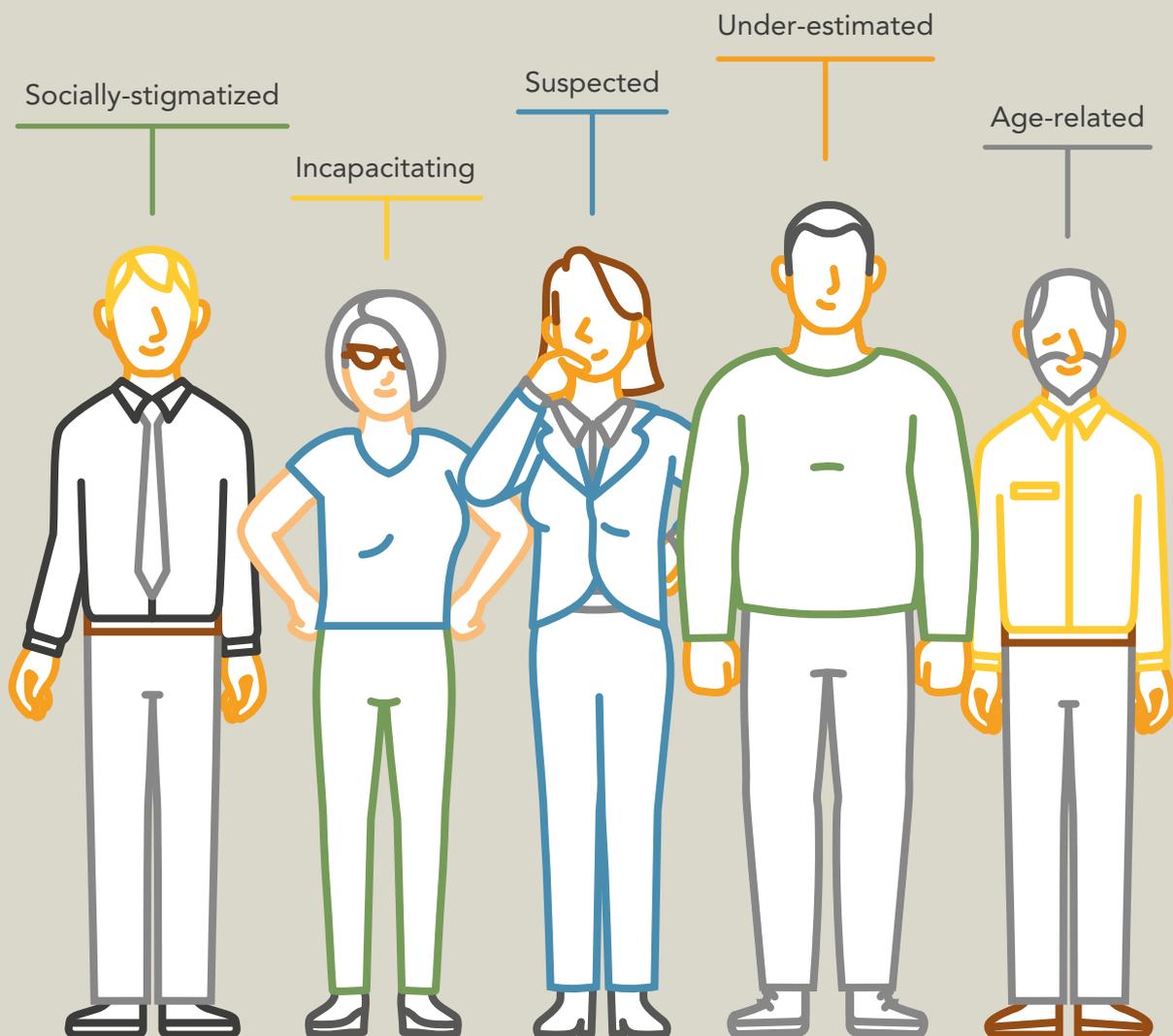


# 2016 e-patient Report

A new way of classifying illnesses from the patient's social perspective.



People Who is an online platform created to accompany e-patients in their day-to-day life. It offers everything that a patient needs in a single place: a Community to talk to others, a Control section to keep track of their illness and a Magazine to stay informed.

This report applies to active users and illnesses listed on People Who in France, Germany, Italy, Spain and United Kingdom. For this reason the data in this study may not be extrapolated to other groups.

We are happy for you to share the content of this report but if you do so, we would ask you to credit us as its author. If you re-use part or all of this report, including images and diagrams, the credit should read: 2016 e-patient Report by People Who, [www.peoplewhoglobal.com](http://www.peoplewhoglobal.com)

Reading time: 60 min.

# The patient's social perspective, a new approach

Before, everything happened in the doctor's office. Now, what happens outside is also important because online technologies mean that patients can participate actively in their treatment, be well-informed, and take responsibility for their illness.

With the arrival of the internet and online services created especially for them, empowered patients (or as we call them in People Who, e-patients<sup>1</sup>) started becoming a reality which is changing the way in which we understand and manage health. To better understand and help them to self-manage their illness, we have created the e-patient observatory.

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1. At the end of the 70s, before the internet changed our society, Dr. Tom Ferguson coined the term "e-patient", inviting all patients to involve themselves in their treatment. The "e" covers four different concepts: **equipped** with the skills to manage their own condition, **enabled** to make choices about self-care, with their choices respected, **empowered** to choose the team of health professional who treat them and **engaged** in their own care. Today, with the internet, e-patients have new technologies at their disposal to make Dr. Ferguson's vision of the future of health a reality.

Dr. Ferguson was born in California (1942-2006) and graduated from the Yale University School of Medicine. He wanted doctors and patients to work together and urged patients' self-education.

Illness has two distinct and complementary aspects, medical and psychosocial, and in People Who we believe that the time has come to pay attention to both of these as part of an integrated and multidisciplinary approach.

People Who is a digital platform and app created to help patients manage their illness on a day-to-day basis, when they are not in the doctor's office. That is why we wanted to move forward in this second annual report with an analysis and classification of illnesses from the patient's social perspective, using qualitative semantic research of the activity on our platform. We have validated and studied in depth from this social perspective the 5 types of illness that we had identified in the 2015 report: Socially-stigmatized, Incapacitating, Suspected, Under-estimated and Age-related illnesses.

It is true to say that illness accompanies us in everyday life, inasmuch as 99% of the time<sup>2</sup> is spent outside the

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2. Let us imagine that we spend 10 minutes in the doctor's office and go to the doctor around 8 times a year (European average according to the OECD, 2013 figures: available on <http://stats.oecd.org/index.aspx#>). Therefore, we would spend 80 minutes a year in the doctor's office, which would account for 0.01% of the time. The remaining time, 99.99%, is spent outside that office.

doctor's office. This report tries to more fully understand patients' everyday reality, with their family, at work, in their social life and on the personal and emotional plane. We believe that knowing about their concerns, problems, motivations and attitudes is essential if patient empowerment is to continue growing. We know that this empowerment is necessary in order to build a sustainable health system and to improve the society in which we live.

We hope that this report is useful and can be used by all healthcare agents, providers, payers, pharmaceutical companies and self-management programs, so that we can contribute to improving patients' quality of life.

# Index

<b>1 Methodology</b>	6
<b>2 Socially-stigmatized illnesses</b>	17
<b>3 Incapacitating illnesses</b>	26
<b>4 Suspected illnesses</b>	35
<b>5 Under-estimated illnesses</b>	44
<b>6 Age-related illnesses</b>	53
<b>7 Conclusions</b>	62

# 1

# Methodology

## Starting point

This is the second annual report from People Who, reporting activity on this platform in 2016 about the illnesses we cover online: allergies, Alzheimer's, arthritis, atrial fibrillation, bipolar disorder, coeliac disease, depression, diabetes, epilepsy, hepatitis, HIV, HPV, infertility, acute leukemia, chronic leukemia, obesity, ovarian cancer, psoriasis, schizophrenia, skin cancer and transplants. We have reported on the five countries where we operate: France, Germany, Italy, Spain and United Kingdom.

The 2016 e-patient Report is a qualitative one, analyzing our Community's activity in detail. This study has looked at user conversations on our platforms from the semantic and motivational point of view, illness by illness. Note that our platform is anonymous and as such the comments we have analyzed cannot be linked to specific people. Thanks to this anonymity, not only does this report help to understand the reality of patients and of the people looking after them on a daily basis, but users have a safe space in which to talk completely freely and spontaneously.

The 2016 e-patient Report takes a different approach to the previous year's edition, the 2015 European e-patient Report. Our first report was a quantitative round-up, explaining each of the sections on our platform:

Community, Control and Magazine. It also included examples of our health contents on social media such as Facebook.

This time, our second, 2016, report uses the findings from the previous 2015 one when we posed ourselves the question: Illness has up to now been treated from a medical point of view, but what about the social perspective? To answer this we carried out a statistical exercise, analyzing the topics of conversation in our Community, finally isolating 5 types of illness as experienced from the patient's social perspective. This new way of classifying illnesses enables us to look at them, not from a medical point of view, but from what daily life is like with each one. From the 20 illnesses analyzed, we grouped together those that displayed similar behavior patterns in terms of the topics of conversation, identifying 5, from illnesses where the caregiver plays a fundamental role to others involving issues such as fear or stereotypes; these are the social categories of these illnesses.

### **1. Socially-stigmatized illnesses**

The illnesses grouped under the socially-stigmatized category are those which by their very nature are negatively represented in the collective imagination and public opinion.

### **2. Incapacitating illnesses**

Although the symptoms and care required vary depending on the case,

illnesses included in this group are characterized by severely limiting the daily performance of all types of tasks, and even incapacitating the patient from carrying out many of them.

### **3. Suspected illnesses**

The illnesses covered by this group, either sexually-transmitted or bloodborne diseases, are associated with certain risk practices. Users of these platforms tend to be unaware of either the specific characteristics of the illness or its symptoms, so they often feel confused and harbour serious insecurities.

### **4. Under-estimated illnesses**

This group includes illnesses which are perceived in society as annoying, but are less serious or even minor.

### **5. Age-related illnesses**

The illnesses in this group are suffered by older people, and the caregiver figure is particularly relevant in the process of coping with the disease.

## **Methodology**

Using qualitative methodology that combines semantic content analysis techniques with certain features more typical of narrative analysis, we have conducted a comparative analysis exploring the consciousness, interests and principal concerns of platform users. This analysis has been enriched by calculating statistics using the quantitative data collated on People Who patient communities and by triangulating methods.

We have carried out a semantic content analysis of the public comments posted on the People Who platform. These comments refer to conversations, questions or replies formulated among the users of every illness in the Community section.

People Who's Research & Analytics department has used data mining on the internal database combined with information on traffic, data on our social media and the browsing of registered users. Although it needs to be said here that one person can register with one illness or with several, this study only takes into account the content of the comments posted, and not the author of the same. The average number of illnesses per person registered is 1.13. We also bore in mind that the time for which each illness Community has been active differs from illness to illness and from country to country.

The data analyzed in this study refer to users registered on our five European platforms. In terms of statistical representativity, all the data refer to

e-patients registered on People Who Global; as such, these data may under no circumstances be extrapolated to other communities or other countries. The data analyzed are not a sample: they correspond to 100% of the comments posted on the Community page between January and September 2016.

In order to conduct this research, we took the following steps over a 2 year period:

### **2015**

1. Creation of tags to qualify the comments.
2. Qualification of comments in 2015 and frequencies.
3. Identification of illness types from the social perspective.

### **2016**

4. Adjustments to the tags qualifying the comments.
5. Qualification of comments in 2016 and frequencies.
6. Validation of types of illnesses from the social perspective.
7. Identification and analysis of semantic fields.

### **Creation of qualification tags**

Using our users' comments, we created some tags for qualifying community users' comments. Using systematic reading methods, processing and exploitation of the internal narratives, including semantic content analysis, we succeeded in creating appropriate tags for breaking down our users' conversations into 4 categories for analysis: subject, motivation, attitude and pro-activeness.

Over the course of 2015 these tags were validated through the daily task of individually assigning these tags to each of the comments posted, as part of the workload of our team of Community managers in the 5 European countries in which we were operating. At the end of that year we reviewed these tags to make the adjustments that might be necessary with a view to qualifying the comments in 2016. We eliminated or grouped together tags with low frequencies and added some new tags to more precisely hone these qualifications.

In order to learn about patients' and caregivers' worries and needs, we set up 4 qualification categories so as to better understand patients' reality when they are not in the doctor's office and to be able to process this data.

#### **SUBJECT**

20 tags covering the subjects people discuss in the different illness communities.

#### **MOTIVATION**

6 tags describing the motive that leads someone to write a comment.

#### **ATTITUDE**

3 tags to identify whether the attitude displayed in each comment is positive, negative or neutral.

#### **PRO-ACTIVENESS**

3 tags to analyze the type of community in each illness in order to determine the balance between requests for help and offers of the same.

### **Qualifying the comments**

In 2015 and 2016 we qualified all the comments made publicly by users on our platform. As a platform for patients and caregivers, as well as having automated mechanisms for identifying potential negative action by users, our Community managers review all the comments published on the Community site. In addition to this review, they qualify the comments on a daily basis from the platform's back office. People Who has created guidelines to guarantee that all members of the internal team assigning these qualifications follow the same criteria.

### **Creation of types of illnesses**

In order to create types from a social perspective, in 2015 the frequencies of subjects that appeared spontaneously in the conversations about different illnesses were analyzed. Based on the points of similarity in these subjects, illnesses were grouped into 5 types that were then validated in the 2016 study: Socially-stigmatized, Incapacitating, Suspected, Under-estimated and Age-related.

### **Identification of semantic fields**

All the comments, now grouped into one or other of the types created when the subject frequencies were noted, were read systematically in order to identify the semantic fields. This reading identified the key words in each type, bearing in mind the characteristics of each illness. The task of identification was carried out by the internal Analytics & Research department, made up of two sociologists with in-depth

understanding of People Who after 4 years of experience on digital platforms for patients.

The key words were identified, assigned frequencies and grouped into families of concepts contextualized by each illness and illness type. After this they were then grouped so as to create a semantic field that represented them; by recording the number of times the word appeared we were able to assign an appearance frequency as a ratio of the total. All the concept families grouped into a semantic field within a type added together do not come to 100% since several different subjects may appear in the same comment. The percentages of each semantic field relate to the number of times it has appeared in the conversations in this illness type.

The semantic fields are a set of related concepts referring to the same idea, notion or phenomenon. The semantic fields group together families of concepts and are created by the identification and semantic analysis of key words in conversations.

## Qualification by subjects

20 tags to identify the subjects that appear in conversations. Each comment is qualified with at least one tag and a maximum of three. To interpret this report properly, it is important to understand exactly to what each tag refers.

### Symptoms

Any manifestation of the illness itself or of the treatment that it is being followed (before or after the diagnosis).

### Diagnosis

Topics relating to illness identification and detection (suspicions before visiting a health professional or after).

### Medication

Issues related to pharmacological treatments (what active principles are taken and their effect).

