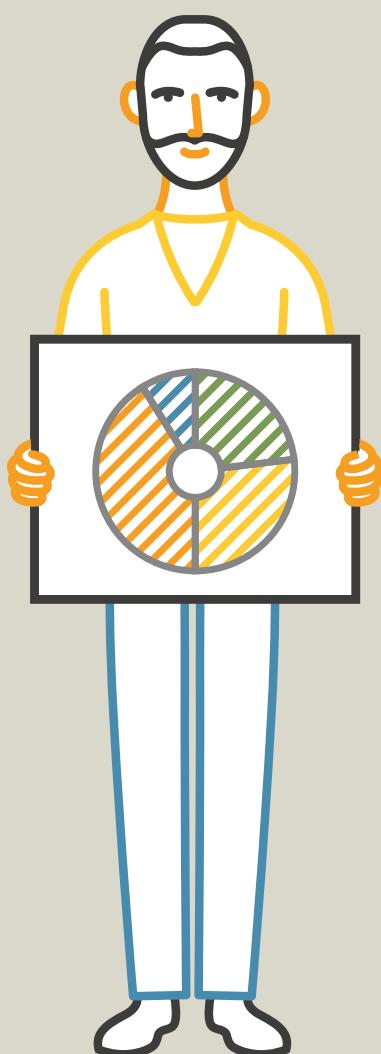


European e-patient Report 2015

An annual report about the everyday life of e-patients, produced by People Who.



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 one 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. Therefore the data in this study can't 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 you should credit us as follows: European e-patient Report 2015 by People Who, www.peoplewho.com

E-patients are already a reality, and health is changing

Before, there were patients. Now, there are e-patients.

Before, everything happened in the doctor's surgery. Now, what happens outside the surgery is also important: patients participate actively in their treatment, are well-informed, and take responsibility for their illness.

With the arrival of the internet and online services created especially for them, the e-patient is now a reality, and healthcare is changing. To better understand them, we have created the e-patient observatory.

This is the first European e-Patient Report from People Who, reporting activity on this platform in 2015 about the illnesses we include online: Allergies, Alzheimer's, arthritis, atrial fibrillation, bipolar disorder, coeliac disease, depression, diabetes, epilepsy, hepatitis, HIV, HPV, infertility, acute leukaemia, chronic leukaemia, obesity, ovarian cancer, psoriasis, schizophrenia, skin cancer and transplants. We have reported on the five European countries where we currently operate: France, Germany, Italy, Spain and United Kingdom.

What are e-patients looking for? Collecting data from our European platforms, we can state that e-patients seek both the support of others in

the same situation as themselves and reliable information in the form of content about their illness. The percentages relating to the type of support sought and areas of interest vary between countries and between illnesses.

There is still a long way to go when it comes to questions relating to the empowerment of the e-patient and their surroundings. It is clearly necessary for there to be greater social awareness of patient and carer realities to dispel current prejudices and to create social interaction forums for all types of profiles where users can receive information, airing their concerns freely (in turn reducing the digital divide). Illness clearly has two distinct aspects, medical and psychosocial, and now is the time to pay attention to both of these as part of an integrated and multidisciplinary approach.

In the end, we can say that illness accompanies us in everyday life, in that 99.99% of the time¹ is spent outside the doctor's surgery.

¹Let us imagine that we spend 10 minutes in the doctor's surgery and we 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 surgery, which would account for 0.01% of the time. The remaining time, 99.99%, is spent outside the doctor's surgery.

European e-patient Report 2015

Created by: People Who Global

Authors: Héctor Puente, Erika García, Manuel Linares,

Purificación Salgado and Eva Baonza.

Design and layout: Won, Grupo Quinteam

Contact: hello@peoplewhoglobal.com

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Almadén 19

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1 User profile

When talking about illness it is easy to think about patients. But when the illness is truly understood in depth, we realise that it is not just a matter of patients. Family members and our surroundings have a lot to say, as is proven by the users of our platform.

We believe that illness should be approached from a broader perspective and we look at three types of users: people who have or may have an illness; people who take care of someone with an illness (in most cases family members); and people interested in the illness (in some cases healthcare professionals).

