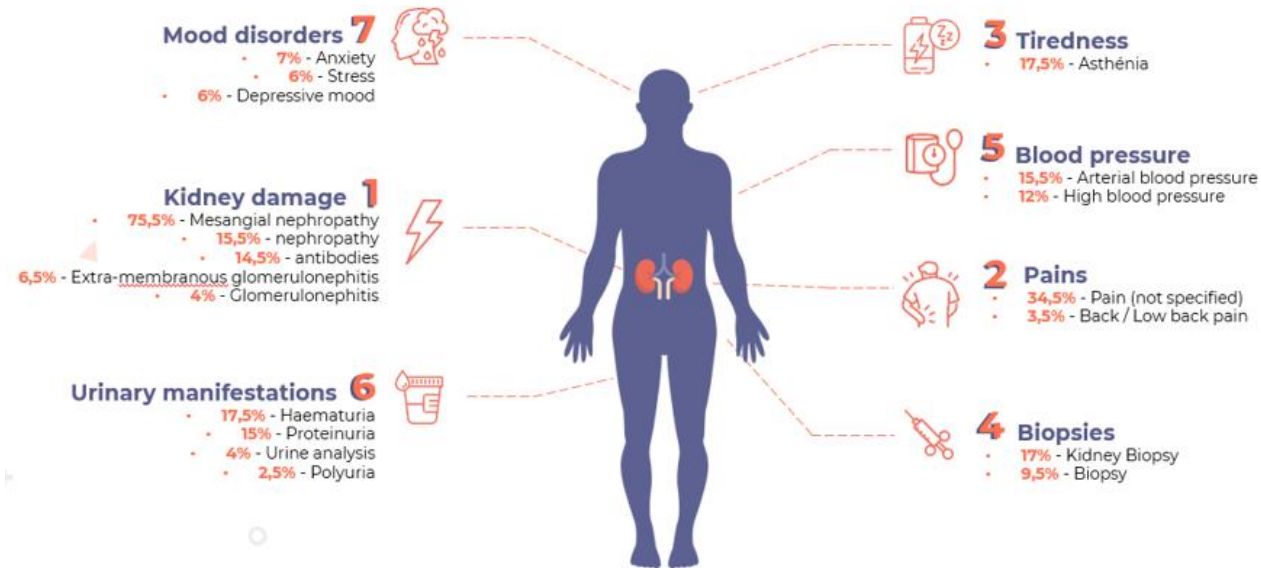
Visualizing patient market through internet

Product launch optimization

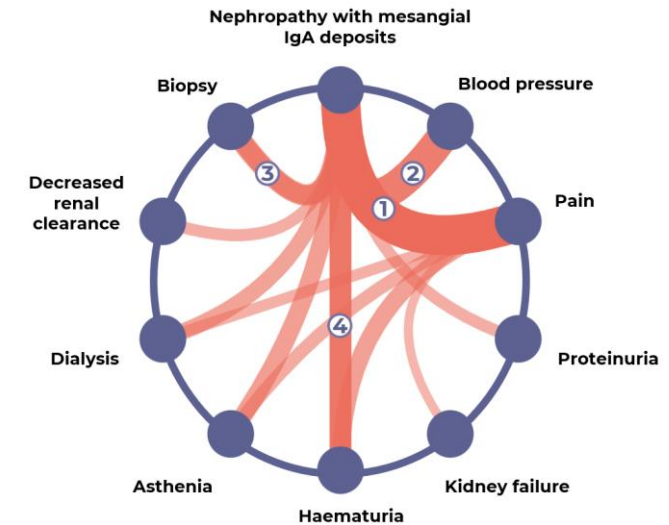
Competitive intelligence analysis

Use case : Patient insights on rare disease

Medical concepts expressed by patients



Links between key milestones (2)