### Healthcare system

Specific topics about the health system and its professionals (inc. public, private or health insurers).

### Psychological aspects

Emotional dimension, personal feelings deriving from the illness and coping with it (being a patient, a caregiver or someone else).

### Diet

Nutrition issues, type of diet, food properties, food-related habits (or concerns around this topic).

### Exercise

Any kind of physical activity of any intensity (e.g. slow or fast walking, swimming, weight training).

### Scientific treatments

Any kind of treatment by any health professional regulated by each country's legislation (e.g. drugs, surgery, radiotherapy... / doctors, psychologists, physiotherapists...).

### Non-scientific treatments

Activities aimed at mitigating the symptoms of the disease but not imparted by legally regulated professions (e.g. yoga, aromatherapy, alternative treatments...).

### Social life

Issues relating to relationships with friends and colleagues in everyday life (e.g. having lunch with friends, going shopping, going for a walk...).

### Online socializing

Greeting other online users with the aim of creating new relationships (in the Community section).

### Family

Topics relating to close family members (e.g. children, parents, siblings) but not including the partner.

### Couple

Matters relating to the partner in all areas (emotional, sexual or as a family unit).

### Current topics

News, events and social debates about a specific illness (e.g. donation

campaigns, viral topic in social media, new vaccine).

### **Work**

Issues relating to the profession, work or professional studies (e.g.. problems at workplace or at university deriving from the illness).

### **Financial matters**

Financial issues deriving from having the illness or dealing with it (e.g. price of treatments, access to medicines, inability to work).

### **Leisure**

Activities relating to free time and leisure (e.g. hobbies or any entertainment such as watching TV or reading).

### **Personal care**

Tasks focused on hygiene and personal image (e.g. beauty treatments, everyday care of oneself or caring for another).

### **Housework**

Domestic tasks that have to be done (e.g. cleaning, cooking, childcare) excluding leisure activities.

### **Mobility**

Issues relating to the movements of the body or to getting around and travel (for any reason, by foot or any mean of transport).

## **Qualification by motivation**

### **Problem-solving**

Users are looking for solutions or help with a question or specific problem, or are asking for support.

### **Emotional**

Based around emotional issues (highly linked to psychological questions). Looking for emotional support.

### **Social**

Looking to establish or reinforce social relationships with other members of the community.

### **Usability**

Referring to use of the platform. Worries or questions about how to use the platform, how to post a message ...

### **Illness awareness**

Information about events, meetings, materials or explanatory conferences about the illness.

### **Complaints**

Complaints or claims about situations or problems that have not been solved (lack of help from the state, lack of support, poor care).

## Qualification by attitude

### Positive

Comments in which the user shows a positive or optimistic attitude. Reflecting positivity, hope, good predisposition ...

### Negative

Comments in which the user shows a negative attitude or one of protest. Reflecting negativity, complaining, bad predisposition ...

### Neutral

Comments in which the user's attitude cannot be determined. Frequently these are greetings or introductions between users.

## Qualification by pro-activeness

### Offers help

The user offers help to other members of the Community, whether by resolving a problem, providing emotional and/or social support or replying to a question.

### Demands help

In these comments, users ask for help from other participants in the Community or from professionals or ask questions.

### Neutral

Comments in which the user's inclination cannot be determined.

## Technical notes

### Universe

Comments posted publicly by users on People Who's European platforms were analyzed (conversations, experiences, questions and answers).  $N = n = 2,908$ , equivalence between the universe (N) and the sample (n) is due to the fact that 100% of the public comments made by users have been analyzed. Our platforms also support private messaging, which has been excluded from this and all other analysis, as stipulated in the platform's conditions of use, to ensure users' total confidentiality and privacy.

### Countries

This report has analyzed the comments from the platforms in the 5 European countries in which we were operational in 2016.

#### FRANCE

[www.lesgensqui.fr](http://www.lesgensqui.fr)

#### GERMANY

[www.menschendie.de](http://www.menschendie.de)

#### ITALY

[www.personeche.it](http://www.personeche.it)

#### SPAIN

[www.personasque.es](http://www.personasque.es)

#### UNITED KINGDOM

[www.peoplewho.co.uk](http://www.peoplewho.co.uk)

### Illnesses

User comments included refer to all the illnesses that were online in the period analyzed: allergies, Alzheimer's, arthritis, atrial fibrillation, bipolar

disorder, coeliac disease, depression, diabetes, epilepsy, hepatitis, HIV, HPV, infertility, acute and chronic leukemia, obesity, ovarian cancer, psoriasis, schizophrenia, skin cancer and transplants.

### Fieldwork period

9 months, January 2016 – September 2016

### Date of publication

March 2017

### Analysis

Users can register in one or more of the illnesses we have online. The time an illness has been active varies from one to another and between countries. For this reason the number of users and the number of comments analyzed in each illness are different. The number of comments analyzed by each type of illness is: Socially-stigmatized illnesses  $n=1,662$ ; Incapacitating illnesses  $n=538$ , Suspected illnesses  $n=19$ , Under-estimated illnesses  $n=162$  and Age-related illnesses  $n=527$ .

### People Who

People Who, an online platform and app that enables patients to manage their chronic illness on a daily basis, was created to accompany e-patients in their day-to-day life. It brings together everything they need in one place: a Community to communicate with others, a Control section to keep track of their illness and a Magazine to stay informed.

People Who Global's observatory studies e-patients in depth and puts this knowledge at the service of

corporations and institutions that support society so that it can live better with illness.

#### ANONYMITY

No forenames or surnames: at People Who users will never be asked to provide personal data such as their forename or surname. We require them to interact using a virtual profile and we warn against publishing any personal data such as a real name or email address in the community. If users wish to enter into contact with others privately they can use the private message functionality.

No photos of people: We want to ensure that user privacy is always protected. For this reason, the use of photos of people as a virtual profile picture is forbidden and we make a collection of avatar images available.

#### NO BRANDS OF MEDICATION

Health is a delicate matter and the prescribing of medicines is the job of doctors in their offices. We want to avoid inappropriate prescriptions or business transactions. If users post medicine brands, these names will be replaced by their active ingredient.

#### NOT A MEDICAL CONSULTATION

People Who is an online platform focusing on the patient's daily life. It was set up to complement the work of doctors in their offices, and never to replace it. Doctors in the People Who team do not take part in the communities, but they do act as advisors and safeguards in terms of content; they also take part of content; of community managers. Medical

consultations never take place on People Who.

#### 2015 E-PATIENT REPORT

Our first report, in 2015, explained our 3 sections: Community, Control and Magazine. This report is the source of the 5 types of illness from the social perspective, based on user comments, narratives, concerns and common problems. A study that enables us to discover the differences in general terms between users of different illnesses and in different European countries (Spain, France, United Kingdom, Germany and Italy). We recommend you read it to better understand e-patients and interpret the 2016 report. You can download it at the link included on the last page of this document.

# How to interpret the graphs

## User profile

In the same graph we show the breakdown of a community by socio-demographic variables: link to the illness, gender and average age.

We believe that illness should be approached from a broader perspective and we look at three types of users: people who have an illness; people who care for someone with an illness (in most cases family members); and people interested in the illness (in most cases professional caregivers or people without the illness but who have a family history of it).

## Semantic fields

We have grouped together the most commonly used concepts into semantic fields, with the most frequently used at the top. These semantic fields bring together experiences, ideas and terms from a particular area of the preconceived ideas about the illness (a family of concepts that stem from the same root). The percentages for these semantic fields do not add up to 100% because a user comment may refer to several concept families. The percentages should be understood as the frequency with which a semantic field appears in the comments taken as a whole. Thus, the percentages tell us all the comments (%) in which the semantic field is mentioned.

In each type of illness, we show several of the comments that have been published so that we can better understand this illness, and the communities we have analyzed.

### **Subject positioning maps**

We have designed positioning maps to display data about the main subjects and concerns depending on the social type of illness. These have two central themes: public/private and emotional/problem-solving. The tags on the subjects covered in the conversations are shown with their frequencies. Their positions in the quadrants follow qualitative positioning criteria.

When the data were processed, the methodological decision was taken to exclude from the positioning maps all tags about issues that are shared across all illnesses: symptoms, medication and diagnosis. The aim was to be able to focus on questions around living with the illness on a day-to-day basis and on the differences between one type of illness and the others.

### **Motivation, attitude and pro-activeness percentages**

As well as analyzing the subject matter in the conversations we decided it was helpful to qualify each comment with another three variables in order to better understand the communities: motivation, attitude and pro-activeness. Each comment has been qualified with tags of the three variables, which are shown in a single graph because it gives more of an insight to read them together than separately. We attach the frequency tables, that analyze each variable in detail.

# 2 Socially-stigmatized illnesses

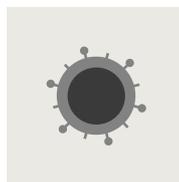
The illnesses grouped under the socially-stigmatized category are those which by their very nature are negatively represented in the collective imagination and public opinion.

Branded by society, they are often a source of shame, embarrassment, guilt and even taboo. In general, even though people can lead a normal life with them, they are burdened with major prejudices and stereotypes (based on ignorance and lack of information).

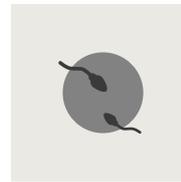
The socially-stigmatized illnesses are:



Bipolar disorder



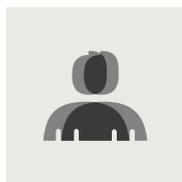
HIV



Infertility



Psoriasis



Schizophrenia

# Social-stigmatized illnesses, new online social relations

Social relationships are particularly important when it comes to illnesses carrying stigma or the weight of prejudice. People in this position experience incomprehension, endure unpleasant situations and often feel the need to hide the existence of their illness (for fear of rejection or embarrassment). The risk of it being discovered, according to Erving Goffman (1963), may not only affect the patient's current well-being, but also their self-image, status and relationships in the future. As a result, the strategies they use to actively hide their illness become part of their own day-to-day identity, i.e. with the adoption of modes of social interaction based on denial and concealment.

Although issues relating to treatment, symptoms or diagnosis have some presence in community conversations and comments, their quantitative and qualitative presence is much less significant than the variables linked to social or interpersonal relationships. Fear of rejection (essentially down to society's lack of understanding and a heavy component of myths and prejudice about people living with these illnesses), is the great challenge facing users of the platform. Fear, episodes of discrimination or isolation all lead to withdrawal and/or loneliness. The concept of stigma is very present in all the illnesses grouped in this category; it is manifest in day-to-day living within the environment, it is visible in the emotions and way in which personal identity is constructed. There is a powerful desire and drive to be thought of as a "normal" person and not a potentially dangerous ill

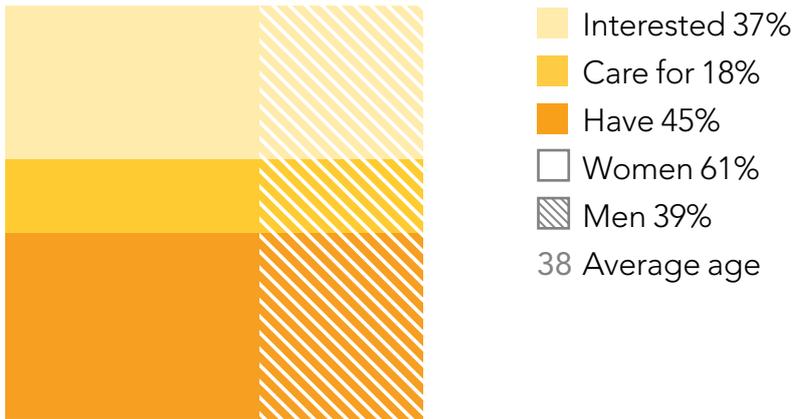
person (labels and prejudices often carry considerable weight in the way we relate to one another and we tend to avoid intimate and close contact with stigmatized people).

The personal image that they project and the procedures taken to hide the illness are two factors that are very much a part of the daily life of people living with these realities (obviously, these become more serious as the symptoms become more pronounced). It seems apparent that the burden of the illness falls clearly on the sufferer and their immediate surroundings, since it is they who have to search constantly for ways of justifying and/or hiding their condition (despite the fact that with monitoring, supervision and medical follow-up they represent no risk or threat to the general population). This is why society needs to be made more aware, through measures such as education and information campaigns that inform citizens and fight the prejudice and discrimination suffered by these groups. Having to face up to publicizing one's condition as a sufferer continues to trigger deep anxiety, distress and fear of possible rejection. For example, in the case of psoriasis, some sections of the population are still under the impression that it can be transmitted from physical contact (with all the attendant attitudes of disgust, distancing or excessive precaution that uninformed people display). In fact, it cannot be passed between patients because it is not contagious.

# Socio-demographic profile

The average age of users of the Socially-stigmatized illnesses group is 38, younger than the average for platform users as a whole, which is 45. This is because most of the illnesses in this group are diagnosed before reaching adulthood.

## Group profile



## Profile by illness

### Bipolar disorder



Interested 20%  
 Care for 27%  
 Have 53%  
 Women 66%  
 Men 34%  
 41 Average age

### HIV



Interested 50%  
 Care for 3%  
 Have 47%  
 Women 41%  
 Men 59%  
 36 Average age

### Infertility



Interested 77%  
 Care for 4%  
 Have 19%  
 Women 64%  
 Men 36%  
 33 Average age

### Psoriasis



Interested 7%  
 Care for 10%  
 Have 83%  
 Women 69%  
 Men 31%  
 42 Average age

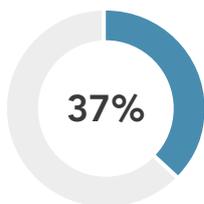
### Schizophrenia



Interested 35%  
 Care for 44%  
 Have 21%  
 Women 69%  
 Men 31%  
 40 Average age

# Semantic fields: Rejection and isolation

The concepts revealed most starkly in Socially-stigmatized illnesses are rejection and isolation. We have grouped together the most commonly used concepts into semantic fields and shown the frequency with which each of these fields appears as a proportion of all conversations.

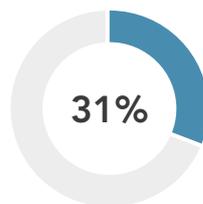


## Treatment

The semantic field of the treatment refers to the purely medical context of the illness. The most frequently appearing concepts are those concerning daily medication and tests. There is concern about the side effects and how the illness will progress, so constant vigilance and regular check-ups are necessary.

### Families of concepts

- Medication
- Symptoms
- Alternative therapy
- Treatment
- Diagnostic tests
- Check-ups
- Vigilance
- Creams
- Side effects
- Seasonality

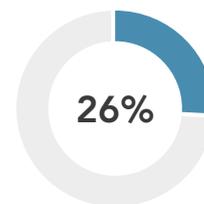


## Isolation

This semantic field refers to the way in which the external social environment is perceived by people who live with these types of illnesses. The concept of stigma is always just under the surface with all of them and is perceptible in the various social relationships they have, such as with friends or their partner, at levels both corporal (infertility, psoriasis and HIV) and mental (schizophrenia and bipolar disorder). There is a desire to "be normal" and be recognized as just another person.