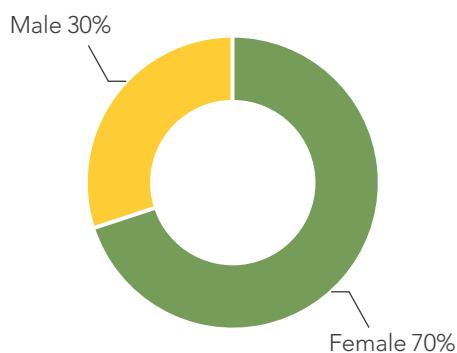
User profile: Gender and age

People Who users in Europe leave no room for doubt: women are more involved in the illness and the average age is 46. In the following charts we can see the distribution by gender and age

in each country, with Europe being the total of the 5 countries. The average age in Europe includes the specific weighting of users in each country.

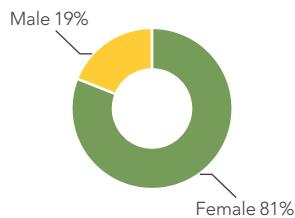
Europe

Average age: 46



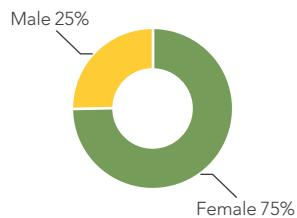
France

Average age: 49



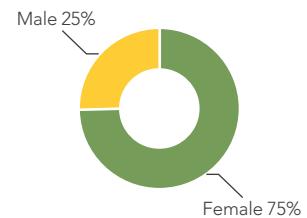
Germany

Average age: 45



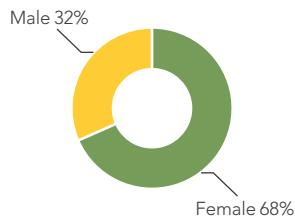
Italy

Average age: 50



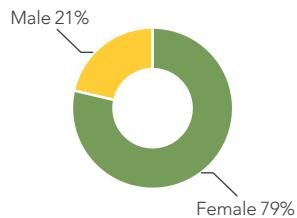
Spain

Average age: 46



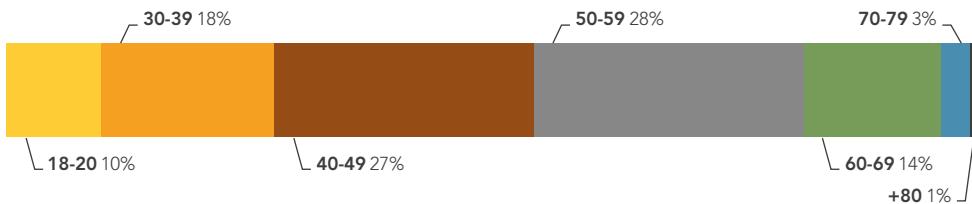
United Kingdom

Average age: 50



Europe

The average age of People Who users is 46 years old. 45% of users are concentrated in the 30-49 age group and 73% are between 30 and 59 years old. We should remember that People Who is a platform for adults only (over-18s).



Manuel Linares,
General Practitioner
Social Medical
Manager Spain at
Personas Que

"Coordinating Personas Que in Spain from a medical point of view in 2015 was a great experience, in terms of both our knowledge and relationships with our e-patients. The different illnesses we cover on the platform have enabled us to distinguish clear behavioural profiles and their specific case-by-case needs, as outlined in this document. The availability of an in-house doctor as a moderator is an added guarantee of security for users. This platform is clearly a future investment into the medical and patient community. This digital platform is also an innovative challenge for those of us who are healthcare professionals, unaccustomed to taking part in forums like this. It represents the search for new spaces and channels of contact with the patient".

Patients, carers and interested parties

At People Who our users are ranked according to their relationship with the illness for which they sign up. Since the outset we have wanted to address the human, and not the medical, dimension of the illness, so we think about how people live with the illness and we know that this goes far beyond a diagnosed person with a treatment. Thus we devised this ranking:

- Have: People who have or may have the illness (patients).
- Take care: People who take care of others with a disease (in most cases family members).
- Interested: People who are interested in an illness (in some cases healthcare professionals).

Why do we say that people "have" the illness? Because in the three years in which we have been operating the online platform, we have listened to many patients and have spoken in depth with patients' associations, who have shown us the importance of the words used when we leave doctor's surgeries and hospitals. They showed us that using statements like "is a patient" or "is schizophrenic" makes the patient experience the illness as a suffering and something that is not temporary, slightly harder to cure or that will never improve. Patients' associations are convinced, as are we, that the words we use can help people and reduce the stigma that many of them still endure. At People Who we do not say that "a person is suffering from an illness" but that "a person has an illness".



