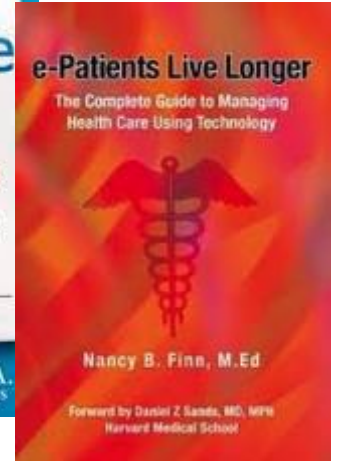
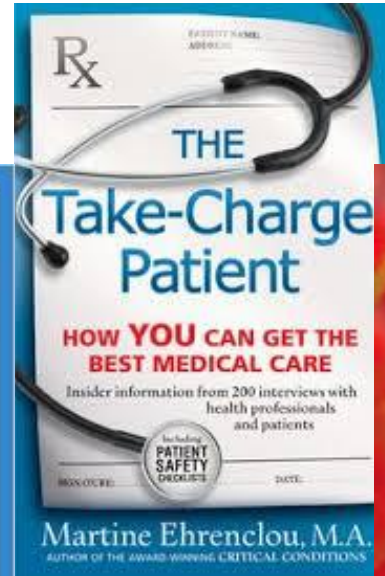
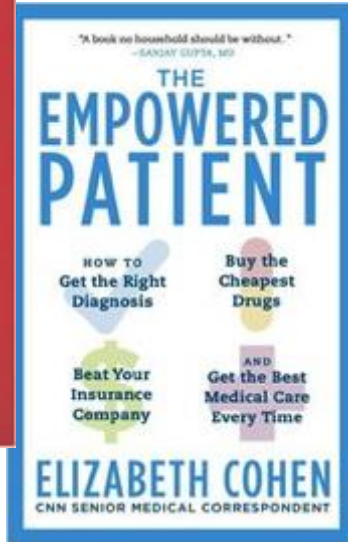




**Outils contribuant au “health literacy” du patient: plateforme de partage d’informations avec et entre les patients**

Mitchell Silva, PhD  
CEO Esperity

# Un monde sans cesse en évolution



# Les patients en veulent plus



**68%** des patients vont sur le net pour chercher d'autres options thérapeutiques



Durant les consultations, **61%** des patients sont actifs et posent des questions précises sur leurs traitements