### Families of concepts

- Friends
- Partner
- Have a fling
- Sexual relations
- Naked
- Isolation
- Loneliness
- Normalcy

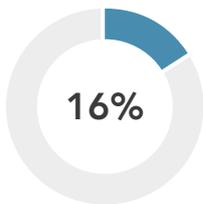


## Rejection

As in the case of the isolation field, the rejection field refers in this case to the psychological processes deriving from living with the illness. Although isolation refers to a more external focus between people, the field of rejection refers to one's own relationship with one's illness and the difficulties it causes, such as shame, complexes and fear, lack of understanding and having to cope with sadness.

### Families of concepts

- Unburdening oneself
- Shame
- Stigma
- Stress
- Prejudices
- Rejection
- Disgust
- Lack of understanding
- Anger/Frustration
- Sadness/Depression
- Complexes
- Fear
- Isolation
- Loneliness



## Personal appearance

This semantic field covers the considerations and perceptions about physical image and the attention paid to it (especially with psoriasis). Users' contributions express their insecurities and fears about their body issues, as well as day-to-day matters that may be more difficult because of the presence of the illness and that require problem solving.

### Families of concepts

Makeup

Normalcy

Hair dye

Nails

Unwanted hair removal

Tattoos

Hair

Suntan

## Comments

A selection of comments from platform users of Socially-stigmatized illnesses follows below. These back up the findings made and reveal the concerns of people living with the illness, expressed in their own words.



Woman  
22 years old  
Has bipolar disorder

"Hi!!

I wanted to tell you that I have been diagnosed with BD and I think it's a complete fabrication, just a label. The only thing it does is make people afraid of themselves and make the situation worse. Everyone has ups and downs; OK, in some people it may be more pronounced, but to go from that to having a chronic disorder, that's a big jump.

Anyway, I'm sure that there are lots of variations and differences within bipolar disorder but they treat us as though we were all the same. I don't believe we all need medication and much less for our whole lives, (as the doctor has insinuated. Let's see who wins that battle)."



Woman  
35 years old  
Has psoriasis

"Good evening. I've just signed up to the group; I suffer from psoriasis on my scalp and inverse psoriasis, that's when it appears in smooth, flat areas, so, under my breasts, on my forearms, my ears and on the rest of my body too, but less so.

It's worst on my head, my scalp is one huge scab and my hair falls out.

I'm sick of trying product after product; my latest treatment was methotrexate but it hasn't worked.

My dermatologist doesn't want to put me onto a biological treatment yet and I'm tired of it all.

I hope I get some help on this forum. Thanks."



Man  
47 years old  
Has schizophrenia

"Hi, guys... how's it going? Today I'm waiting for my friend to arrive so we can spend the weekend watching films, going online and going out for dinner. I wanted to tell you that yesterday evening I spent an hour playing chess online: it was really great. You know what, it raised my "self-esteem" and I thought afterwards: you didn't play "too badly" at all. I mean, bearing in mind my "level" I can give you a decent game on the board...ha ha. And this morning I started reading Red and Black, by Stendhal. It is the defining romantic novel of the 19th century. And I'm also reading a book on "motivating yourself to study". The book is supposed to "motivate" adolescents... but, hey, the forties are the new twenties, right? Ha ha... There is lots of detail on study techniques in this manual, and that's why I'm reading it."



Woman  
36 years old  
Interested in infertility

"A friend of mine was diagnosed with it after not managing to get pregnant and on the third embryo transfer (she had to resort to fertilization in vitro) she's now about to give birth!

It's all a bit of a gamble and until you try you don't know whether you're going to get pregnant or not. It is definitely going to be much more difficult than for someone who is not infertile...

The very best of luck."

# Subject positioning map

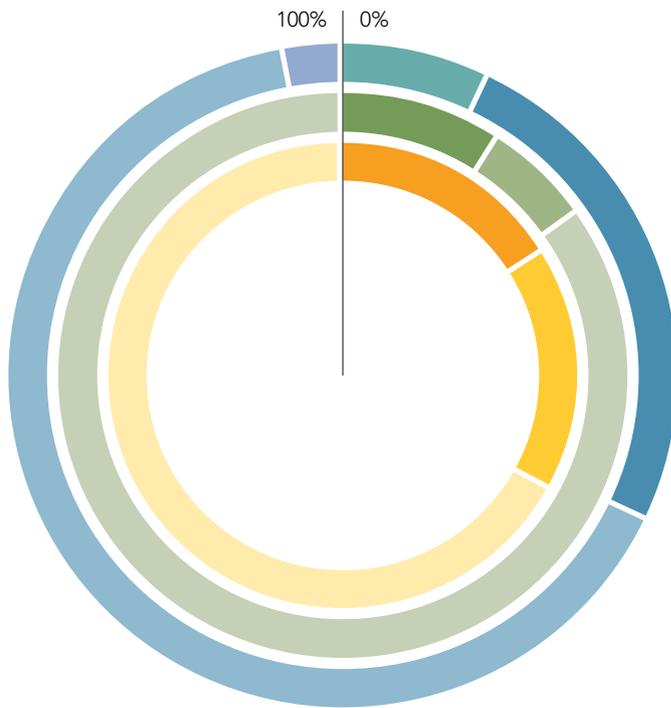
When displaying data on the issue categories referred to above, we have decided to construct a map around two key and opposing contexts: social (public)/private and emotional/problem solving. The most popular subjects in Socially-stigmatized illnesses appear as percentages in this positioning map.



- Social dimension
- Wellbeing
- Everyday life

# Motivation, attitude and pro-activeness

This graph shows three variables from the Socially-stigmatized illnesses community. User's general motivation when posting on the Community, the attitude displayed in the comment and the user's pro-activeness in terms of requesting help and offering support when interacting with others.



## Motivation

Interaction	Numer of comments	Percentage
Problem-solving	117	7%
Emotional	408	25%
Social	1,067	65%
Usability	53	3%
Illness awareness	6	0%
Complaints	2	0%
<b>Total</b>	<b>1,653</b>	<b>100%</b>

## Attitude

Interaction	Numer of comments	Percentage
Positive	154	9%
Negative	94	6%
Neutral	1,405	85%
<b>Total</b>	<b>1,653</b>	<b>100%</b>

## Pro-activeness

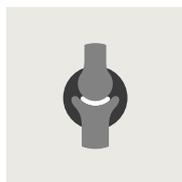
Interaction	Numer of comments	Percentage
Asks for help	257	16%
Offers help	285	17%
NA	1,111	67%
<b>Total</b>	<b>1,653</b>	<b>100%</b>

# 3 Incapacitating illnesses

Although the symptoms and care required vary case by case, illnesses included in this group are characterized by the limitations they impose on the daily performance of all types of tasks, in some cases incapacitating the patient from carrying out many of them.

Whether on a physical or psychological level, carrying on the business of normal life is significantly hampered by doctor's visits, treatments and associated symptoms. This alteration may be temporary (because of hospitalization or specific outbreaks) or prolonged, and/or chronic (with hospitalization, chemotherapy, waiting lists, etc.).

The incapacitating illnesses are:



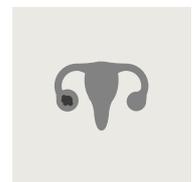
Arthritis



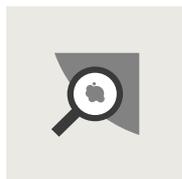
Diabetes



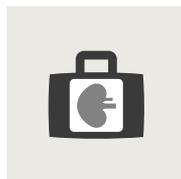
Epilepsy



Ovarian cancer



Skin cancer



Transplants

# Incapacitating illnesses, problem-solving conversations

On the whole, users who live with these diseases are characterized by forming fairly goal-oriented or practical communities, using the platform as a strategy for resolving uncertainties or questions about their illness. There are a lot of information requests about medical procedures, new therapies and treatments, the likelihood of being unable to work because of the disability or risks they may face whilst living with the illness. They are usually quite direct and ask concise questions in order to gain practical information to help them in their daily lives.

These illnesses tend to be characterized by a progressive worsening of patients' quality of life, which generates much more complex effects than those that are superficially apparent. Even though people living with incapacitating illnesses are aware of the physical impairment they are facing, often their surroundings and wider society do not take into account the socio-emotional issues inherent to these conditions. Although everyone acknowledges the limitations and barriers to carrying out daily tasks, the gradual deterioration translates into consequences that may be more serious than the difficulties and physical obstacles themselves, in which case we are talking about despair.

People who live with incapacitating illnesses have to cope with daily lives in which their environment is focused on their health and physical capacities. However, despite society's commonly held belief, these are illnesses that deeply compromise the individual on an emotional level (revealing itself

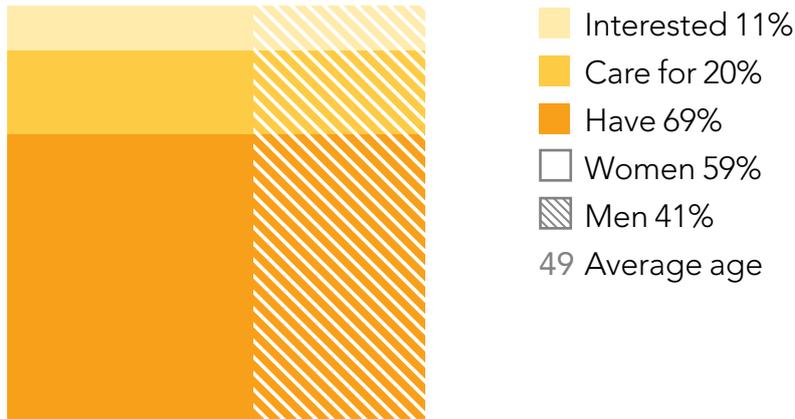
in frustration, fears and despair). Therapies designed for people living with illnesses of this nature do not always achieve the desired results as quickly as the patients would like, so they are open to new treatment suggestions (even though they are aware of their difficult situation). Symptoms of ennui and despair are frequently found in people living with incapacitating illnesses, because they feel that nothing is any good for them or will make any improvement, even in the very best scenario, to keeping their state of health stable over time.

People who live with an incapacitating illness display a need for the company of other people with similar symptoms, to find a degree of understanding that goes beyond the illness. They need to find shared support and reinforcement and, more than anything, try to make their environment aware that what they are going through is real and that their reasons for complaining to family members and friends are justified. So, we can conclude that incapacitating illnesses not only strongly condition day-to-day life and performance, but also have serious effects on people's states of mind and social relationships.

# Socio-demographic profile

The Incapacitating illnesses group includes some illnesses that are mostly diagnosed at around 50. The weight of those interested in the cancers indicates that there are users who are undiagnosed but who think they might develop the illness because of their family history or because of their symptoms.

## Group profile



## Profile by illness

### Arthritis



Interested 11%  
 Care for 14%  
 Have 75%  
 Women 77%  
 Men 23%  
 49 Average age

### Diabetes



Interested 9%  
 Care for 23%  
 Have 68%  
 Women 53%  
 Men 47%  
 51 Average age

### Epilepsy



Interested 16%  
 Care for 35%  
 Have 49%  
 Women 51%  
 Men 49%  
 42 Average age

### Ovarian cancer



Interested 50%  
 Care for 15%  
 Have 35%  
 Women 83%  
 Men 17%  
 41 Average age

### Skin cancer



Interested 38%  
 Care for 40%  
 Have 22%  
 Women 63%  
 Men 37%  
 41 Average age

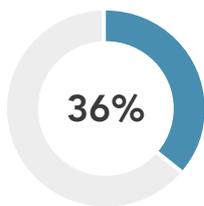
### Transplants



Interested 17%  
 Care for 31%  
 Have 52%  
 Women 53%  
 Men 47%  
 45 Average age

# Semantic fields: Limitations and despair

The concepts that stand out most strongly in Incapacitating illnesses are limitations and despair. We have grouped together the most commonly used concepts into semantic fields and shown the frequency with which each of these fields appears as a proportion of all conversations.

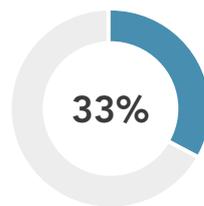


## Therapies

Therapy-related issues bring together all the references to medications, treatments, diagnostic tests and control. Therapies arouse great interest among patients with incapacitating illnesses because this enables them to suppress or mitigate certain symptoms and limitations that condition their daily lives. From medical prescriptions to alternative and homemade remedies, users share and demand this type of information.

### Families of concepts

- Medication
- Alternative therapy
- Treatment
- Diagnostic tests
- Check-ups
- Vigilance
- Creams
- Side effects
- Seasonality
- Bee-keeping

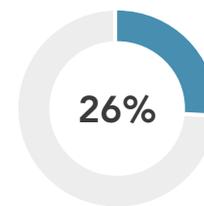


## Limitation

The barriers and difficulties that patients have to cope with on a daily basis come under this semantic field. Any daily task or activity can turn into a challenge for a patient (requiring help, over-exertion, barriers...).

### Families of concepts

- Help
- Incapacity
- Limitations
- Dependency
- Autonomy
- Overexertion
- Inadequacy

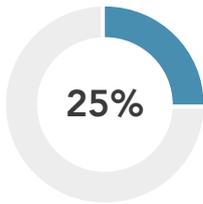


## Symptoms

The semantic field of symptoms includes all the references to signals, signs or effects produced by incapacitating illnesses. Due to the range of illnesses covered in this group (cancers, arthritis, diabetes and transplants), the variety of symptoms is very wide.

### Families of concepts

- Outbreaks
- Inflammation
- Rash
- Reddening
- Pain
- Discomfort
- Dryness
- Nausea
- Thirst
- Weakness

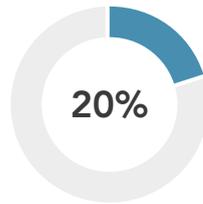


## Despair

Listlessness, tiredness, discouragement and emotional impairment make up the semantic field of despair. Incapacitating illnesses severely erode people's motivation and vitality and that of their closest surroundings. Even though society tends only to focus on the physical deterioration caused by illnesses in this group, the psychological and emotional wear and tear is very deep and a major conditioning factor.

### Families of concepts

Listlessness  
Tiredness  
Impairment  
Sadness  
Demotivation



## Concern

Although all illnesses involve a degree of concern, this is particularly palpable in the communities of this category of patients. The significant threats, risks and effects of illnesses in this group trigger fears (of not being understood, of rejection, of the illness getting worse, of the stigma), frustrations and even complexes.

### Families of concepts

Fear  
Shame  
Stigma  
Stress  
Prejudice  
Rejection  
Lack of understanding  
Anger/Frustration  
Sadness/Depression  
Complexes

# Comments

A selection of comments from platform users of Incapacitating illnesses follows below. These back up the findings made and reveal the concerns of people living with the illness, expressed in their own words.