Objectifying patient experience

Disease impact on Quality of Life

Healthcare pathway with patient perspective at every step

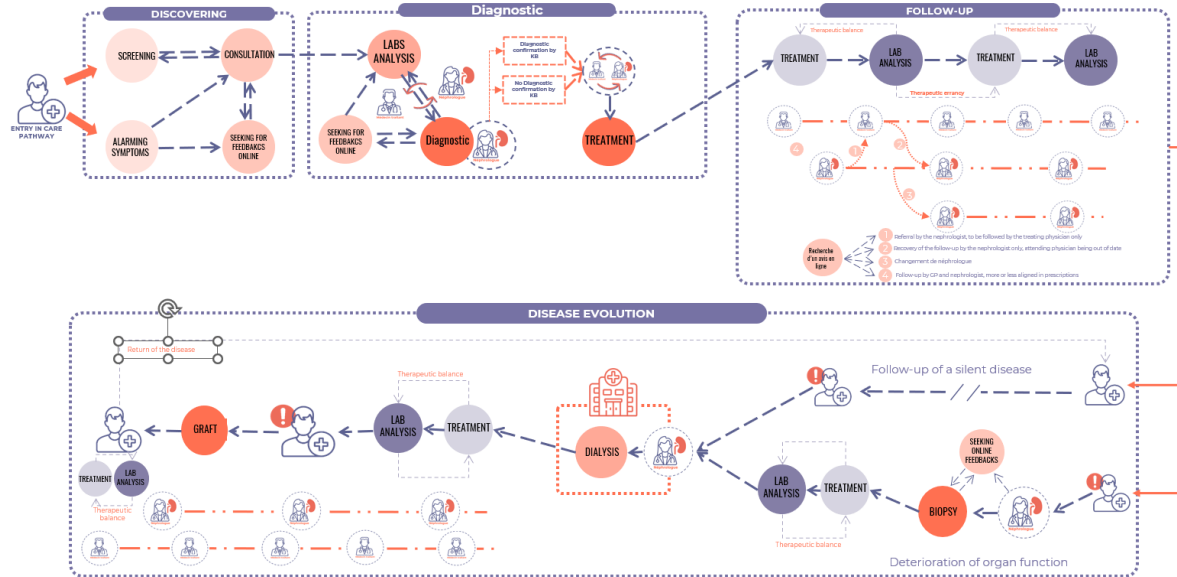
Patients experience and pain points

Caregivers perspective

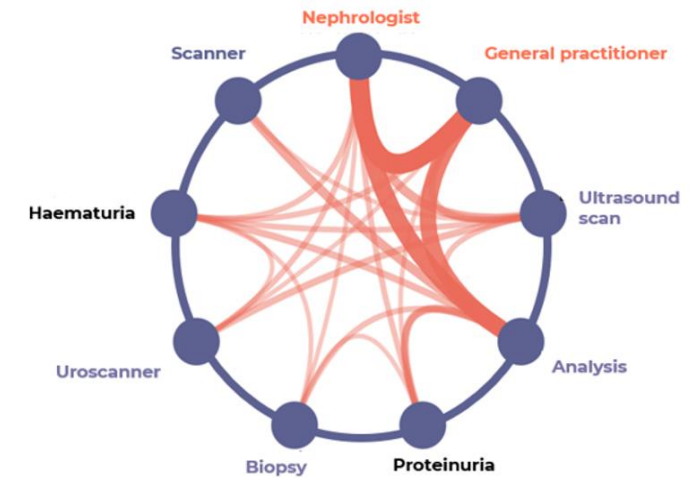
Unmet Needs

Use case: rare disease patient care pathway

Care pathway reconstitution thanks to patients verbatims



Links between key milestones



Objectiver l'expérience du patient

Impact de la maladie sur la qualité de vie

Parcours de santé avec le point de vue du patient à chaque étape

Difficultés rencontrées

Caregivers perspective

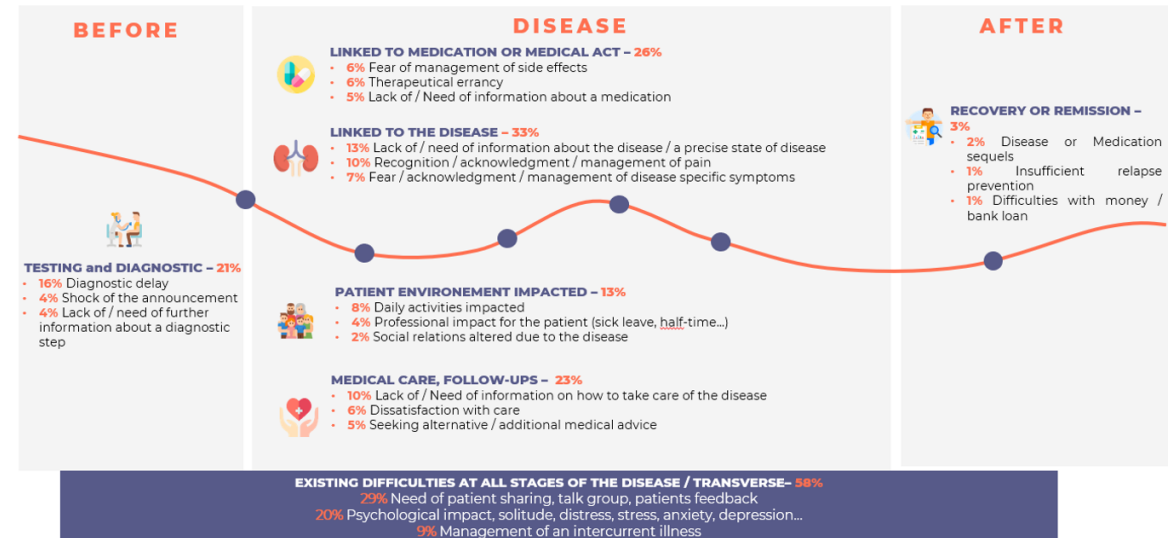
Besoins non couverts

Use case : Patient insights on rare disease

Categories of difficulties