**71%** veulent utiliser des applications mobiles touchant le domaine de la santé

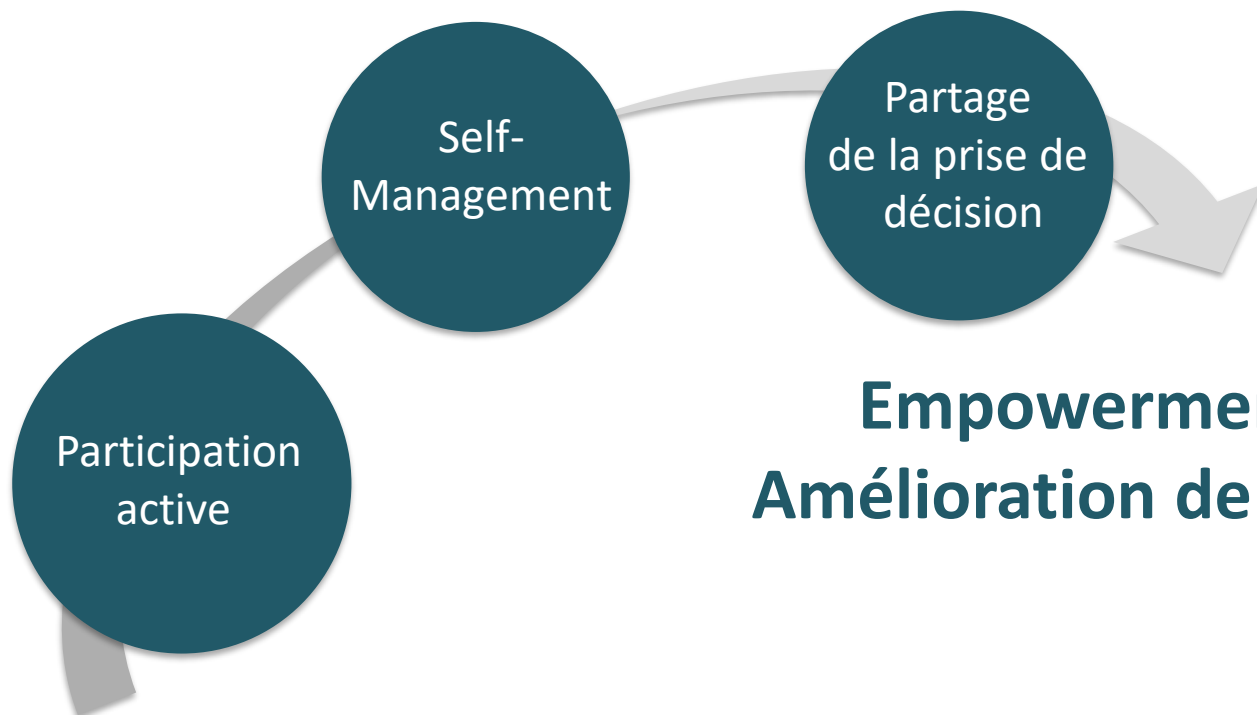


**90%** sont prêts à partager leurs données si cela permet d'améliorer leurs options thérapeutiques



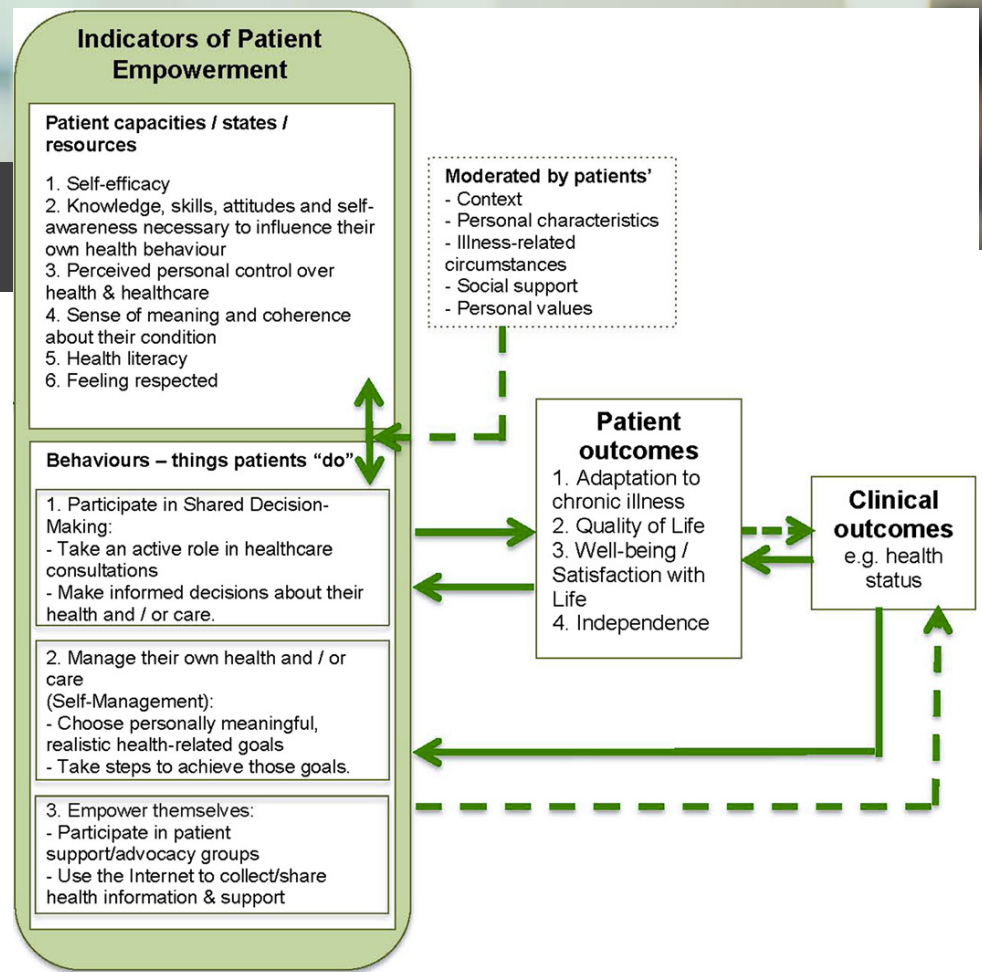
**61%** partagent leurs données avec d'autres médecins; **28%** ne sont pas opposés à partager ces données avec des groupes pharmaceutiques

## Qu'est-ce que l'empowerment du patient ?

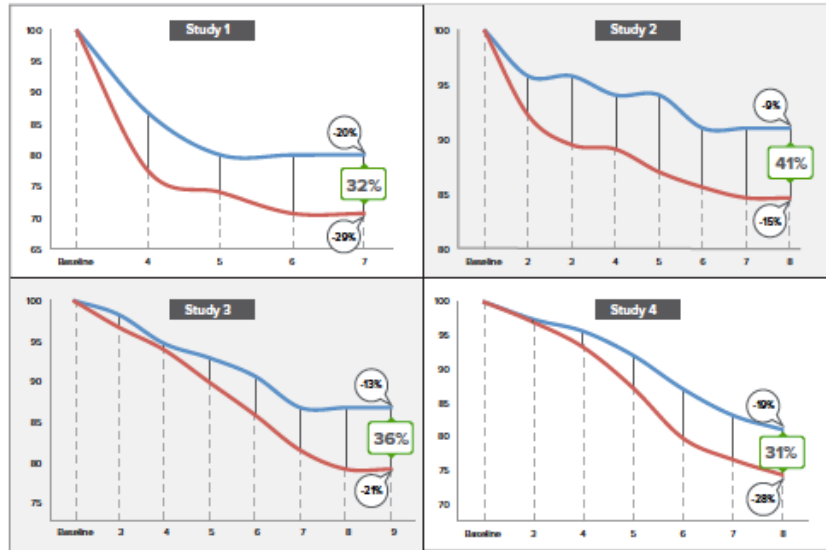


**Empowerment du patient,  
Amélioration de la Qualité de Vie**

# Empowerment du patient



# Empowerment du patient



## Indicators of Patient Empowerment

### Patient capacities / states / resources

1. Self-efficacy
2. Knowledge, skills, attitudes and self-awareness necessary to influence their own health behaviour
3. Perceived personal control over health & healthcare
4. Sense of meaning and coherence about their condition
5. Health literacy
6. Feeling respected

### Behaviours – things patients “do”

1. Participate in Shared Decision-Making:
  - Take an active role in healthcare consultations
  - Make informed decisions about their health and / or care.
2. Manage their own health and / or care (Self-Management):
  - Choose personally meaningful, realistic health-related goals
  - Take steps to achieve those goals.
3. Empower themselves:
  - Participate in patient support/advocacy groups
  - Use the Internet to collect/share health information & support

### Moderated by patients'

- Context
- Personal characteristics
- Illness-related circumstances
- Social support
- Personal values