Woman  
37 years old  
Has rheumatoid arthritis

"Good morning, the main thing I want to do is to encourage those of us who have arthritis. Let me tell you my story. I have suffered this illness since I was 26, and I've been through good, bad and indifferent times. The worst thing is when I have an outbreak ... Like when I can't look after my children because simply putting a T-shirt on them is like scaling a mountain. I am now 36, I have had operations on various parts of my body; I have total arthrodesis (fusion) in one hand, a swan-neck finger and lumps on my feet that stop me from walking properly, but I can tell you that since I started the biological treatment I have felt much better. But there are still days when I think that this illness is just too complicated for people around me to understand. I also want to tell you that your attitude is really important; that's why I haven't given up, because I think that I can beat it and even if I don't, learn how to live with it ... I don't generally talk about myself at home, that's why I've decided to share this with all of you today! Thank you very much."



Woman  
48 years old  
Has epilepsy

"Hello, my name is Eva, I am 48 years old and I have had epilepsy all my life... I have refractory epilepsy, that is, my body rejects medications or they have a bad reaction on me. At the moment I'm on carbamazepine (my seventh attempt). But I still suffer lots of side effects and I don't know whether it's because of the drug or the seizures, but my memory often fails me. Sometimes I'm on my way to doing something and in a second I can forget what I was intending to do; it's the same with words: the moment I need them, they're gone, out of my head ... In fact, I don't have many memories because they've been wiped from my brain. Now I have long-term occupational disability, but when I was at work and managed a department, in the last few months the meetings were terrible because when I had to talk about what was going to happen that day or about upcoming contracts, my mind would go blank and the words just didn't come out... My boss started to worry about the change in how I was expressing myself and my mental agility. In short, I don't know whether it is a result of having had lots of seizures, or because of the medication we take, or a bit of everything. Signing off now."



Man  
46 years old  
Has rheumatoid arthritis

"Hey, I've just found you guys. I am pretty down because of the spondyloarthritis and sacroilitis that I've been diagnosed with, plus a worsening of an eye inflammation (uveitis). I've had several flare-up so far this year, after two bouts of pneumonia, one at the end of last year and another at the beginning of February. My state of health is worse, my left hip hurts a lot, to be honest I don't know whether this will be a major episode, but it's been going on for two months and it doesn't even get better with methotrexate or corticosteroids. I'm thankful I found you, this will help me be better informed and at least I hope I can keep my mind occupied because I don't know whether I should go to a psychologist; this has a bad effect on the way you think, you become really negative about everything. Thank you, and best regards."

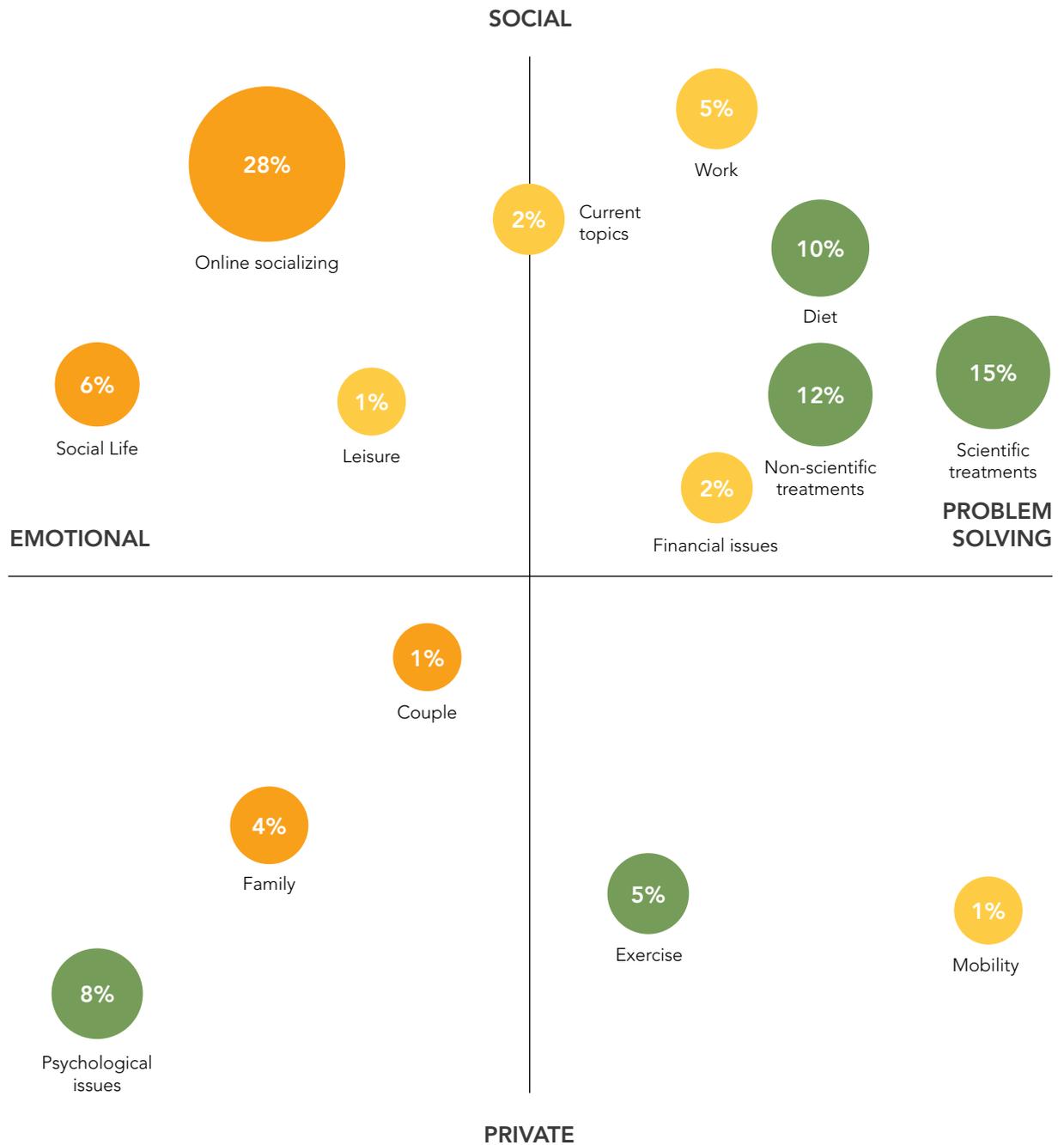


Man  
50 years old  
Has psoriatic arthritis

"I've used all types of medication, always with the support of a good doctor. I'm using several at the moment, ozone therapy (auto hemotherapy with ozone, and by the way, let's hope Social Security gets on to this, it works really well, it's cheap and it doesn't involve a lot of complicated equipment). Your nutrition is key (careful with refined cereals and with gluten content, try to remove them from your diet and let me know). Get rid of Solanaceae (egg plants, peppers, tomatoes, potatoes), when you're in pain. Don't stint on the exercise (each person within their limits), stretching and walking for at least 30 minutes a day. And stay in good spirits... The very best of luck, and go for it, champs."

# Subject positioning map

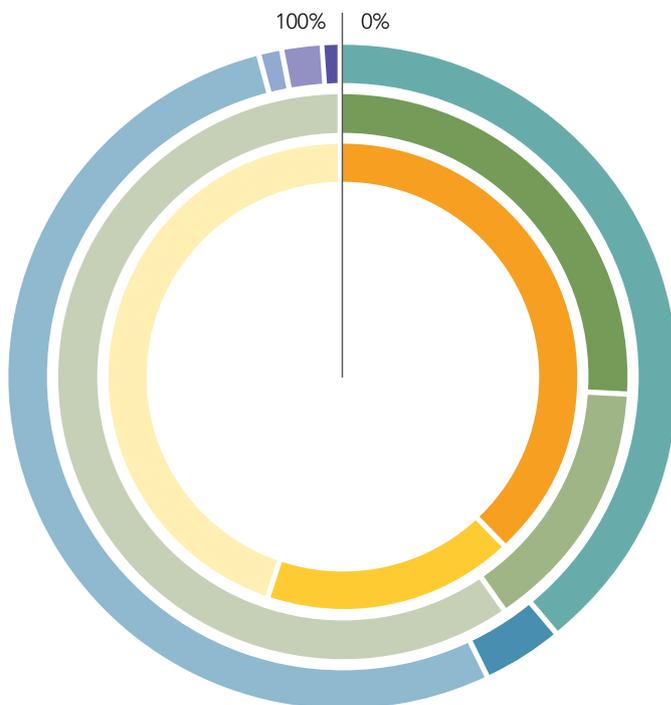
To display data on the issue categories referred to above, we have decided to construct a map around two key and opposing contexts: social (public)/private and emotional/problem solving. The most popular subjects in Incapacitating illnesses appear as percentages in this positioning map.



- Social dimension
- Wellbeing
- Everyday life

# Motivation, attitude and pro-activeness

This graph shows three variables from the Incapacitating illnesses community. User's general motivation when posting on the Community, the attitude displayed in the comment and the user's pro-activeness in terms of requesting help and offering support when interacting with others.



## Motivation

Interaction	Numer of comments	Percentage
Problem-solving	207	39%
Emotional	22	4%
Social	284	53%
Usability	8	1%
Illness awareness	10	2%
Complaints	5	1%
<b>Total</b>	<b>536</b>	<b>100%</b>

## Attitude

Interaction	Numer of comments	Percentage
Positive	122	23%
Negative	70	13%
Neutral	344	64%
<b>Total</b>	<b>536</b>	<b>100%</b>

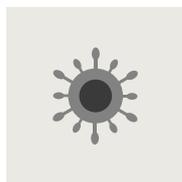
## Pro-activeness

Interaction	Numer of comments	Percentage
Asks for help	202	38%
Offers help	92	17%
Neutral	242	45%
<b>Total</b>	<b>536</b>	<b>100%</b>

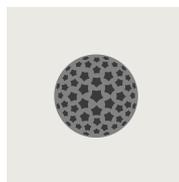
# 4 Suspected illnesses

The illnesses covered by this group, either sexually-transmitted or blood-borne diseases, are associated with certain risk practices. Users of these platforms tend to be unaware of either the specific characteristics of the illness or its symptoms, so they often feel confused and have major uncertainties.

The suspected illnesses are:



Hepatitis



HPV  
(Human Papiloma  
Virus)

## Suspected illnesses, do I have the illness?

Might I have the illness? Thousands of users visiting any of the People Who platforms (both in Europe and in the United States) ask themselves this kind of question. Even though a large number of users accessing the Community (or the contents in the Magazine) are patients, a not inconsiderable number of visitors to the Community are people who suspect they may be living with hepatitis or human papilloma virus.

This group of illnesses has been of interest to the Community in areas around online socializing, scientific treatments and alternative therapies. This latter group mainly covers complementary treatments and natural remedies that may be borne in mind for dealing with the illness, to palliate it or as protection from some of its symptoms. In this report we have decided to focus less on the purely medical issues, and more on normal daily life with the illness, as well as the strategies adopted by e-patients.

The profiles that seem most interested or who live with illnesses of this type are the younger ones (more sexually active and with higher likelihood of having more than one sexual partner). They are mainly women, with an average age of 36, who are mainly concerned about the papilloma virus in themselves or in family members (vaccinations for girls or adolescents under 14 years old). They come to the platform to learn more about their illnesses and to take part in a space where they can express their uncertainties and concerns that have not been resolved as a result of the contradictory information they may

have found online, because of different levels of ignorance or even shame.

Users seem more inclined to talk about specific issues surrounding illnesses instead of trying to create and reinforce ties with other members of the Community; their queries made on this platform are probably the step before a visit to the doctor.

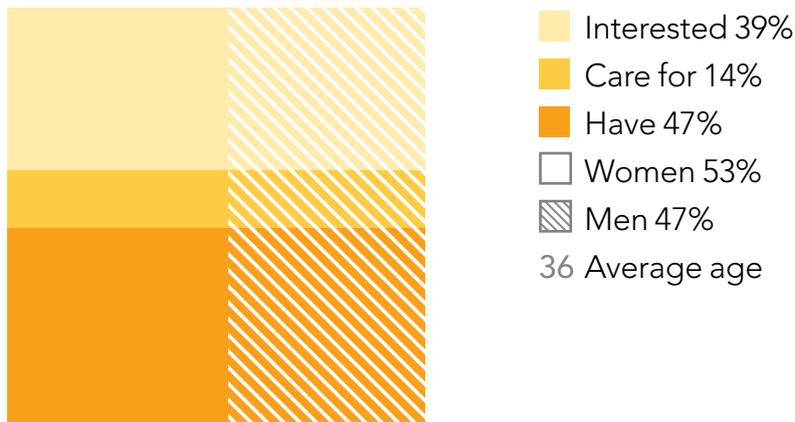
With all the information they have collected from a number of sources, as well as their trip to the specialist, they will be better prepared and empowered to confirm or dismiss their suspicions about the illness.

Finally, it is apparent from the comments made by Community users that these are illnesses for which there is very little reliable information available (other than in healthcare environments) and, above all, that these are illnesses about which there are strict taboos because of their close connection to sexuality or to the most intimate surroundings. A significant percentage of the most active members in the community demand more information on diagnosis and symptoms (in many cases to confirm their doubts about the possibility of having contracted the illness).

# Socio-demographic profile

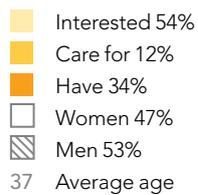
Suspected illnesses have a socio-demographic component that results in a large representation on the part of interested parties. When this happens, a close look at the conversations shows that people are more active online in the phase immediately before the diagnosis, and therefore they self-identify as interested in the illness.

## Group profile

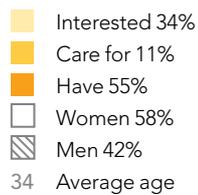


## Profile by illness

### Hepatitis

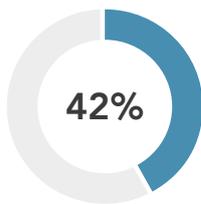


### HPV



# Semantic fields: Uncertainty and contagion

The concepts that stand out in Suspected illnesses are control and uncertainty. We have grouped together the most commonly used concepts into semantic fields and shown the frequency with which each of these fields appears as a proportion of all conversations.

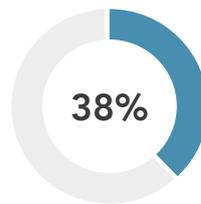


## Control

This semantic field covers e-patients' key concerns as they relate to the diagnosis (confirmation of suspicions) or supervision of their illness. It then becomes necessary to monitor their analyses and verify the treatments they are following, as well as to be informed of whether other types of alternative treatments exist that might palliate or otherwise help to mitigate the symptoms they are suffering.

### Families of concepts

- Treatment
- Tiredness
- Alternative therapy
- Diagnostic tests
- Check-ups
- Vigilance
- Analyses
- Food supplements
- Placebo
- Immunity

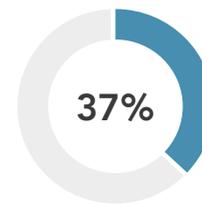


## Uncertainty

Since these are illnesses that are not easily detected and whose symptoms are often unclear, a strong sensation emanates from the texts of insecurity about whether the writer has the illness or not and, above all, a fear of infecting other people, especially the partner. There are perceptible feelings of shame, stress and guilt around this type of illness and, in particular, doubts as to what is the right thing to do (in the case of the human papilloma, whether the vaccination is advisable or not).