Classification of difficulties through care pathway



Objectifying patient experience

Disease impact on Quality of Life

Healthcare pathway with patient perspective at every step

Patients experience and pain points

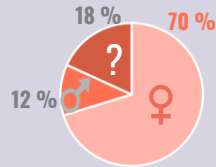
Caregivers perspective

Unmet Needs

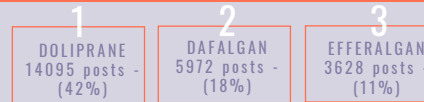
Use case : Drug monitoring

SOCIO-DEMOGRAPHIE

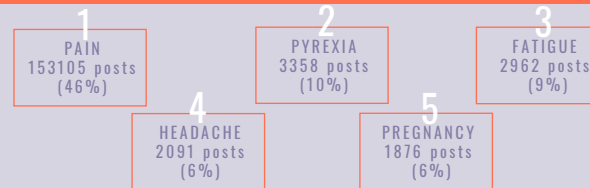
33 196 messages
17 070 auteurs
1.9 posts/users



SPECIALITES



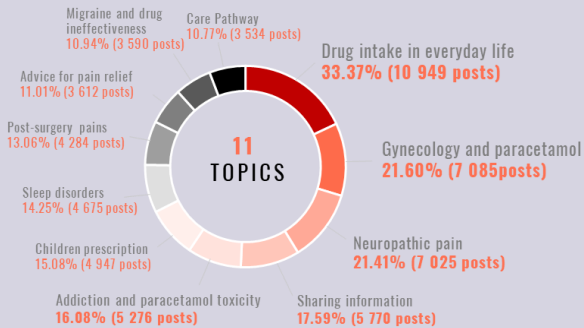
CONCEPTS MEDICAUX



EI POTENTIELS

POTENTIEL EI	n	%	FREQUENCE	ATTENTE
FATIGUE	643	5.01%	COMMUN	ATTENDU
DEPENDENCE	334	2.60%	COMMUN	INATTENDU
NAUSEE	306	2.38%	COMMUN	ATTENDU
VOMISSEMENT	292	2.27%	COMMUN	ATTENDU
SOMNOLENCE	225	1.75%	COMMUN	INATTENDU