Ewan Bleiman
Social Community
Manager UK at
People Who

"Users in the UK frequently look for confirmation that their symptoms or assigned treatment is normal: they often come not with specific questions about treatments, but rather looking for reassurance about something their doctor has said. In other cases, users are looking for practical advice about managing their symptoms. The most active communities have been diabetes, arthritis and bipolar disorder. In all three of these illnesses users are looking for information about new and alternative treatments and solutions to common problems with the illness, while in bipolar disorder users are often also looking for emotional support and an opportunity to share their feelings. Compared to other countries, in the UK more users have the illness themselves rather than caring for others. Arthritis, in particular, has been a success both on the platform and on social networks, with many comments suggesting that users feel that the illness is not taken seriously by society as a whole (suggesting that the platform gives a legitimacy to their feelings as well as a space to ask questions and share feelings)".

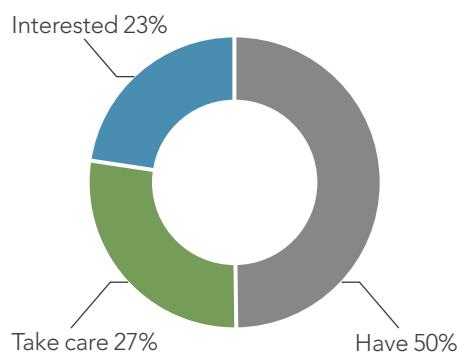
User profile: Type of user

The profiles of users registered as patients are a clear majority, representing 49.8% of all platform users. However, it should be noted that nearly half of all people in the community (50.2%) are not patients,

but are rather in the role of a carer or someone interested in the illness. This clearly proves that the illness affects not only the patient, but also involves many people in their surroundings in the day-to-day reality of the illness.

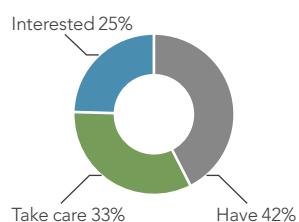
Europe

Average age: 46



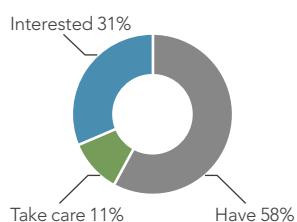
France

Average age: 49



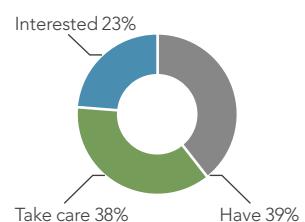
Germany

Average age: 45



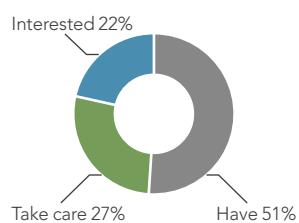
Italy

Average age: 50



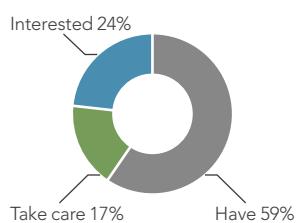
Spain

Average age: 46



United Kingdom

Average age: 50



User profile: By illness

In this comparison of illnesses, we can see how People Who users are distributed by the type of relationship they have with the illness. We normally think about the patient's age but not the carer's. For example, there are illnesses which are diagnosed in older people and yet the average age we see is younger. In such cases, we should consider that quite a few users of this illness on

People Who may be children of people with this condition (as in, for example, the case of Alzheimer's). There are also cases of illnesses such as infertility which belong to another field of healthcare. As it is an illness without a diagnosis but with a series of attempts, users identify themselves as interested parties and not as patients.