### Families of concepts

- Confusion
- Bewilderment
- Doubt
- Shame
- Trepidation
- Stress
- Guilt
- Rejection
- Insecurity

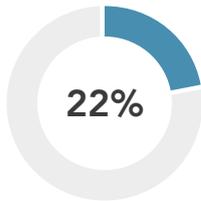


## Symptoms

The semantic field of symptoms contains all the references to signals, signs or effects produced by the suspected illnesses (generally confusing and unclear for people who are not medical specialists). The range of symptoms is also wide, as occurs with other illnesses, but we have put our focus here on the key concepts around discomfort, warts, as well as specific, locatable areas of pain.

### Families of concepts

- Warts
- Swelling
- Discomfort
- Lesion
- Genital warts
- Pain



## Transmission

This semantic field is closely linked to uncertainty and symptoms. There is clearly a need to know exactly what should be avoided in order not to pass the contagion on to others (for example, whether physical contact has an influence, and if so, what kind), how these illnesses are transmitted and all sorts of strategies for living with them, as well as how to live with people in the environment of the illness.

### Families of concepts

Contagion  
Vaccinations  
Protection  
Sexual relations  
Precautions  
Transmission  
Contact

## Comments

A selection of comments from platform users of Suspected illnesses follows below. These back up the findings made and reveal the concerns of people living with the illness, expressed in their own words.



Man  
24 years old  
Interested in HPV

I think I have HPV, I'm not sure, but if I do I've had it since puberty (that's a bit longer than 10 years ago). I would like to know whether it's possible to be infected without having had contact (or not direct, at any rate), because I haven't had sexual relations of any kind and the warts in the photos don't look like the ones I have."



Woman  
38 years old  
Caregiver to a patient  
with Hepatitis C

Is anyone here on a treatment with Sofosbuvir and Ledipasvir? My mother is 73 years old and has started taking Sofosbuvir and Ledipasvir. She's been on it for 4 weeks now, they have told her not to take one of the pills in the morning because she is a little anemic. Her feet and ankles swell up; is that normal?"



Man  
45 years old  
Has Hepatitis B

"Natural treatments.  
I've read several things about natural treatments, for example with milk thistle, that it's good for your liver... What do you think? Have you tried any natural therapies?"

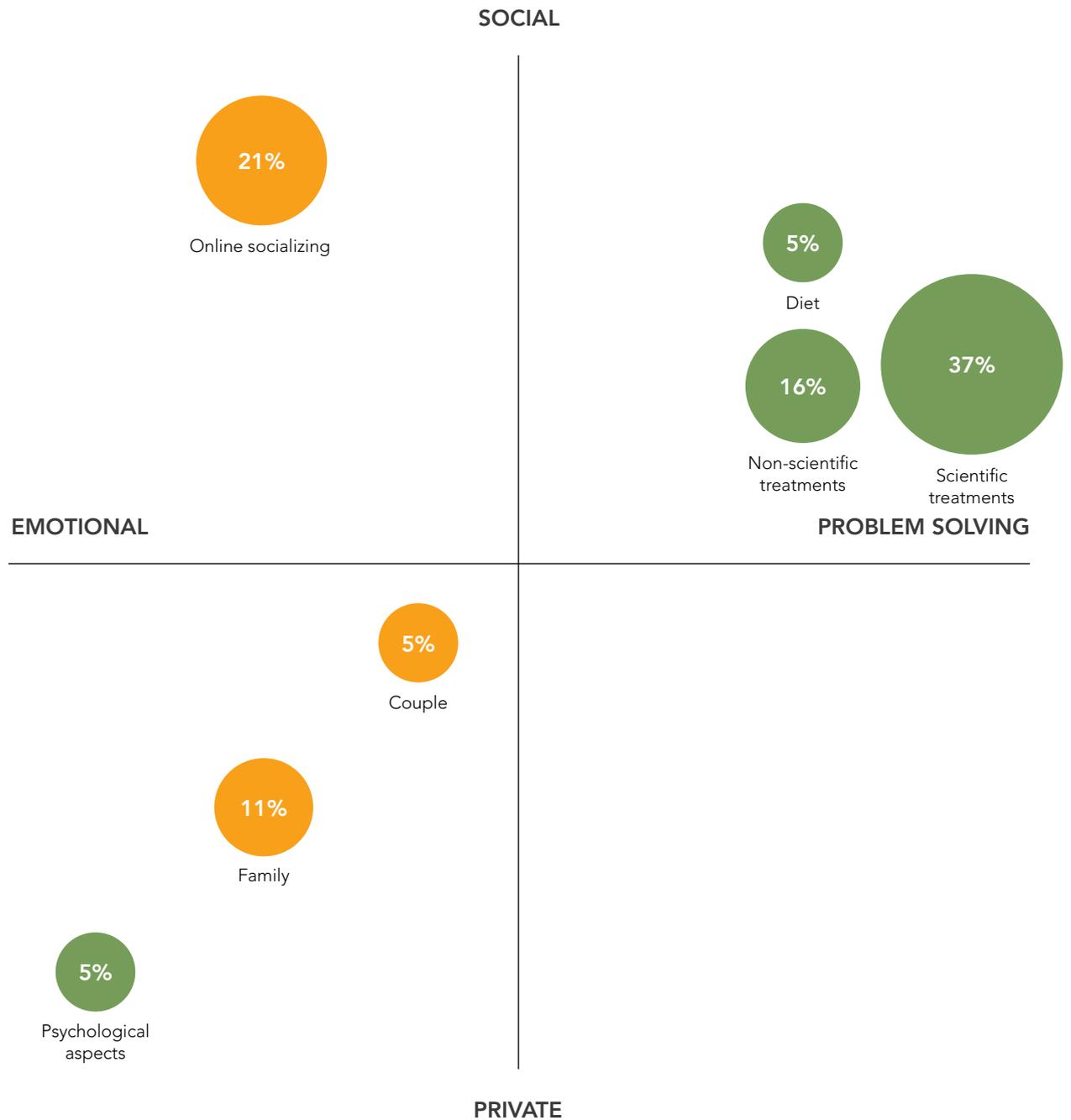


Woman  
37 years old  
interested in HPV

"When is it recommendable to have a vaccination? I have an 8-year old daughter and I don't know whether it is still too soon to vaccinate her or whether it is advisable at all, given that sometimes there are complications."

# Subject positioning map

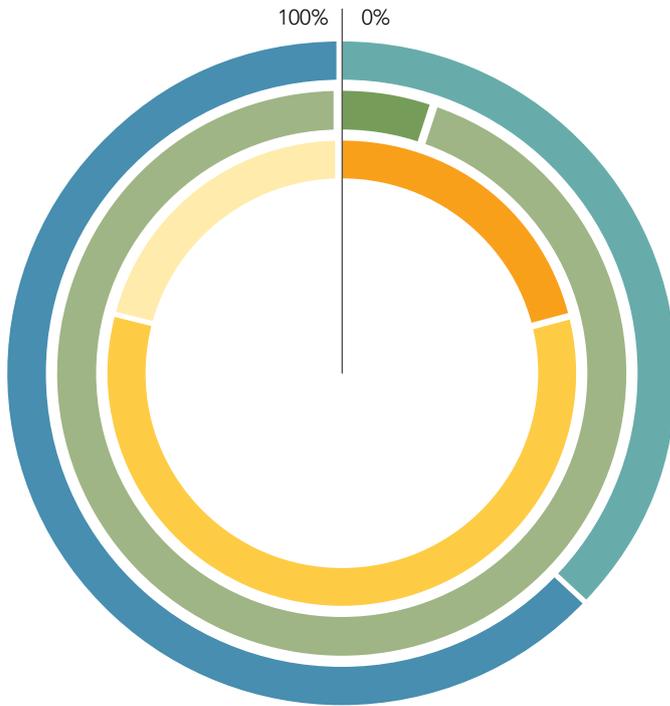
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- Social dimension
- Wellbeing
- Everyday life

# Motivation, attitude and pro-activeness

This graph shows three variables from the Suspected illnesses community. User's general motivation when posting on the Community, the attitude displayed in the comment and the user's pro-activeness in terms of requesting help and offering support when interacting with others.



## Motivation

Interaction	Numer of comments	Percentage
Problem-solving	7	37%
Emotional	0	0%
Social	12	63%
Usability	0	0%
Illness awareness	0	0%
Complaints	0	0%
<b>Total</b>	<b>19</b>	<b>100%</b>

## Attitude

Interaction	Numer of comments	Percentage
Positive	1	5%
Negative	0	0%
Neutral	18	95%
<b>Total</b>	<b>19</b>	<b>100%</b>

## Pro-activeness

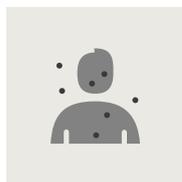
Interaction	Numer of comments	Percentage
Asks for help	4	21%
Offers help	11	58%
NA	4	21%
<b>Total</b>	<b>19</b>	<b>100%</b>

# 5 Under-estimated illnesses

These medical conditions have become everyday illnesses, commonly found in our surroundings and which in many cases are interpreted more as “setbacks” than as “major illnesses”, since they are not perceived as particularly serious.

A significant number of people have at least one acquaintance or relative affected by one of them, which for the sufferer does not remove the fact that unfair generalizations are often made, undervaluing the condition and not according it the importance it is due.

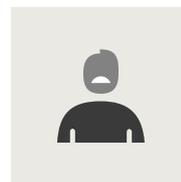
**The Under-estimated are:**



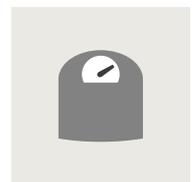
Allergies



Coeliac disease



Depression



Obesity

# Under-estimated illnesses, everyday life may seem normal

This group includes illnesses which are perceived in society as annoying, less serious or even minor.

During the period of study, the interests of the Community around this group of illnesses have been in areas around psychological issues and online socializing, that is, the exchange of comments and interests relevant to the users themselves, wondering about their day to day and the contents generated by the Community itself. In this report we have decided to focus less on the purely medical issues, and more on normal daily life with the illness.

The profiles of people who are most interested in or living with these illnesses are quite common in our communities. They are people who come to learn more about their illnesses and to take part in a space where they can talk about the difficulties they are facing. In this social type of illness, the profile of the participants is mainly female and the average age is around 42 years old.

Nowadays, depression, allergies, obesity and coeliac disease are receiving more attention in the media, because of the need to focus attention on them and for the scope of these illnesses to be better understood, as well as the difficulties they may cause in people's daily lives, given that they can be triggered at any point over the course of one's life.

Depression is one of the most common causes of sickness from work and affects up to 120 million people around

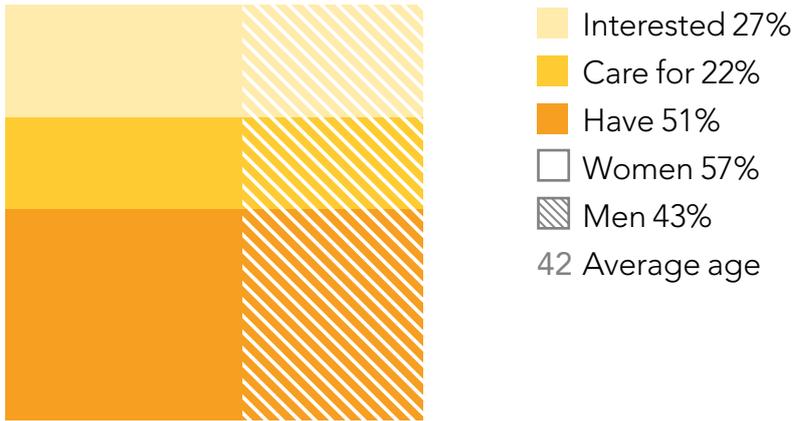
the world. In many situations it is taken for granted that it is simply a passing affliction or a series of "bad patches" that ought to be weathered without too much difficulty, but in fact it is a much more complex problem, that goes much deeper, and makes daily life and social relationships difficult. Furthermore, this underestimation of the patient's condition actually makes the burden and the problems of patients living with this type of illness worse. It is not always feasible to overcome it just by willing it to be so, and the associated costs of the illness increase because of the therapies, of medication on occasion and, of course, the economic losses generated because people living with these conditions cannot always fulfil their work functions at 100%.

Although awareness about this type of illness has on the whole increased, thanks to a number of information campaigns, there is still a tendency to think of people with these illnesses as "not really ill" (coeliacs and those with allergies); in the best case scenario, they are considered to have such a mild condition that it scarcely merits attention (with the patient even, on occasion, being blamed for it, in the case of obesity, as being responsible on account of eating badly). So it is very important to transmit to the general population that the potential risks associated with these illnesses are significant, and to start supporting this type of underestimated groups more strongly.

# Socio-demographic profile

The average age of those active on the Under-estimated illnesses communities is similar, but the user profile is different. The high percentage of people who are interested in allergies and obesity reveals the existence of people with symptoms, but who have not yet been diagnosed, and who are thus not yet being treated.

## Group profile



## Profile by illness

### Allergies



Interested 48%  
 Care for 7%  
 Have 45%  
 Women 52%  
 Men 48%  
 45 Average age

### Coeliac disease



Interested 11%  
 Care for 35%  
 Have 54%  
 Women 56%  
 Men 46%  
 39 Average age

### Depression



Interested 21%  
 Care for 16%  
 Have 63%  
 Women 62%  
 Men 38%  
 42 Average age

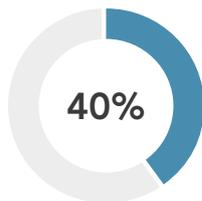
### Obesity



Interested 37%  
 Care for 15%  
 Have 48%  
 Women 59%  
 Men 41%  
 42 Average age

# Semantic fields: Lack of understanding and being different

The concepts that feature most strongly in Under-estimated illnesses are lack of understanding and being different. We have grouped together the most commonly used concepts into semantic fields and shown the frequency with which each of these fields appears as a proportion of all conversations.

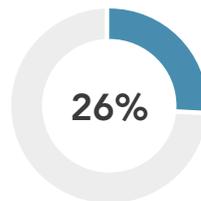


## Treatment

Issues relating to treatment cover subjects around medication, therapies and tests of all kinds, as well as progress or alternatives in matters relating to physical and mental health (limitation and prevention of break outs, advice on nutrition and healthy living, alternative and complementary therapies...).

### Families of concepts

- Medication
- Alternative therapy
- Treatment
- Diagnostic tests
- Check-ups
- Vigilance
- Side effects
- Seasonality

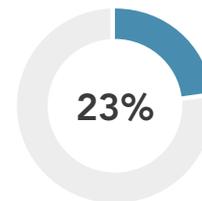


## Lack of understanding

Under this semantic field fall all user posts about rejection by those around them, whether in daily social relations or in their places of work. There is great concern because the illness and what it implies is not understood, together with a faulty interpretation of the attendant symptoms, especially in the case of depression.