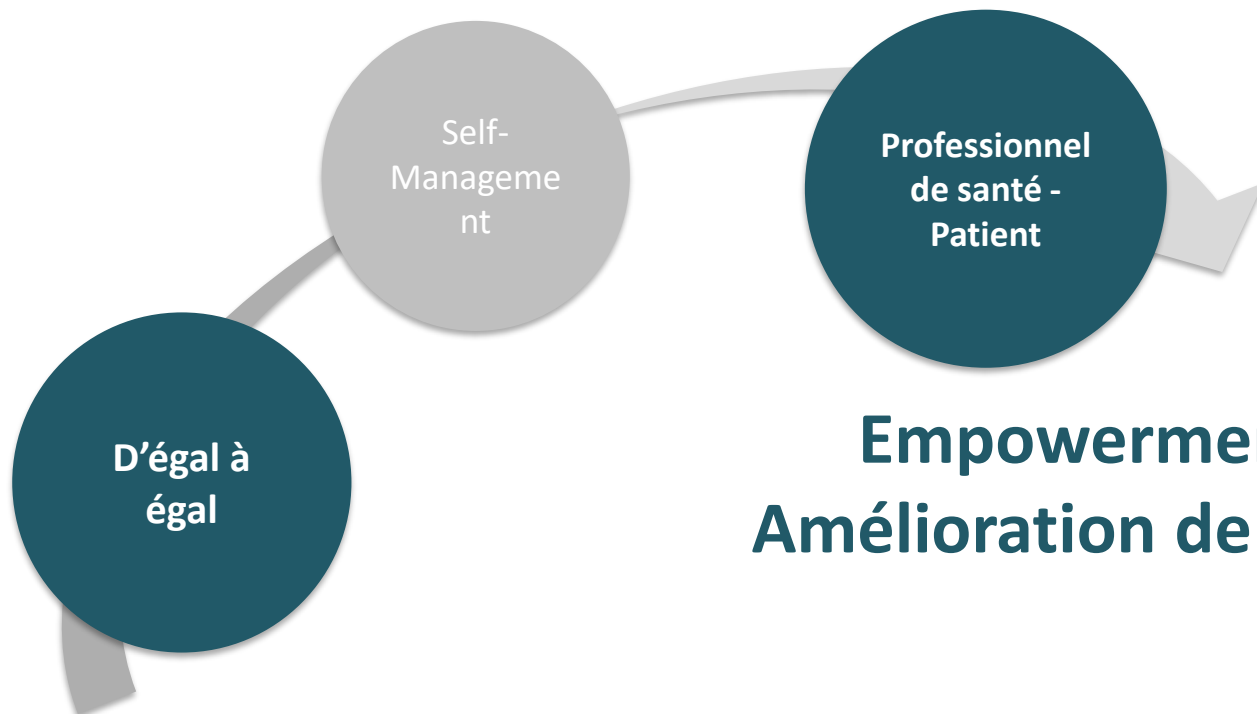
### Patient outcomes

1. Adaptation to chronic illness
2. Quality of Life
3. Well-being / Satisfaction with Life
4. Independence

### Clinical outcomes

e.g. health status

# Quelle place pour les communautés ?



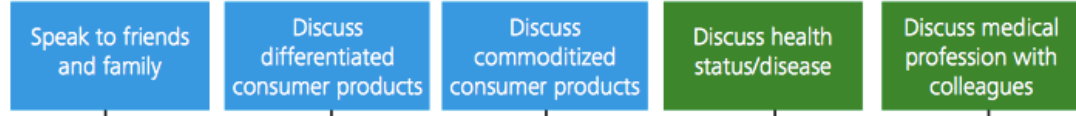
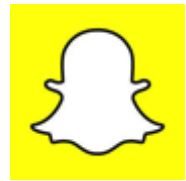
**Empowerment du patient,  
Amélioration de la Qualité de Vie**

Pairs





# Différents types de médias sociaux



Social network purpose

*Recreational*

*Transactional*

Platforms

General network

*Facebook*

*www.disease.org, www.physiciangroup.com*

Health focus commonality, screening and validation of participants




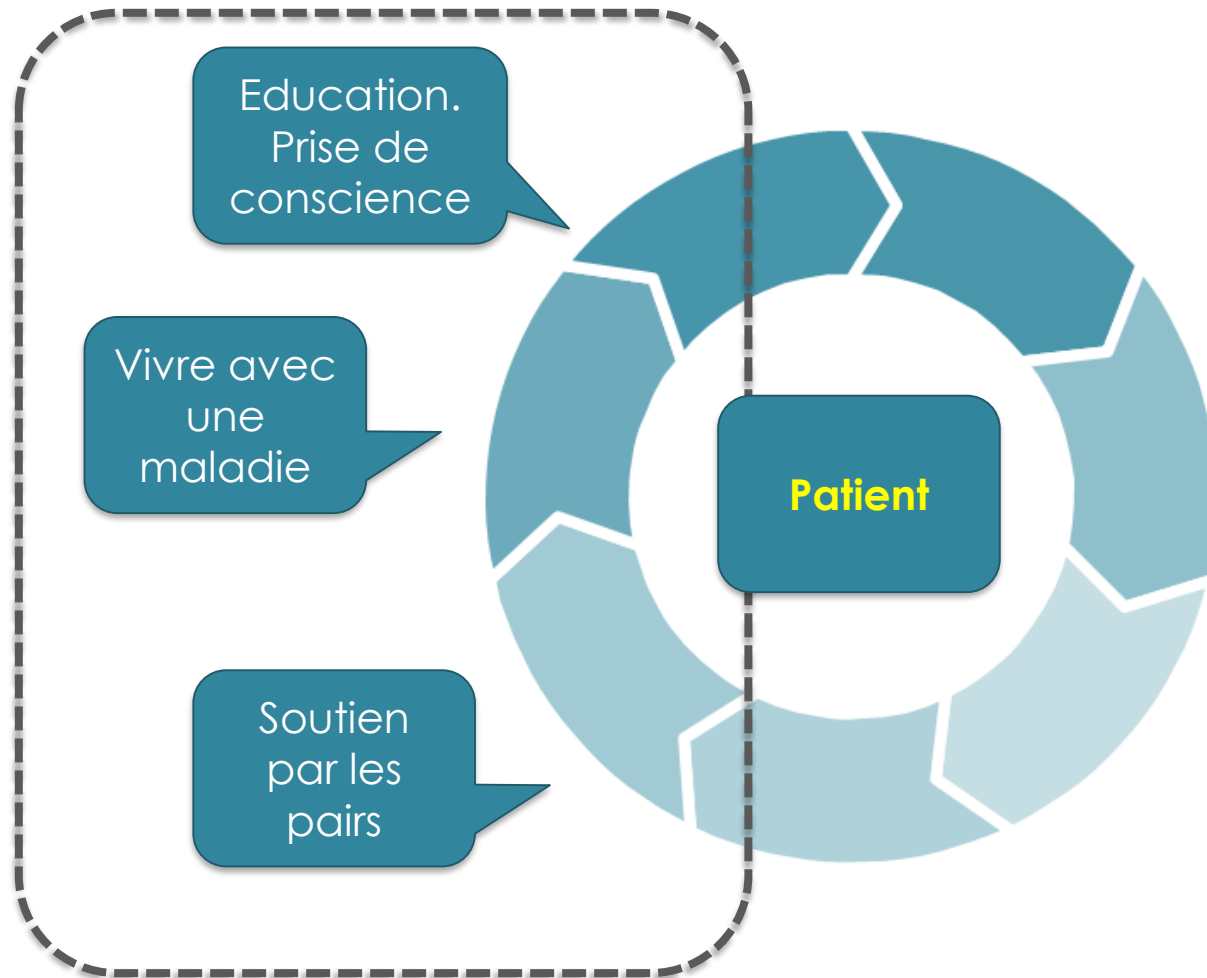
*instapeer.org*

*myHealthTeams*



## Bénéfices pour les patients, les aidants-proches & leurs supporters

- 
- **Apprenez** ce que les autres ressentent : symptômes, réactions aux traitements
  - **Accédez** aux informations en temps réel : devenez actif dans votre parcours de soins en améliorant votre connaissance
  - **Connectez-vous** à d'autres patients : trouvez du soutien. Vous n'êtes pas seuls !  
**Devenez pro-actif** : cherchez les informations pour poser les bonnes questions aux professionnels de santé



# Let's build our community together!

You will always be among friends on esperity.  
Join our community today!