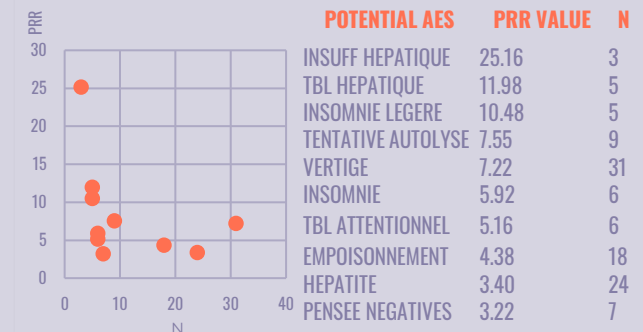
TOPICS DISCUSSED



PRISES CONCOMITTANTES



DETECTION DE SIGNAL



Patients experience and pain points

The patient reality

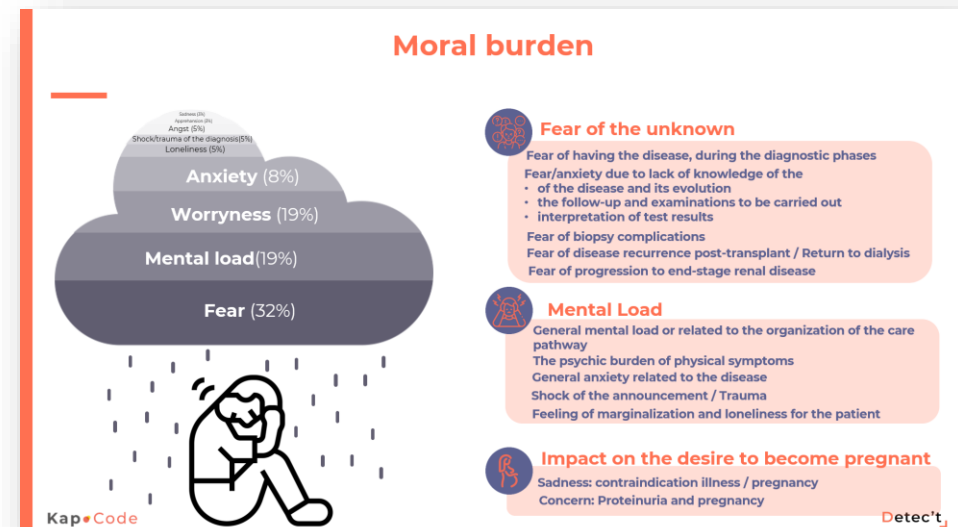
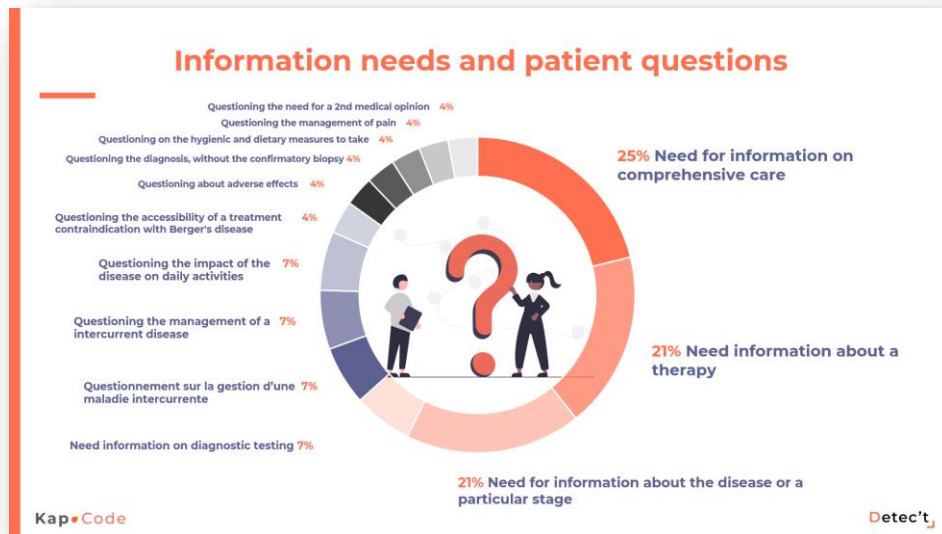
Beyond the analysis, taking into account their testimonies, understanding their daily burdens and unmet needs, are tools for improving care.

“

Let's not confuse "patient-centeredness" with "customer orientation. For medicine, being patient-centered is not a strategy. It is the condition of its existence, the process from which it emerges:

Richards T, Montori VM, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. BMJ. 14 mai 2013;346:f2614. its origin.