### Families of concepts

- Loneliness
- Shame
- Stress
- Prejudices
- Anger/Frustration
- Sadness/Depression
- Incapacity
- Rejection
- Insecurity

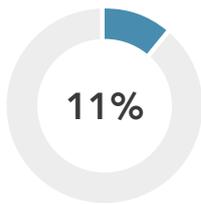


## Integrating

The comments classified under this semantic field refer to strategies carried out by users to overcome the sensation of feeling "odd" or a limitation in the daily routine of their environment. For example, going out for a meal in a restaurant with a person with dietary restrictions (allergies, intolerances, diets...) may be complicated or frustrating for the patient and their circle because the sufferer may feel that they are a burden, out of place in the group or that they are putting limitations on the rest.

### Families of concepts

- Complexes
- Normalcy
- Exclusion
- Makeup
- Leisure



## Nutrition

The semantic field of nutrition appears, above all, among the various allergies relating to foodstuffs, coeliac disease and intolerances (as well as diets associated with obesity). Most of the discussions cover foods that are allowed and those that are not, and how these affect symptoms and the progression of the illness.

### Families of concepts

Diet

Food

Intolerance

Eating habits

Control

Measuring

## Comments

A selection of comments from platform users of Under-estimated illnesses follows below. These back up the findings made and reveal the concerns of people living with the illness, expressed in their own words.



Woman  
58 years old  
Has allergy

"Hello, I'm already in other People Who live with communities... I have other chronic illnesses.... Dust mites give me mild asthma. I was on a treatment for three years, with a drip under my tongue and now I'm ill again. I go swimming and I can't breathe, so I hope that I can see a lung specialist in a few days because I'm finding it difficult to swim or do any kind of exercise because I can't breathe through my nose and the worst thing is that I have had a nose operation, so I don't know what to do, at night it is so uncomfortable..."



Woman  
30 years old  
Caregiver for coeliacs

"My nieces are coeliacs and I get the impression that there is a lot of confusion about labeling. I think the law should be much clearer and make it obligatory for products to specify whether it contains gluten or not."



Woman  
33 years old  
Has depression

"Hello everyone!

As I was looking for information about depression I stumbled on this website. I'd like to tell you about my situation so that you can advise me how to deal with it, because I find it very hard to share what I feel with the people around me.

Two years ago I started to feel terribly tired and gradually that progressed into deep sadness and apathy. I always used to do sport, until the day arrived when going to a Pilates class represented a huge effort; what is more, I couldn't clear my head with sport, I just ended up twice as tired and just as sad.

The situation went on with ups and downs. I started feeling anxious, to lose my appetite and find it difficult to sleep. It got to the stage that I let all the plants in my house die, I stopped cooking, I didn't wash the dishes every day, etc. I used to be able to control these episodes, but now I feel that I've lost control. It's getting harder and harder to recover.

All this is affecting my relationship with my partner a great deal. Amongst other things because I became totally uninterested in sex and I am desperate to be alone, which is the only time I don't feel under any kind of pressure. I would be so grateful if you could give me some advice on all this.

Thank you so much."



Woman  
24 years old  
Has obesity

"I got a call yesterday for a job interview: my first interview! I called my mother on the phone to tell her. When I got home the first thing she asked me was what I was going to wear, and straight away she said: don't go in short sleeves, and of course right behind it was "It's for your own good."

# Subject positioning map

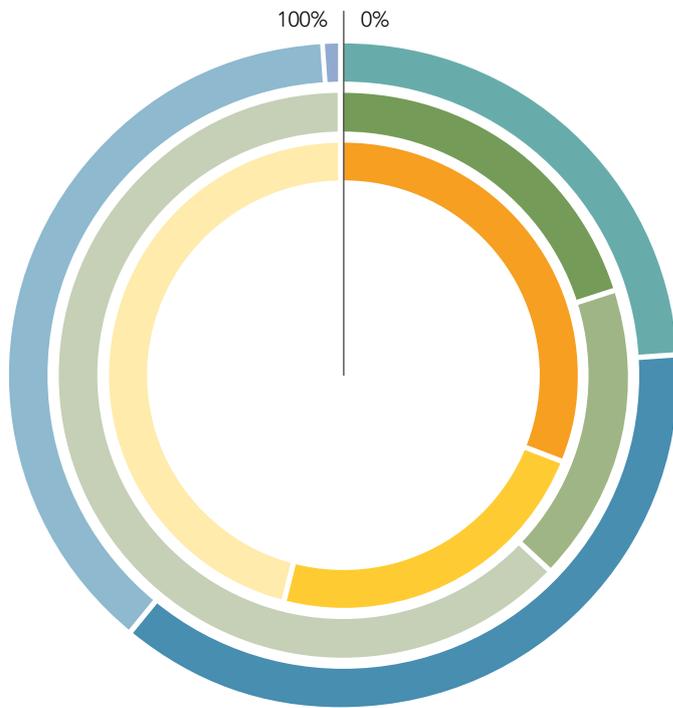
To display data on the issue categories referred to above, we have decided to construct a map around two key and opposing contexts: social (public)/private and emotional/problem solving. The subjects that come up most frequently in Under-estimated illnesses appear as percentages in this positioning map.



- Social dimension
- Wellbeing
- Everyday life

# Motivation, attitude and pro-activeness

This graph shows three variables from the Under-estimated illnesses community. User's general motivation when posting on the Community, the attitude displayed in the comment and the user's pro-activeness in terms of requesting help and offering support when interacting with others.



## Motivation

Interaction	Numer of comments	Percentage
Problem-solving	39	24%
Emotional	60	37%
Social	61	38%
Usability	2	1%
Illness awareness	0	0%
Complaints	0	0%
<b>Total</b>	<b>162</b>	<b>100%</b>

## Attitude

Interaction	Numer of comments	Percentage
Positive	32	20%
Negative	28	17%
Neutral	102	63%
<b>Total</b>	<b>162</b>	<b>100%</b>

## Pro-activeness

Interaction	Numer of comments	Percentage
Asks for help	51	31%
Offers help	37	23%
NA	74	46%
<b>Total</b>	<b>162</b>	<b>100%</b>

# 6

## Age-related illnesses

The illnesses in this group are those where the caregiver figure is particularly important in the process of coping with the disease. This is because the caregiver is challenging the illness almost as much as the patient, who in turn requires a great deal of attention, company or guidance (on issues like medication, hygiene, personal care or meals). In the countries covered by this study, a higher relative number of caregivers was detected in this category than in the other two registration profiles (patient and interested party).

The caregiver-related illnesses are:



Alzheimer's



Atrial fibrillation



Chronic leukemia

## Age-related illnesses, where the caregiver participates more than the patient

The need for assistance and extended care over time is also explained by the fact that these illnesses are generally associated with older age groups, who often require more guidance or assistance (sometimes leading to a complete loss of self-sufficiency). In addition, they are illnesses which take a major physical and emotional toll on the caregiver. In fact, such an intense involvement can trigger serious problems for the caregiver because of the absorbing nature of the tasks involved in caring, which can lead to burnout syndrome.

Caregiver burnout syndrome is distinguished by the presence of physical, emotional and mental exhaustion. Very briefly, it can be described as a disorder characterized by high levels of demotivation which is often accompanied by anxiety, fatigue and even depression, affecting those caring for the sick.

Therefore, caregivers often express their frustration and unburden themselves with other people in the community (psychological and emotional issues); we also frequently see the search for shared experiences, symptoms and habits, particularly among Alzheimer's patients (online sociability).

Returning to a more general approach to these illnesses, the problems relating to the family and the environment (caring, dependency, emotional relationships ...) are frequently under-estimated; in fact, in terms of living together on a daily basis, they seem to be as -or more-

important than other more frequently identified issues such as symptoms or treatment.

The need to provide higher visibility and social awareness about these illnesses is founded on criticisms and demands based on the lack of understanding on the part of the State (requiring financial support and more generous service provision from healthcare professionals and caregivers). Indeed, among the issues that users bring up most often are those referring to treatments (up to 22%) and the healthcare system.

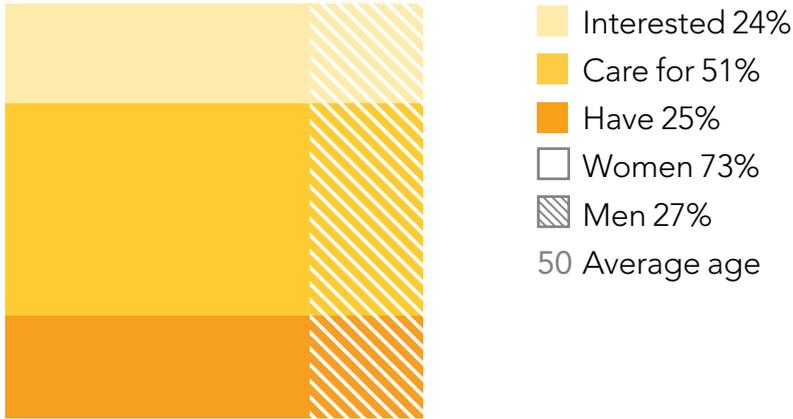
There are also many complaints about the situation of patients, both in terms of the difficulties that the illness itself involves, and the added problems that families have (for example, attending medical check-ups and taking financial responsibility for the expenses that arise from the need for specialist care and residential homes).

We see references to a lack of fluid communication between patients and their own doctors or specialists, since the side effects or factors involved in the illnesses are not always well explained. Thus, they frequently view themselves as "victims of medical protocol" and as a result see a need for clarity and greater flexibility in the relationship between doctor and patient. Users of this group of illnesses stand out for the very detailed descriptions they give of the procedures they go through and they type of things they have to know. They demand better and clearer communication with their doctor.

# Socio-demographic profile

The Age-related illnesses group has, as one would expect, a higher average age, 50 years old, compared to the platform's overall average of 45. When considering the average age of each group we should bear in mind the composition of the community: the presence of caregivers, particularly patients' children in the case of Alzheimer's, can bring down the group's average age considerably.

## Group profile



## Profile by illness

### Alzheimer's



- Interested 26%
- Care for 71%
- Have 3%
- Women 79%
- Men 21%
- 49 Average age

### Atrial fibrillation



- Interested 24%
- Care for 19%
- Have 57%
- Women 57%
- Men 43%
- 55 Average age

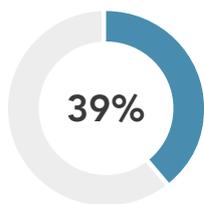
### Chronic leukemia



- Interested 27%
- Care for 19%
- Have 54%
- Women 53%
- Men 47%
- 43 Average age

# Semantic fields: Dependency and mobility

The concepts that stand out most strongly in age-related illnesses are dependency and mobility. We have grouped together the most commonly used concepts into semantic fields and shown the frequency with which each of these fields appears as a proportion of all conversations.

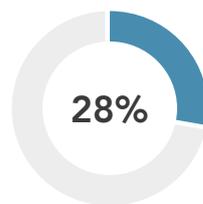


## Dependency

The semantic field of dependency includes all the references to situations of incapacity, limitations, lack of autonomy and need for help that are intrinsic to illnesses classified as caregiver-related. The queries about financial and legal issues (subsidies, provisions, caregiving help) relating to situations of dependency also arouse great interest among Community users.

### Families of concepts

- Need
- Tutoring
- Caregiver
- Slowness
- Incapacity
- Supervision
- Vigilance
- Autonomy
- Environment
- Subsidy
- Provision

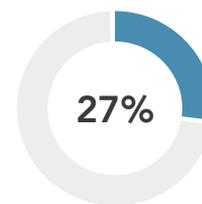


## Impairment

Physical worsening, deteriorating faculties, discouragement and progressive loss of fine motor skills are all grouped together in the semantic field of impairment. These illnesses involve major encroachment on people's autonomy and ability to function, affecting the people nearest to them. Although society tends only to consider the factors most closely related to physical impairment, the illnesses in this group involve serious physical and emotional wear and tear for patients and those in their environment (with caregiver burnout syndrome being of particular importance among Community users).

### Families of concepts

- Worsening
- Difficulties
- Regression
- Exacerbation
- Mobility
- Frustration
- Weakness

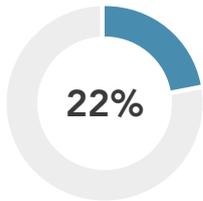


## Concern

Caregiver-related illnesses trigger a series of concerns both among patients and caregivers. Issues such as fears, stigma, stress and complexes may create an environment in which sadness, frustration and rejection can, as a matter of routine, have a very negative impact on the patient's surroundings.

### Families of concepts

- Fear
- Shame
- Stigma
- Stress
- Prejudices
- Rejection
- Disgust
- Lack of understanding
- Anger/Frustration
- Sadness/Depression
- Complexes



## Treatment

Issues relating to treatment bring together references to medications, therapies, diagnostic tests and control of the illness. Given that the patients are elderly, issues such as forgetfulness and managing large numbers of pills and/or medications a day are recurring themes that have widespread presence in the Community.

### Families of concepts

- Medication
- Alternative therapy
- Treatment
- Diagnostic tests
- Check ups
- Vigilance
- Side effects
- Seasonality

## Comments

A selection of comments from platform users of Age-related illnesses follows below. These back up the findings made and reveal the concerns of people living with the illness, expressed in their own words.



Man  
52 years old  
Caregiver for Alzheimer's

"Good evening. I registered on your website a few days ago but haven't posted until now. In my case it is my father who was diagnosed with AD two and a half years ago. He will be 80 in September. I'm not going to tell you how tough it is, both to accept it, and to live with the illness because you know all about it. Looking on the bright side (if there is one), he has always been and still is (even in his difficult moments) very docile and a happy person. In the last few months we have noticed that he has gone downhill a lot: he is slower, more fearful, more obsessive, clumsier... And the worst thing: incontinence. Every night we have to change him completely two or even three times, so both my mother and I sleep in fits and starts and on top of it all he is still wet. Can someone give me some ideas of how to convince him to wear a diaper? It is a very tricky subject. I imagine it's hard for them... I don't want to force him because going to bed has for the last few months been one of the most complicated times of the day. He doesn't want to take off his clothes and I have to keep distracting his attention to get him to do so, and that's why, even the idea of putting a diaper on him... Oh, I don't think I can do it. At the moment we are making do with an absorbent sheet, at least that way we don't have to wash the sheets every day and he is less wet. Best wishes to everyone, and keep strong, this is really tough ..."



Man  
51 years old  
Has chronic leukemia

"Like everything in this life, it depends...  
As a CML patient I have found support in groups created voluntarily by other patients on social networks, that enable you to stay in "virtual" but close contact, sharing concerns, improvements, information, and receiving a lot of encouragement above all... But these groups are not patient associations.  
Some of the bodies set up to encourage scientific research and, in particular, to support the youngest sufferers of leukemia, can be very useful for those who unfortunately are in a situation that requires them to be helped in a hospital or to be living near to one for a while so that their child can follow a course of treatment.  
For CML patients, those of us who, fortunately, have a chronic disease that has been fairly well studied, if what we want is to be informed, we can find information on many websites online.  
  