[CREATE YOUR FREE ACCOUNT](#)



## GET CONNECTED

You are not alone! Connect to other patients and caregivers



## MANAGE YOUR LIFESTYLE

Measure your quality of life, track your evolution and benefit from recommendations that help you maintain a healthy lifestyle.



## TRACK YOUR HEALTH

Follow your condition over time to get richer personalized insights



## FIND CLINICAL TRIALS

Discover ongoing clinical trials in your area



# Education Portal

## My Health Journal

[My Profile](#)[My Lifestyle](#)[My Health](#)[My Condition](#)

## My Communities

[General](#)[Breast Cancer](#)[Colorectal Cancer](#)[Jejunum Cancer](#)[Lung Cancer](#)[Pancreatic Cancer](#)[Prostate Cancer](#)[Research Project](#)[Search for more...](#)[Settings](#)[My Messages](#)[My Friends](#)[Clinical Trials](#)[Information & Blog](#)

## Community

Breast Cancer

[STORIES](#)[DISCUSSIONS](#)[MEMBERS](#)[INFORMATION](#)[CLINICAL TRIALS](#)[BACKEND](#)

## The importance of a healthy lifestyle



An improved lifestyle can have a significant **impact on quality of life**. In some cases, a better lifestyle can lead to a better tolerance of a treatment and reduced side effects after or during a treatment. Several research papers have individually confirmed the positive correlation between lifestyle and quality of life for specific cancer types.

Scientific literature links the following indicators to **lifestyle**: **level of physical activity, sleep quality, nutrition, smoking behavior, alcohol consumption and stress level**. These indicators are used to [calculate a 'Lifestyle Score'](#) on Esperity. By following your lifestyle score over a certain period of time you might see fluctuations that can make you aware about specific indicators of lifestyle that deserve a bit more attention.

## What are the recommendations?

[BRCA and can](#)[Triple Negative](#)[Physical activit](#)[Stress](#)[Nutrition](#)[Supplements](#)[Sleep](#)[Drinking alcoh](#)[Smoking](#)



# Clinical Trials



## Colorectal Cancer

[STORIES](#)[DISCUSSIONS](#)[MEMBERS](#)[INFORMATION](#)[CLINICAL TRIALS](#)

### What is a clinical trial?



A clinical trial is a research study conducted with patients to evaluate whether a new treatment is safe (safety) and whether it works (efficacy). Clinical trials are performed to test the efficacy of drugs but also non-drug treatments such as radiotherapy or surgery and combinations of different treatments.

Click [here](#) to search for clinical trials.

[Why test a new treatment?](#)[Possible risks and benefits](#)[How can I participate?](#)[What are my rights?](#)[Search a clinical trial](#)

This content has been written in collaboration with the [Anti Cancer Fund](#).



# Maintaining a healthy lifestyle

- My Health Journal
- My Profile
- My Lifestyle
- My Health
- My Condition

- ### My Communities
- General
  - Breast Cancer
  - Colorectal Cancer
  - Jejunum Cancer
  - Lung Cancer
  - Pancreatic Cancer
  - Prostate Cancer
  - Research Project
  - Search for more...

- ⚙ Settings
- ✉ My Messages
- 👤 My Friends
- 📄 Clinical Trials
- 📖 Information & Blog

Your Profile is 100% Complete

### Calculate Your Score

Monday, Feb 1, 2016 

**Physical Activity**   


0 min 30 min

**Hours of Sleep**   


0 h 7 h

**Stress**   
0

**Fruit & Vegetables Servings**   
0 servings

0 1 2 3 4 5 6 7

**Did you Smoke today?**   
no

**Alcohol Intake**   
0 glasses

0 1 2 3





# Health tracking module

## My Health Journal

[My Profile](#)
[My Lifestyle](#)
[My Health](#)
[My Condition](#)

## My Communities

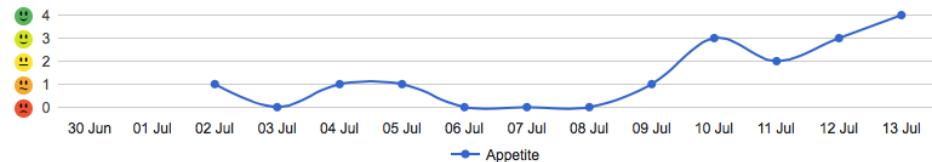
[General](#)
[AKIO](#)
[Breast Cancer](#)
[Caregivers](#)
[Colorectal Cancer](#)
[Groupe Maladie de Pompe](#)
[Jejunum Cancer](#)
[Lung Cancer](#)
[Lymfklierkanker Vereniging Vlaanderen](#)
[LVV](#)
[Mésiothéliome \(tumeur pleurale, peritonéale, péricardiale\)](#)
[Ons Steentje](#)
[Pancreatic Cancer](#)
[Prostate Cancer](#)
[Research Project](#)
[StopDarmkanker](#)
[Vie et Cancer](#)
[Search for more...](#)
[Quality Of Life](#)
[Symptoms](#)
[Treatment](#)
[Consultations / Medical Exams](#)
[Genetics](#)
[Evolution](#)
[Agenda](#)

## Evolution

Quality Of Life

[Appetite](#)
[Depression](#)
[Mood](#)
[Pain](#)
[Sex drive](#)
[Sleep quality](#)
[1 Week](#)
[2 Weeks](#)
[1 Month](#)

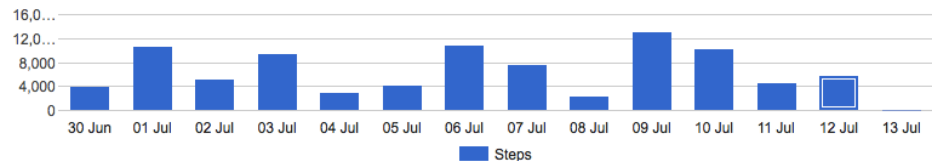
✕



## Number of steps

[1 Week](#)
[2 Weeks](#)
[1 Month](#)