Allergies



- 40% have allergies
- 7% take care
- 53% interested

Average age: 45

Alzheimer's



- 3% have Alzheimer's
- 70% take care
- 27% interested

Average age: 49

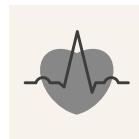
Arthritis



- 74% have arthritis
- 14% take care
- 12% interested

Average age: 50

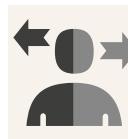
Atrial fibrillation



- 54% have atrial fibrillation
- 18% take care
- 28% interested

Average age: 52

Bipolar disorder



- 48% have bipolar disorder
- 28% take care
- 24% interested

Average age: 41

Coeliac disease



- 55% have coeliac disease
- 35% take care
- 10% interested

Average age: 39

Depression



- 61% have depression
- 15% take care
- 24% interested

Average age: 42

Diabetes



- 67% have diabetes
- 22% take care
- 11% interested

Average age: 50

Epilepsy



- 48% have epilepsy
- 35% take care
- 17% interested

Average age: 42

Hepatitis



- 31% have hepatitis
- 10% take care
- 59% interested

Average age: 37

HIV



- 47% have HIV
- 3% take care
- 50% interested

Average age: 36

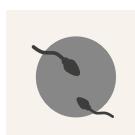
HPV



- 52% have HPV
- 9% take care
- 39% interested

Average age: 35

Infertility



- 19% have infertility
- 4% take care
- 77% interested

Average age: 33

Acute leukaemia



- 19% have acute leukaemia
- 6% take care
- 75% interested

Average age: 42

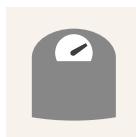
Chronic leukaemia



- 53% have chronic leukaemia
- 19% take care
- 28% interested

Average age: 43

Obesity



- 49% have obesity
- 15% take care
- 36% interested

Average age: 42

Ovarian cancer



- 35% have ovarian cancer
- 15% take care
- 50% interested

Average age: 40

Psoriasis



- 80% have psoriasis
- 11% take care
- 9% interested

Average age: 42

Schizophrenia



- 20% have schizophrenia
- 42% take care
- 38% interested

Average age: 40

Skin cancer



- 20% have skin cancer
- 41% take care
- 39% interested

Average age: 40

Transplants



- 52% have transplants
- 30% take care
- 18% interested

Average age: 44

Conclusions

Analysing the sociodemographic profile of registered users has demonstrated the existence of major differences among users in gender, age, country and illness. Women account for 70% of the community (3 out of every 10 members are men). The average age of the European e-patient on People Who is 46 years old (Germany and Spain have a slightly younger profile than France, Italy and the UK).

A particularly high proportion of registered users are carers in countries

such as Italy (38%), France (33%) and Spain (27%), well above the percentage of carers in the UK (17%) and Germany (11%), where communities are far more geared towards the patient. This highlights cultural differences in living with the disease.

The role of the carer will be considered in more detail in Chapter 3.

2 Social types of illness

Illness has up to now been treated from a medical point of view, but what about the social point of view?

In this chapter, we will present the methodology of a study about illness on a social level by proposing a certain type of illness: Socially-stigmatised, Incapacitating, Suspected, Under-estimated and Age-related illnesses.

This new way of classifying illness enables us to look at them, not from a medical point of view, but from what daily life is like with each one. At People Who we call this approach a social point of view.

Five types of illnesses from a social point of view

Socially-stigmatised, Incapacitating, Suspected, Under-estimated and Age-related illnesses.

Illness, as a part of people's lives, has a social dimension. Both patients and people in their immediate environment undergo different experiences and emotions depending on the characteristics of each illness and how it is perceived by the rest of society. Even though illness is associated with healthcare centres and hospitals, we spend most of our time outside these places (at home, with friends, at work, with family...).

But does the way of dealing with illness vary according to a person's situation? Absolutely. Living with illness depends on each context of social interaction. Therefore, we must bear in mind that the way we behave in an online community is very different from the way we interact in the physical world, as questions such as anonymity, prejudice, embarrassment or insecurity determine the way we interact in the digital environment.

Fortunately, thanks to the anonymity that some digital environments like People Who guarantees, people can express themselves more freely on virtual platforms. These are places where users communicate without inhibitions and overcome the burdens of prejudice, incomprehension and social stigma which they usually have to face.

In this chapter, we will segment the illnesses covered on People Who from a social point of view, that is, from the perspective of living and interacting with both the illness itself and with other people. To do this, we have grouped the illnesses under analysis into five categories according to the socio-situational features present on our platform. From illnesses where the carer plays a fundamental role to others involving issues such as fear or stereotypes, these are social types of illnesses.



Héctor Puente, PhD
in Sociology
Research and Analytics
Manager at People
Who Global

"The social aspect of illness is frequently overlooked and often considered to be less important. By studying the daily reality of the online community in such detail, we have noticed the lack of current analytical methodologies and the need to advocate a more people-sensitive approach. The social type of an illness is a thought-provoking contribution which will open up new lines of research".

Socially-stigmatised

New online social relations

Illnesses: Bipolar disorder, HIV, infertility, psoriasis and schizophrenia.

The illnesses grouped under the socially-stigmatised 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).

People in this position experience incomprehension, endure unpleasant situations and often feel the need to hide the existence of the illness (for fear of rejection or embarrassment). The fact of it being discovered, according to Erving Goffman (1963), may not only affect the patient's present 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 identity on an everyday basis, i.e. modes of social interaction based on denial and concealment are adopted.