If what we want is to have the right for the side effects that the medications we take to be acknowledged by our hematologists and properly assessed by Social Security, we need to find a way of joining forces, to make our case more strongly.  
  
I think we need a patient association that collects real information about the quality of life of CML patients, of the side-effects we suffer, of what we ought to do to get better [...]"



Man  
51 years old  
Has chronic leukemia

“Well, firstly I have to say that in my case the worst thing is the constant and unwarranted feeling of fatigue (the doctors call it asthenia), together with gastro-intestinal alterations (random diarrheas), cramps in my feet when I lie down, joint pain and quite a few moments of absence that I never used to have, cholesterol surges, a cold that has lasted 4 weeks, problems in an aortic valve ... And I’m sure I’ve forgotten something...

But then, secondly, I feel like a ping-pong ball; at the GP and the psychologist’s they tell me that the hematologist ought to monitor these side effects, but the hematologist takes absolutely no notice...

Who should treat these side effects, monitor them, try to remedy them? What can we do so that Social Security makes sure that someone pays some attention to us?

As to what we ought to do to lessen the symptoms... Rest when your body tells you to (I am on sick leave and I was fired) ... And cross your fingers that the next day will be better.

Kind regards.”

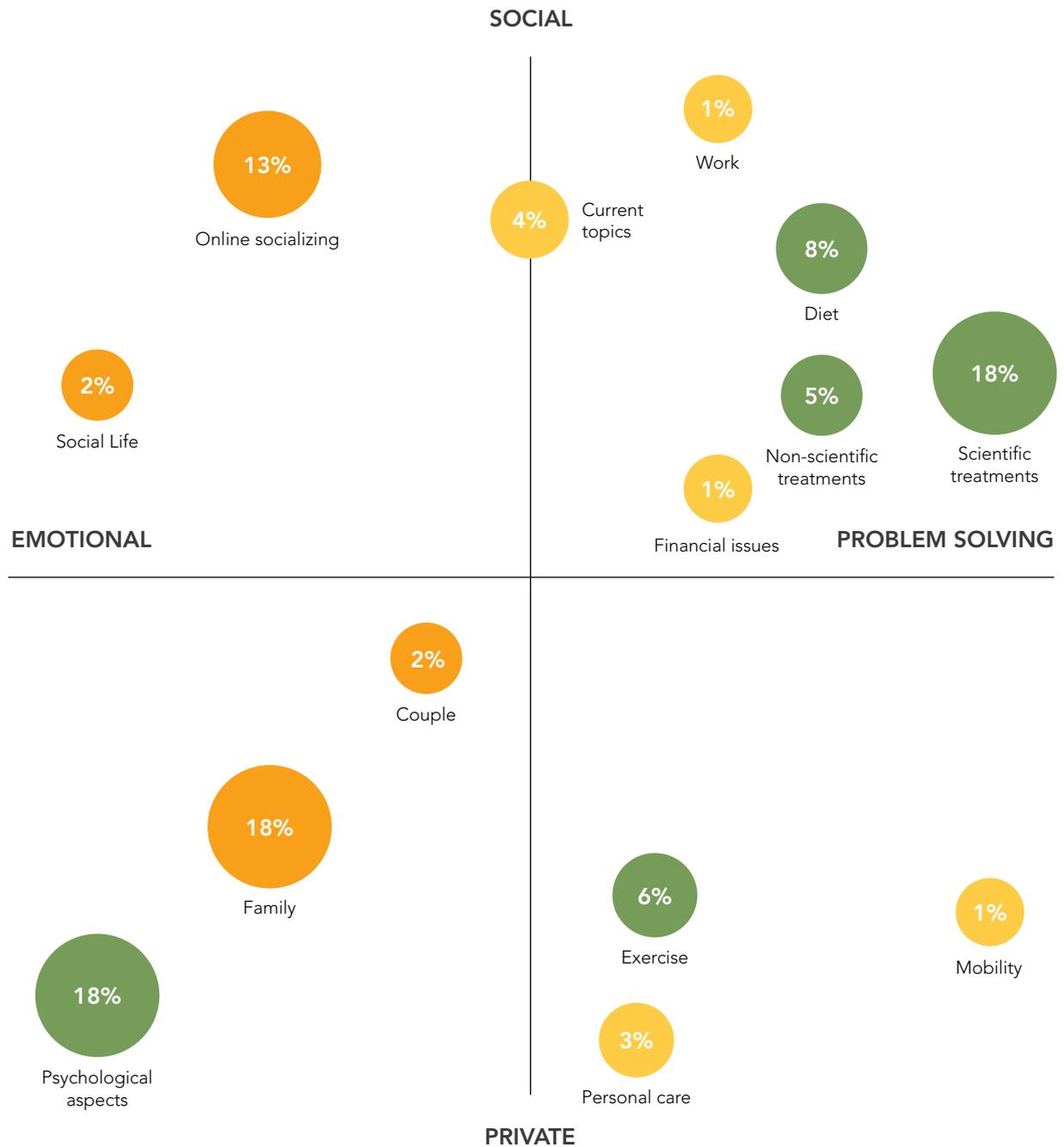


Man  
64 years old  
Has atrial fibrillation

“Today it’s been 9 months since I had my fourth, and for the moment, last operation for atrial fibrillation. It’s been 8 months since I’ve had any new arrhythmia episodes. I don’t know whether they will come back one day, but to really appreciate how it feels not to have arrhythmias, first of all you have to have them. What I mean by this is to send a message to encourage everyone who has been affected because you need to know that atrial fibrillation can be cured.”

# Subject positioning map

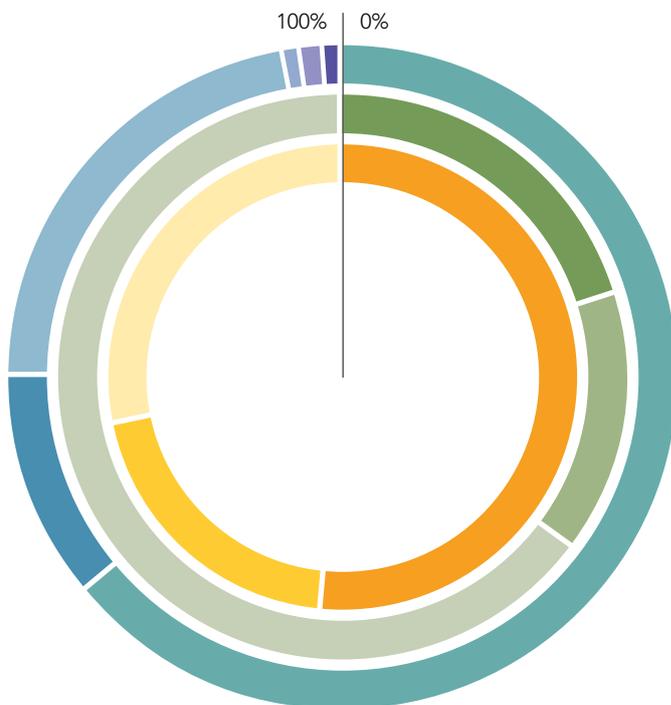
To display data on the issue categories referred to above, we have decided to construct a map around two key and opposing contexts: social (public)/private and emotional/problem solving. The subjects that come up most frequently in Age-related illnesses appear as percentages in this positioning map.



- Social dimension
- Wellbeing
- Everyday life

# Motivation, attitude and pro-activeness

This graph shows three variables from the Age-related illnesses community. User's general motivation when posting on the Community, the attitude displayed in the comment and the user's pro-activeness in terms of requesting help and offering support when interacting with others.



## Motivation

Interaction	Numer of comments	Percentage
Problem-solving	340	64%
Emotional	60	11%
Social	119	22%
Usability	3	1%
Illness awareness	5	1%
Complaints	4	1%
<b>Total</b>	<b>527</b>	<b>100%</b>

## Attitude

Interaction	Numer of comments	Percentage
Positive	104	20%
Negative	79	15%
Neutral	344	65%
<b>Total</b>	<b>527</b>	<b>100%</b>

## Pro-activeness

Interaction	Numer of comments	Percentage
Asks for help	271	51%
Offers help	106	20%
NA	150	28%
<b>Total</b>	<b>527</b>	<b>100%</b>

# 7

## Conclusions

What are illnesses such as schizophrenia and psoriasis doing in the same illness classification? Or depression and coeliac disease? Or arthritis with ovarian cancer? From the physiological point of view, or the medical specialty that treats them, they are completely different. Nevertheless, they have many similarities in terms of the patient's reality or that of the caregiver living with these illnesses.

Schizophrenia and psoriasis are grouped together in Socially-stigmatized illnesses because in both cases there is a high degree of rejection from society, which means that these people end up becoming isolated. Depression and coeliac disease are Underestimated illnesses because, for different reasons, they are not considered as illnesses by society, and this means that they are not borne in mind when people relate with others, triggering a feeling that they are different and of not being understood by others. Arthritis and ovarian cancer are both included under Incapacitating illnesses because in both cases, although again for different reasons, they suffer limitations of differing degree to daily life (in the case of cancer because of the side-effects of treatments). And in both illnesses when these limitations last for long periods they end up leading to despair.

## A fresh point of view

This report about illness types from the patient's social perspective validates how the patient's perception of the illness is very different to that of the medical world. The doctor has the purpose of treating the illness in order to cure it or halt its progress, using a combination of science and experience. The patient, however, must include the illness into their daily routine and manage the daily challenges it presents.

There is little new about the insight that patient and doctor have different roles in managing the illness, but whereas the medical dimension is highly developed, that of the patient still has a long road to travel. If we want to build sustainable health systems that involve the patient in the self-management of their illness we need to take this new approach fully on board. For this reason, People Who has used the conversations in our communities to create a new classification of illnesses from a social perspective.

## 5 types from the patient's social perspective

By analyzing user conversations from the communities of each of the illnesses we have online, in 2015 we identified 5 types of illness, and grouped together those with similar patterns of behavior.

### **1. Socially-stigmatized illnesses.**

Illnesses that are negatively represented in the collective imagination and public opinion. Interacting with other people in the real world is difficult and they seek socialization in the online world.

**2. Incapacitating illnesses.** Illnesses that limit the daily performance of all types of tasks. People are looking to the communities to solve day-to-day problems and share them.

**3. Suspected illnesses.** Sexually-transmitted illnesses or bloodborne diseases are associated with certain risk practices. Interactions in these communities generally have the aim of finding answers to questions that allow participants to deduce whether they have the illness before going to the doctor.

**4. Under-estimated illnesses.** Illnesses which are perceived in society as annoying, less serious or even minor. Lack of understanding from other people of the reality they are going through is the main reason for starting these conversations.

**5. Age-related illnesses.** Illnesses in this group are those in which the figure of the caregiver is particularly relevant in the process of coping with the disease. The communities are made

## 2 types of communities by motivation

up of caregivers who try to resolve the problems arising from looking after an incapacitated person.

These 5 types of illnesses will continue to be validated and grow as People Who includes more new illnesses. We should bear in mind that the 5 types have been defined on the basis of the illnesses we have included on the platform: Allergies, Alzheimer's, arthritis, atrial fibrillation, bipolar disorder, coeliac disease, depression, diabetes, epilepsy, hepatitis, HIV, HPV, infertility, acute leukemia, chronic leukemia, obesity, ovarian cancer, psoriasis, schizophrenia, skin cancer and transplants.

The methodology used in this report, which is qualitative in nature, has enabled us to dig deeply into some of the issues that were identified in the previous report in 2015, which was substantially more descriptive. While we recognize the need for the descriptive and exploratory approach we used there, this time we have dived into a semantic analysis of the comments. This means that we have observed the phenomena relating to daily life with the illness from a richer and more robust body of knowledge.

Grouping behavior patterns together has enabled us to identify two types of communities with different dynamics. Although the format is always that of comments, the motives triggering the conversations are different, which is why we can divide them into two.

**Socializing.** Communities which primarily seek interaction with other people as a way to socialize and share daily experiences. The aim is to have a relationship with other people, with no further motivation. They are communities of illnesses in which stigma or lack of understanding make interaction in the physical world difficult.

**Problem-solving.** Communities in which the conversations have the purpose of solving a doubt or a problem. Although the comments are preceded by an introduction to initiate the interaction, they are clearly motivated by the need for a solution and tend to include a question.

We should point out that within socializing communities, those

## A different set of dynamics

including mental illnesses work differently to others because of their high degree of activity. Consider that in many cases the people who suffer them cannot work, or interact with the physical world easily, so they spend much of the day on the community site, establishing friendly interactions with other patients.

When we talk about online communities, we generally think about social networks such as Facebook, where there is a lot of activity by users who are constantly interacting with others, sharing other people's publications or posting directly. Communities of illnesses work differently, for several reasons:

**Illness is not a pleasant thing.** By its very nature we try not to think about it whenever possible. Whereas other social networks share the good things in life, in communities of illnesses the opposite is true. As a result, the intensity of someone's interaction changes depending on the moment, the type of illness, the age and the environment in which they live. It is important to highlight that it all hinges on the moment, for example whether the diagnosis is recent, and not on the phase of the illness from the medical perspective.

**You don't know anyone.** On mainstream social networks we incorporate our real-world relationships into the online world. We create an account and invite our friends. From this initial network, where the relationships have already been created, we bring in new people.

In communities of illnesses it is exactly the opposite. We don't know anyone and we go there to meet people in the online world who are in the same situation and whom it would be very difficult to meet in the physical world. This means that friendships do not exist beforehand and if someone wants to create them, it will require time. But

## Necessary anonymity

do users want to create friendships? Our conclusion, after observing these communities for 4 years, is that it is not a motivation, but a consequence; we have only seen this desire to create friendships in the case of mental illnesses.

**Different rhythms.** An outcome of the two previous points is that the rhythm of communities of people living with an illness is different to that of other social networks. They are not places where there is continuous activity, it is rather more measured: the replies come in through the day, they are not immediate; sometimes responses are very long, because of the complexity of the illness.

We made a distinction, above, between socializing and problem-solving communities. We could say that socializing communities have more in common with Facebook, where people seek to interact or catch up with one another, while problem-solving communities are more like TripAdvisor, where users go only when they are planning a trip or have decided to go out to dinner and want an answer to a specific question.

Right from the beginning, at People Who we were in favor of maintaining people's anonymity. We prevent users from uploading photos that allow them to be recognized and we provide a series of avatars so that they can choose their online identity. Nor do we allow user names that contain forenames and surname, to prevent people from being identified in real life. Although initially we thought this might be uncomfortable for users, we have found over time that it is not.

When users take part in our online communities, protected by this anonymity, they feel that they are in a safe space that allows them to share their reality, including intimate details that they would not share with the doctor and, in some cases, not even with those closest to them. Anonymity allows users to "be themselves" in these communities and to express themselves freely without fear of being judged or socially stigmatized.