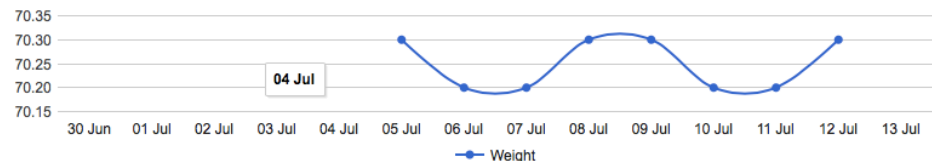
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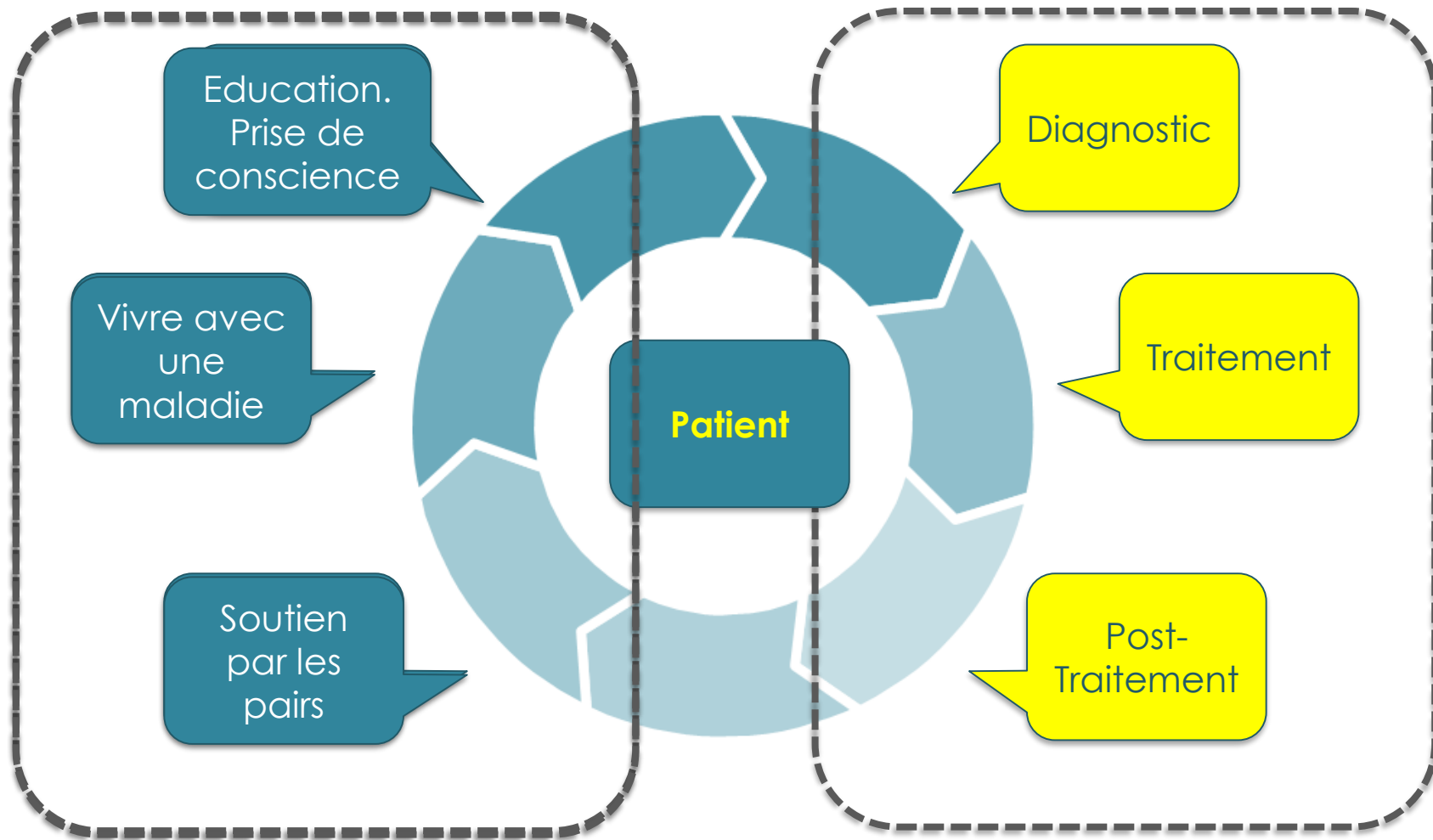
## Weight & Temperature

[Weight](#)
[1 Week](#)
[2 Weeks](#)
[1 Month](#)

✕







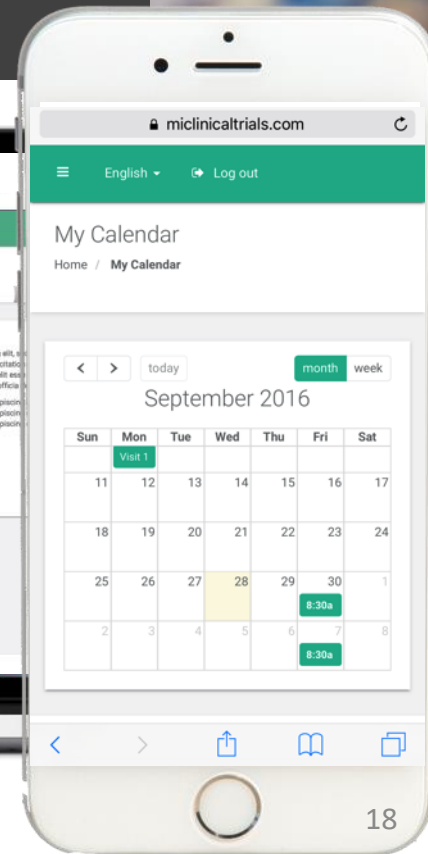
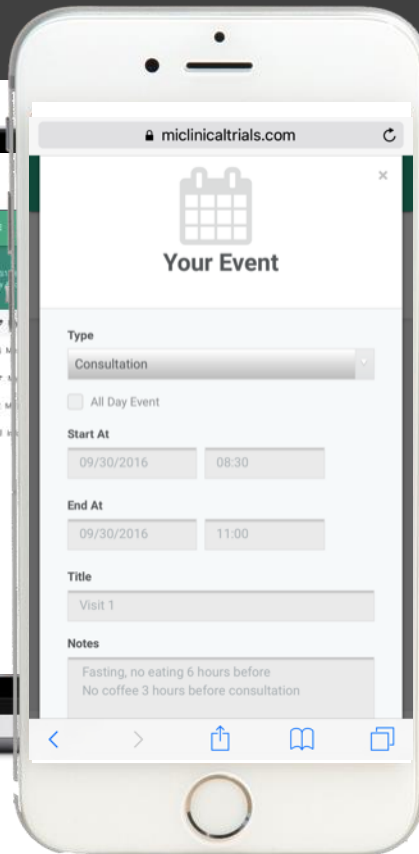
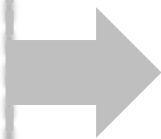
# Impliquer les patients à 360°

Fournir des infos  
médicales

Répondre aux  
questionnaires

Obtenir des informations  
directement des patients

Agenda



# Tableau de bord du patient

MS1980  
My Account ▾  
Un hôpital pour la Vie

## My Portal

Home / My Portal

### My Portal

Messages

Detailed Info

My Side Effects

Questionnaires

My Goals

My Evolution

My Calendar

Information



## My Treatment

The purpose of this study is to determine whether Meplizumab (a monoclonal antibody against interleukin-5) is a safe and well-tolerated therapy that will allow for steroid tapering in patients with steroid-dependent Churg-Strauss Syndrome (CSS).