”



Kap Code – from regional to global

4 continents



11 countries

United States

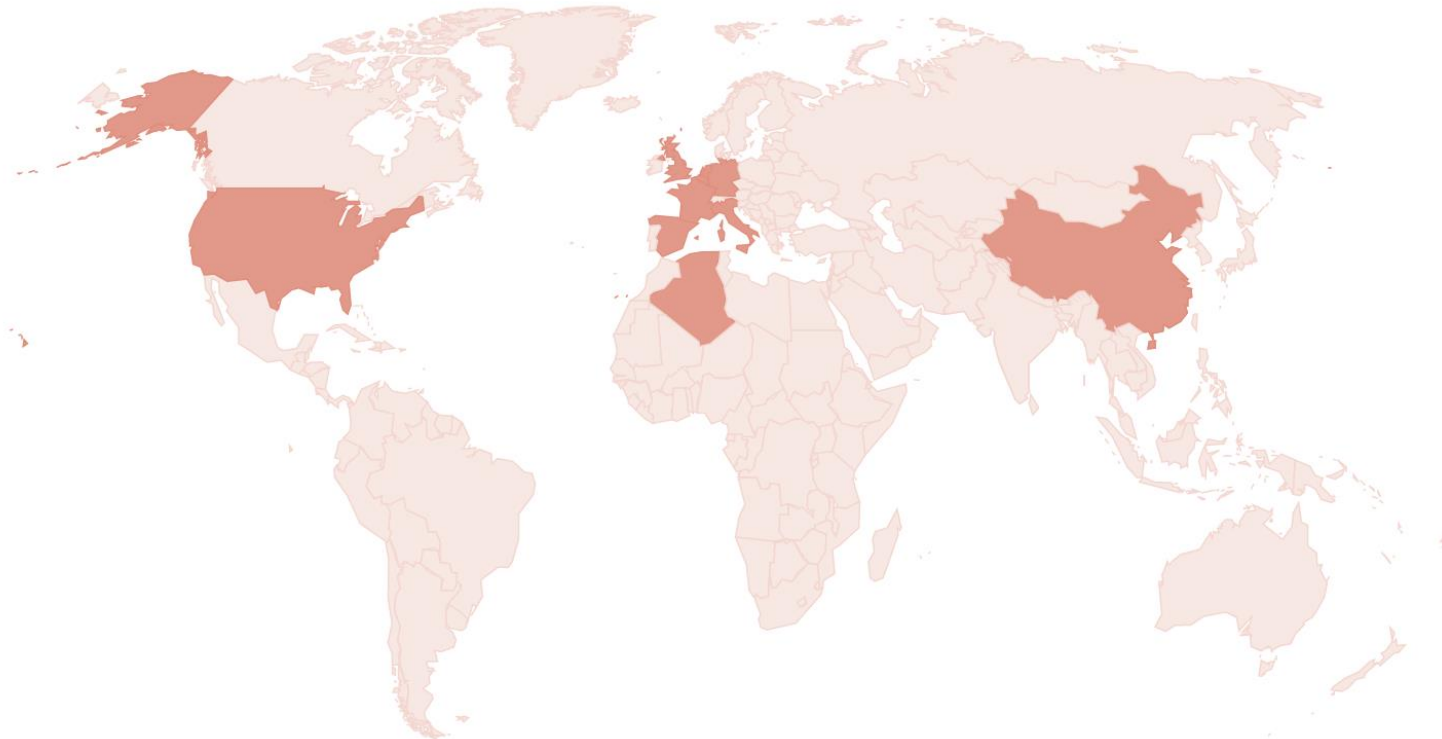
United Kingdom

France

Spain

+ Italy

Algeria



China

Netherlands

Luxembourg

+

Belgium

Germany

Today, our ecosystem

Excellence
ACADEMIC

PR[AI]RIE

PaRis Artificial Intelligence Research InstitutE



Excellence
PHARMACEUTICAL



Excellence
CORPORATE



Trust earned

 Bristol Myers Squibb^{MC}




Pierre Fabre

The Sanofi logo consists of the word "sanofi" in a bold, black, sans-serif font. A small purple dot is positioned above the letter "i".

NORDIC
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INVENTING FOR LIFE

 Chiesi
People and ideas for innovation in healthcare

AstraZeneca 

MERCK



 Pfizer



Boehringer
Ingelheim

 Amicus
Therapeutics[®]

 NOVARTIS

 FMA
OBSERVATOIRE FRANÇAIS
DES MÉDICAMENTS ANTALGÉSIQUES

leem
les entreprises
du médicament

 Santé
publique
France

 Cancer
Contribution

 FERRING
PHARMACEUTICALS

 Inserm

ansm
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et des produits de santé



 Shire

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healthcare with passion and conviction



contact@kapcode.fr



+33 9 72 60 57 55

+33 6 23 75 54 68



www.kapcode.fr



146, rue Montmartre 75002 Paris FRANCE



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FROM DATA TO HEALTH