## Communities separated by illness

Our communities are different for each illness and the conversations about one illness do not overlap with those about others. We know that in order for these communities to exist they must have something in common with one another and being a patient is not, on its own, enough. What unites people in this kind of community is the illness itself and the reality it creates. Someone with psoriasis is not interested in the reality of someone with epilepsy and vice versa. An Alzheimer's caregiver, for example, is not interested in interacting with someone with cancer. That is why the division by illness is needed, so that conversations spring up based around a shared interest.

At People Who we take the approach of one community per illness, but users can register with several illnesses, and switch from one to another quickly. The analysis we have carried out of conversations in our 2015 and 2016 reports have demonstrated that the community, its dynamics, motivations and user needs change from one illness to another.

## Involvement through socialization

For several years there has been talk of the need to educate patients so that they engage in managing their illness. Communities of illnesses are an essential tool to make real headway in that involvement. Socialization is a human need and when illness strikes, the balance that a person had in this field wobbles because the reality they are living is different. To soften the backlash against the illness, social relationships need to continue after diagnosis, but they can no longer be as full as they were in the existing environment and should be extended to people living through the same situation. With the internet and patient community platforms, an illness can be managed in a more natural way, surrounding oneself with people in the same circumstances.

At People Who we work to get the patient engaged, not only by catering to the social dimension with a community, but also in practical ways, with an area to monitor the illness, and in terms of information, with a magazine on each illness. In upcoming editions of this report we will tackle the analysis of these dimensions in depth.

# 10 findings

Our years of experience have given us the scope to detect certain striking issues and behavior patterns that, although already mentioned in the analysis we have carried out, are deserving of mention, either because they sum up the behavior of the illness community or because they reveal little-known aspects of the illness. The fact that our community mixes patients and caregivers, plus interested people, gives us a broader, richer vision of the social reality which we can explore in depth, illness by illness.



## **Arthritis**

### **Incapacitating illness**

The desperation caused by pain makes sufferers prepared to seek all sorts of treatments that might improve on the situation in which they find themselves, with biological treatments being talked about in particular. The community also talks about how to manage the difficulties caused in daily life by more serious outbreaks, mobility and complications.



## **Alzheimer's**

### **Age-related illness**

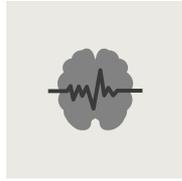
In the narrative of many caregivers in this community there is an underlying current of guilt about not being able to give the patient all the quality of care that could be wished. This feeling is alleviated to some extent when they discuss their problems and receive replies that provide new strategies and help to deal with the difficult situation they are living through. For this reason they are the groups most inclined to participate in an online community.



## **Atrial fibrillation**

### **Age-related illness**

In their conversations the community reveals the difficulty they have in understanding cardiologists during their visits and the need to have a series of clearer, more easily understandable protocols.



### **Epilepsy**

Incapacitating illness

There is concern as to how to live with the illness and manage its crises. There is also the worry as to whether this neurological illness may also be connected to other illnesses of a mental nature. Medication and its effects on the patient's sex life and other daily areas of life are the subjects most often discussed in the community.



### **Depression**

Under-estimated illness

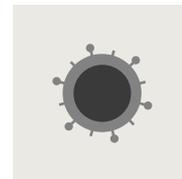
There is a battle for this illness to be recognized as a potential cause of occupational disability. More visibility is wanted even though the illness is increasingly widespread. There is much psychological and social support among participants in the community, who come online to recount their daily lives in response to a need to socialize anonymously.



### **Coeliac disease**

Under-estimated illness

More awareness about the illness is wanted because the wider society does not really perceive it as one, labeling it an "intolerance". Users ask one another about whether they can eat certain foodstuffs and provide tips. Despite the general information available online, these people have day-to-day difficulties and demand that the same criteria should be used for all labeling.



### **HPV (Human Papilloma Virus)**

Suspected illness

Huge uncertainty still exists about what it is, how it is detected and what are the implications of human papilloma virus. The community is mostly made up of mothers, concerned that their daughters may be affected, who ask for information about the vaccination to prevent the illness.



### **Psoriasis**

Socially-stigmatized illnesses

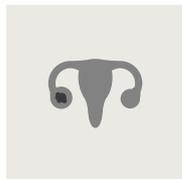
The conversations between patients reveal a lack of confidence in the efficacy of treatments and focus on how to conceal the scales or whether certain nutritional habits such as vegetarian diet help with the illness.



### **Schizophrenia**

Socially-stigmatized illnesses

This illness carries a lot of stigma, which leads to it being concealed from friends and at work, and even in family environments. An illness like this needs family support and this tends to fall on the mother. However, we are seeing in the community that this responsibility is also falling on the sisters, much closer to the reality of the person diagnosed, particularly among young people when the relationship between siblings is very close.



### **Ovarian cancer**

Incapacitating illnesses

Almost certainly thanks to the fact that good information about cancer in women is widely available, we note that in this community the conversations fit other profiles, such as caregivers and interested parties, whereas the women themselves who have the illness only express some doubts when they have just been diagnosed. Perhaps the cancer information awareness campaigns that have been so helpful to sufferers could be supplemented with support for caregivers at the beginning of the cancer treatment.

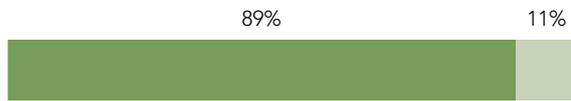
# Main characteristics of the 5 types of illnesses from the patient's social perspective

<b>Socially-stigmatized illnesses</b>	<p>Problems they face Rejection and isolation.</p> <p>Searching for Online social relations.</p>	<p>Illnesses included in this group: Bipolar disorder, HIV, infertility, psoriasis, schizophrenia.</p>
<b>Incapacitating illnesses</b>	<p>Problems they face Limitations and despair.</p> <p>Searching for Problem-solving in daily life.</p>	<p>Illnesses included in this group Arthritis, diabetes<sup>2</sup>, epilepsy, ovarian cancer, skin cancer and transplants.</p>
<b>Suspected illnesses<sup>1</sup></b>	<p>Problems they face Control and uncertainty.</p> <p>Searching for Answers to "Do I have the illness?"</p>	<p>Illnesses included in this group Hepatitis and HPV (Human Papilloma Virus).</p>
<b>Under-estimated illnesses</b>	<p>Problems they face Lack of understanding and being different.</p> <p>Searching for Sharing the feeling that everyday life seems normal but is not.</p>	<p>Illnesses included in this group Allergies, coeliac disease, depression and obesity.</p>
<b>Age-related illnesses</b>	<p>Problems they face Dependency and mobility.</p> <p>Searching for Meeting other caregivers to solve the problems they face.</p>	<p>Illnesses included in this group Alzheimer's, atrial fibrillation and chronic leukemia.</p>

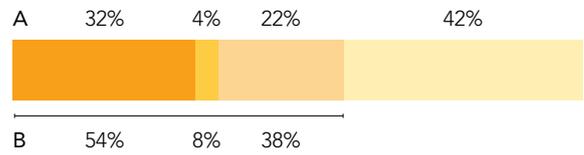
1. The sample for these types of illnesses is too small to take the community's behavior as being statistically reliable, but we have noted that it is different to all the others. We will be able to follow its development in subsequent reports.

2. Our diabetes community includes patients, caregivers and people interested in both types of diabetes: T1 and T2.

### Motivation types



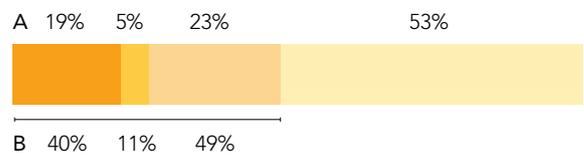
### Range of topics



### Motivation types



### Range of topics



### Motivation types



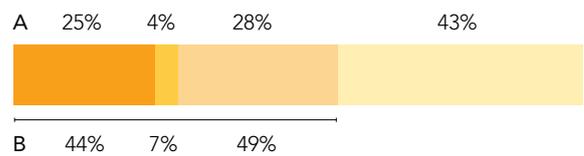
### Range of topics



### Motivation types



### Range of topics



### Motivation types



### Range of topics

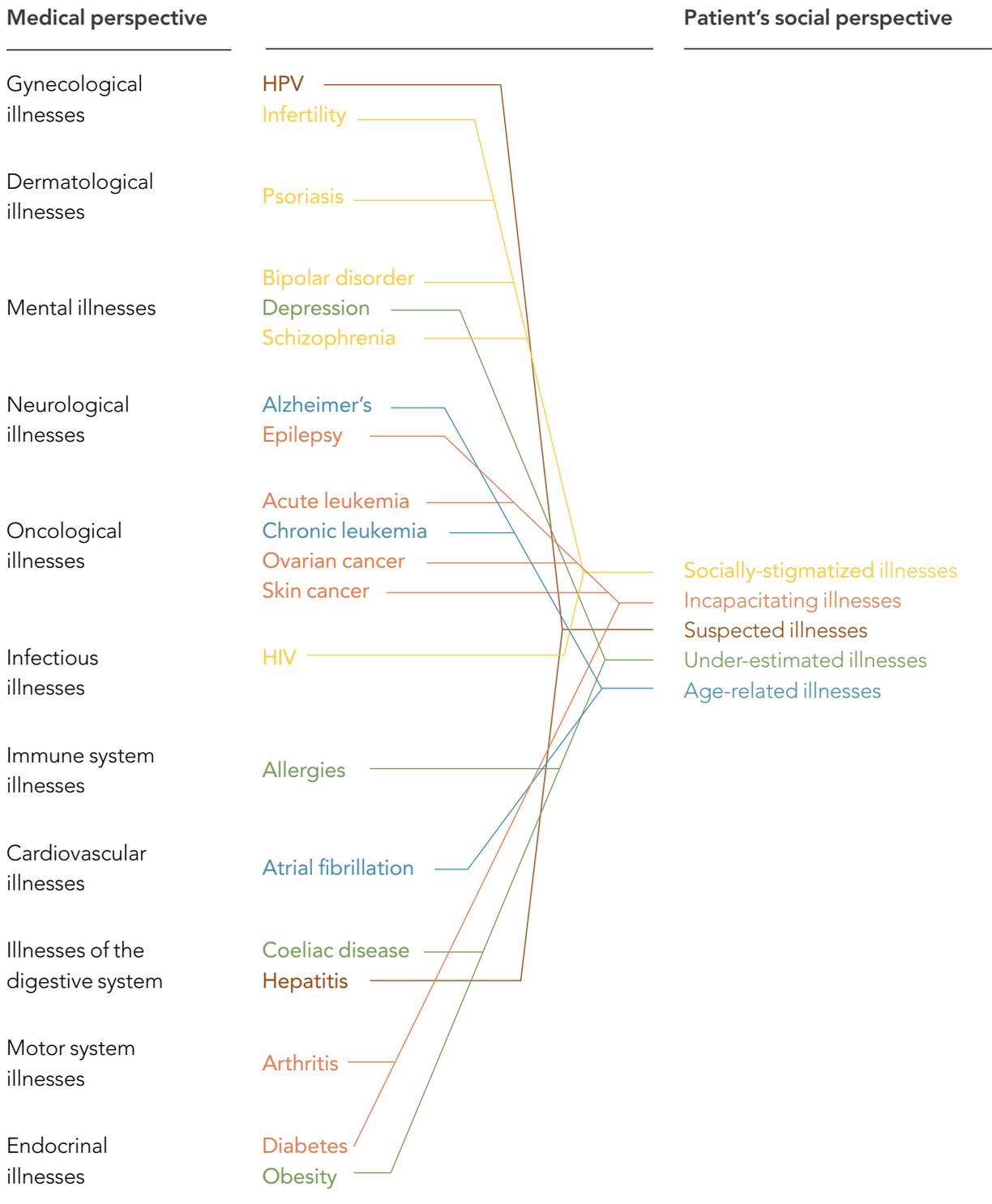


- Socializing
- Problem-solving

- **Social dimension:** Couple, Family, Online socializing, Social life
- **Everyday life:** Current topics, Financial issues, Household, Leisure, Mobility, Personal care, Work
- **Wellbeing:** Diet, Exercise, Non-scientific treatments
- **Medical treatment:** Symptoms, Diagnosis, Medication, Healthcare system
- A** All topics
- B** Excluding medical treatment topics

# Medical perspective vs. patient's social perspective

By analyzing the conversations in our communities we reveal a new way of classifying illnesses. This graph shows a dual classification of the illnesses we have studied, from the medical perspective, on the one hand, and from the patient's social perspective, on the other.



# Conclusions from the medical perspective

An approach to health and illness that blends biology, psychology and sociology from an integrated perspective is neither new nor alien to doctors. However, current medical practice is in most cases very different. The expansion of scientific knowledge, progress in diagnostic techniques and treatments, increasing burden of work and responsibilities being shouldered by professionals, together with defensive medicine, are some of the underlying reasons why many doctors focus so much of their attention on the «bio» part of the illness.

This study helps to move forward this integrated approach to health from the theory into the realm of practice; it reminds us that the individual is the center and ultimate purpose of the profession. Understanding patients; putting oneself in their place, imagining – and asking – what their day-to-day, their fears and their hopes are like; being aware that what is on the receiving end of the medical care is not an illness, but the person suffering it... All this reasoning becomes more straightforward if the content of these pages is kept in mind.

This report shows, in the mouths of the patients themselves, that an illness is much more than a set of symptoms and signs which have to be treated. It teaches us that medicine should not be reduced to the study of illnesses classified by the organs and systems they affect; there are other classifications, other perspectives, which include the patient's point of view.

Doctors are used to figures, to medical terms that are difficult for others to understand, to clinical studies. Good doctors should study throughout their lives, to extend their scientific knowledge. But they should also study and learn about the people who are the ultimate recipients of all this science: the patients. Qualitative analysis of patients' virtual communities, such as those in this study, make a valid contribution to this learning.

The practice of medicine should not throw up barriers between the biological, psychological and sociological components, because those who live with illnesses do not make this distinction. On the other hand, the healthcare that patients receive should not be restricted solely to the environment of the doctor's office or the hospital, because the illness persists outside these places. To achieve these goals, virtual spaces represent a key tool, both in bringing health closer to patients, and in bringing patients closer to the doctor.

In the ideal practice of medicine, doctors are able to put themselves in their patients' skin, and whilst in that skin they apply their scientific knowledge; doctor and patient are working in the same direction in an environment of comprehension and respect.

There is a great deal of work left to do before we reach this ideal stage of medicine. This report is a good start. Strictly speaking, it is not science that is taught in this report; but rather, medicine; of that there is no doubt. Here the patients talk. Let us listen to them.



## 2015 European e-patient Report

An annual report about the everyday life of e-patients

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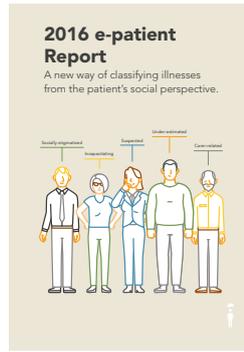
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## 2016 e-patient Report

A new way of classifying illnesses from the patient's social perspective

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