1. Document the safety of meplizumab therapy in patients with CSS.
2. Demonstrate the steroid sparing effect of meplizumab therapy by decreasing corticosteroid dosage while using this anti-IL5 therapy.
3. Demonstrate the efficacy of anti-IL5 therapy in improving the signs and symptoms of CSS by:
  1. Measuring serum markers of CSS disease activity, including: peripheral eosinophilia, erythrocyte sedimentation rate, anti- neutrophil cytoplasmic antigen, C-reactive protein and IgE levels.
  2. Assessing the activity level of vasculitis via the Birmingham Vasculitis Activity Score
  3. Evaluating asthmatic response via

### Timeline

- 02/28/2017**  
1:00 PM  
**Consultation**  
 Be prepared: bring your medication list. Do not drink coffee 3 h before the visit.
- 03/07/2017**  
12:00 PM  
**Consultation**  
 Come to the hospital early for registration (15' ahead). Lung function test VO2max test

Upcoming events

### Latest Entries

- Rated Diarrhea  
 Feb 27, 2017 12 hours ago
- Rated Muscular pain  
 Feb 26, 2017 a day ago
- Rated Wheezing  
 Feb 24, 2017 4 days ago
- Rated Muscular pain  
 Feb 24, 2017 4 days ago
- Rated Diarrhea  
 Feb 24, 2017 4 days ago
- Rated Fatigue  
 Feb 24, 2017 4 days ago
- Rated Fatigue  
 Feb 21, 2017 6 days ago
- Rated Wheezing  
 Feb 21, 2017 6 days ago

Répondre aux questionnaires

- My Portal
- Messages
- Detailed Info
- My Side Effects
- Questionnaires**
- My Goals
- My Evolution
- My Calendar
- Information

Title
Medical Adherence
Wellbeing Questionnaire

## Wellbeing Questionnaire

Title	Updated
Wellbeing Questionnaire	02/06/2017
Wellbeing Questionnaire	02/06/2017

How stressed are you on a scale from 0 (not stressed at all) to 10 (extremely stressed out)?



### Possible reasons of elevated stress

- Practical issues
- Work related / study related
  - Finances
  - Difficulties to come to the consultations
  - Housing issues

- Emotional issues
- Afraid / worried
  - Sad

# My Side Effects

Home / My Side Effects

Suivi des symptômes

- My Portal
- Messages
- Detailed Info
- My Side Effects
- Questionnaires
- My Goals
- My Evolution
- My Calendar
- Information

## Daily Entries

Please indicate the side effects you are experiencing.

### Mepo related symptoms

#### Diarrhea ?

- No diarrhea
- Less than twice a day
- More than twice a day



#### Muscular pain

- No
- Yes



#### Wheezing

- No wheezing
- Moderate wheezing
- Severe wheezing



## Latest Entries

Rated Wheezing  
Feb 27, 2017 a few seconds ago

Rated Muscular pain  
Feb 27, 2017 a few seconds ago

Rated Diarrhea  
Feb 27, 2017 a few seconds ago

Rated Muscular pain  
Feb 26, 2017 a day ago

Rated Wheezing  
Feb 24, 2017 4 days ago

Rated Muscular pain  
Feb 24, 2017 4 days ago

Rated Diarrhea  
Feb 24, 2017 4 days ago

Rated Fatigue  
Feb 24, 2017 4 days ago

## Obtenez des conseils personnalisés

### Advice

- Drink plenty of water in between your meals: water (except water rich in magnesium, laxatives: Hepar - Contrexeville ...) - herbal tea - salted broth - 2l to 2,5l / day
- Avoid milk as a beverage, you can replace it with vegetable juices or lactose free milk
- Limit consumption of raw fruits and vegetables, as well as juice, except bananas which work constipating
- Limit greasy, fried foods
- Replace whole grains with white bread, white pasta, white rice
- Make several small meals during the day
- Drink Vichy water, dehydrated soups, isostar®, rice water

Close

#### Muscular pain

No

Yes

#### Wheezing

No wheezing

Moderate wheezing

Severe wheezing



#### st Entries

Rated Wheezing

Feb 27, 2017

a few seconds ago

Rated Muscular pain

Feb 27, 2017

a few seconds ago

Rated Diarrhea

Feb 27, 2017

a few seconds ago

Rated Muscular pain

Feb 26, 2017

a day ago

Rated Wheezing

Feb 24, 2017

4 days ago

Rated Muscular pain

Feb 24, 2017

4 days ago

Rated Diarrhea

Feb 24, 2017

4 days ago

Rated Fatigue

Feb 24, 2017

4 days ago



Alerts 1

English ▾

Log out

Alertes intelligentes :  
apprenez quelles actions  
à mettre en oeuvre

+ Create New

## Alerts

Home / Alerts

- My Portal
- Messages
- Detailed Info
- My Side Effects
- Questionnaires
- My Goals
- My Evolution
- My Calendar
- Information

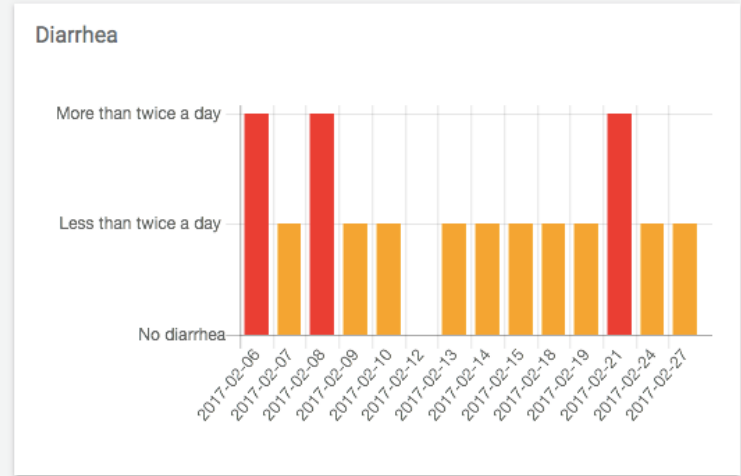
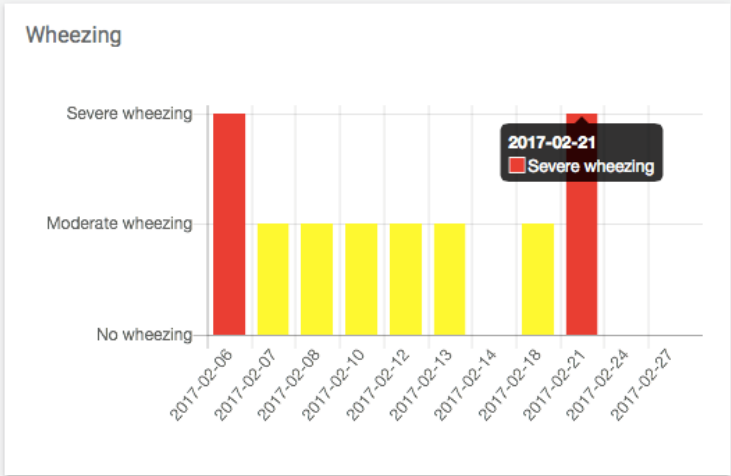
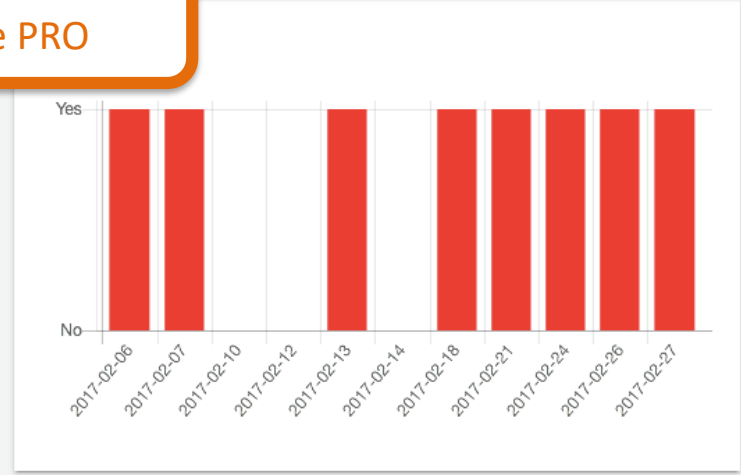
	Patient	Date	Deadline
	MS1980	02/27/2017 11:41 PM	02/28/2017 11:41 PM (in 23:50:26)

You have reported severe wheezing. Contact your physician or nurse on the following number: 989 999 999

Acknowledge

Evaluez l'évolution de manière PRO

- My Portal
- Messages
- Detailed Info
- My Side Effects
- Questionnaires
- My Goals
- My Evolution
- My Calendar
- Information





# Statistiques de l'utilisateur

## User Statistics

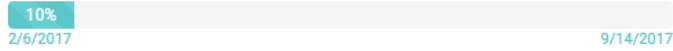
Home / User Statistics / MS1980

My Portal

My Patients

My Calendar

### Participation



### Information

7  
Visits

### Account

Created  
2/6/2017 4:51:19 PM

Updated  
2/27/2017 12:34:32 PM

### Logins

60  
Last Login  
2/27/2017 12:28:41 PM

### Captured Events

Event	Date	Extra Info
Logout	2/27/2017 12:34:32 PM	
Login	2/27/2017 12:28:41 PM	
Logout	2/27/2017 12:12:32 PM	
custom.stats_types.CP_IE	2/27/2017 12:11:01 PM	
custom.stats_types.CP_IE	2/27/2017 12:10:57 PM	

- My Portal
- My Patients
- My Calendar

Evaluez les patients

### Schedule Event

- Details
- Outcome**
- Mentions

month week

Rate the patient's compliance, from none (1) to perfect (5)



Add Mentions

- Delete
- Cancel
- Save

MS1980

< >

- all-day
- 6am
- 6:30am
- 7am
- 7:30am
- 8am
- 8:30am
- 9am
- 9:30am
- 10am
- 10:30am
- 11am

Fri 3/3 Sat 3/4

# Analyse sémantique des données non structurées



Robert B., 33, male, United States  
leukemia



Hello Friends,

I was first diagnosed in 2011 with Ewing's Sarcoma in my right shoulder. After a year of intensive chemotherapy and a surgery that removed and replaced the upper half of my dominant arm, I was given a clean bill of health. I even ended the chemo before the protocol suggested because I was doing so well and didn't want to over do it. I should have stopped even earlier because nine months later I was diagnosed with Treatment Related Acute Myeloid Leukemia. Yep I am one of those lucky cases where my initial treatment caused a secondary cancer. I then received four more rounds of high-dose chemotherapy, full body radiation, and was the fortunate recipient of a bone marrow transplant. My last bone marrow biopsy in July of 2014, once again showed me disease free.

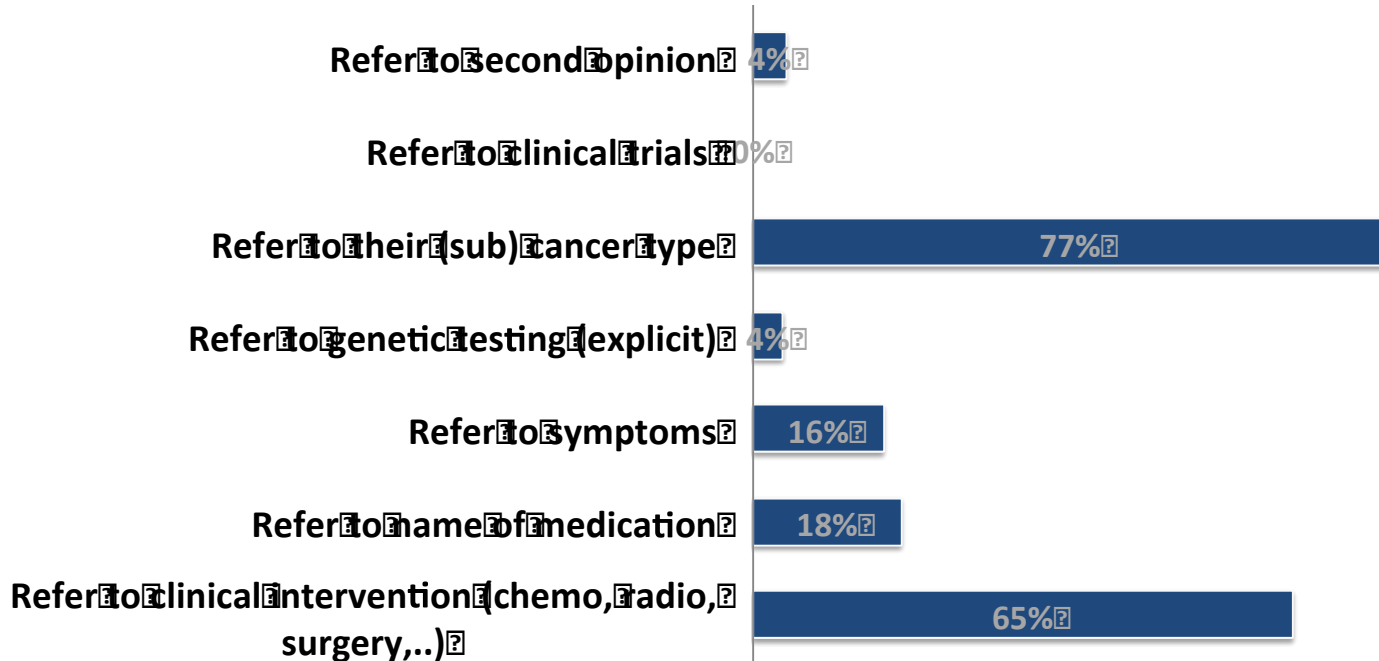
I must say that after all I have been through, I have never wished for a different path. I am lucky enough to still be here. I am still alive and that is enough for me to be eternally happy. I was given something in this process that both humbles me and fills me with endless pride. I was given an opportunity to know the true value of life. Before my diagnosis I squandered my good fortune and worried about the minutia that no man has any business worrying about.

The war with cancer never ends as we all know. I have won my last two battles with it and they were hard fought battles. I may not win another one. I could sit and worry about that and waste the good days that I have now. Or I can refuse to let the unknown future scare me into delaying my dreams. I am here today and I intend to live like I mean it.



Non structurées

# Analyse sémantique des données non structurées



# Cherchez des exemples

Diagnostic

Symptômes

Ressentis



Structurées

Sémantique

Non structurées



RobertB, 33, male, United States  
leukemia

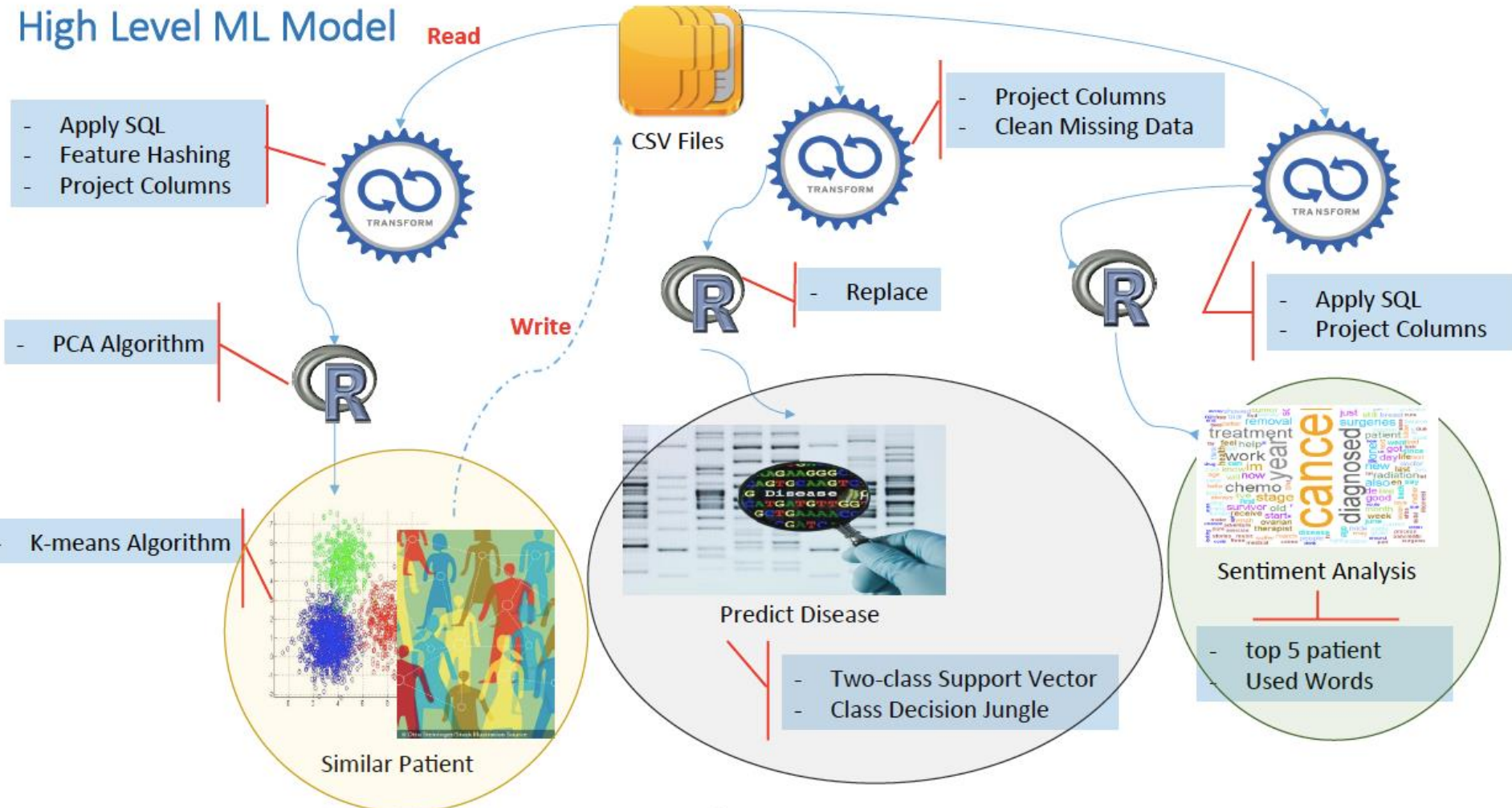
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# High Level ML Model





Merci !

Merci pour votre attention !

e-mail : [mitchell@esperity.com](mailto:mitchell@esperity.com)