The anonymity provided by some online communities like People Who allows these people to escape the problems of the physical world, lose their inhibitions and find new sources of support, as they feel understood and, therefore, liberated. Taboos are more

easily overcome and it is possible to address issues which in other everyday situations would not be discussed.

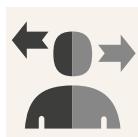
With regard to the interests of the community, whose comments have been divided into subject categories, the users in this group show a particularly keen interest in issues related to social life (39%). Aspects such as sociability, interaction with other users (exchange of personal experiences), support or mutual understanding account for 1 in 4 comments made (well above that found in other segments). It seems obvious that it is a question of very stigmatised illnesses where users mainly seek to be heard, to act freely and to feel supported by people in the same situation. As a result of the incomprehension and prejudice suffered, psychological issues (11%) also play an important role in this community. However, diagnosis-related information (9%) plays a secondary role.

For them, the idea of mentoring and having a group reaching out to them is the best reason to go back. Social and emotional interactions are channelled more naturally, they are more abundant and self-repression is minimised. In fact, schizophrenia and bipolar disorder are the most active of all the existing communities.

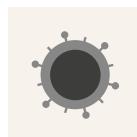
Thanks to online communities, these people have changed their perception of their situation and illness, reconverting negative experiences and feelings into positive ones and transforming their lives for the better.

Socially-stigmatised illnesses

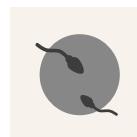
Bipolar disorder



HIV



Infertility



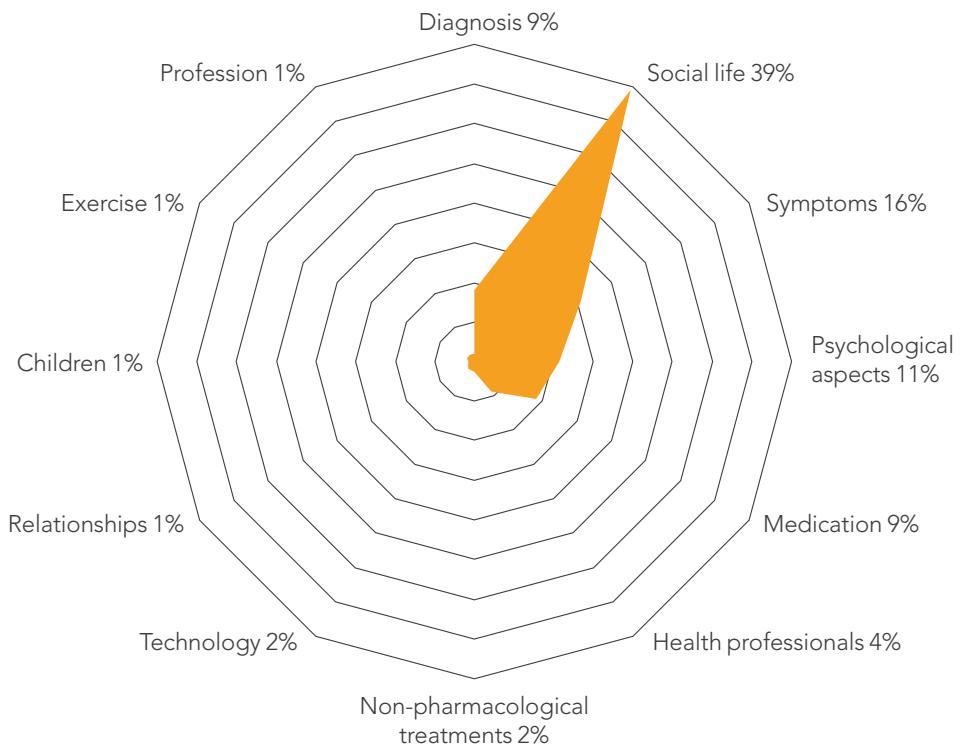
Psoriasis



Schizophrenia



Themes of conversations on Socially-stigmatised illnesses



Incapacitating

Problem-solving conversations

Illnesses: Arthritis, diabetes, epilepsy, acute leukaemia, ovarian cancer, skin cancer and transplants.

Although the symptoms and care required vary depending on the case, illnesses included in this group are characterised by severely limiting the daily performance of all types of tasks, and even 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 hospitalisation or specific outbreaks) or prolonged and/or chronic (with hospitalisation, chemotherapy, waiting lists, etc.).

Fortunately, all these alterations may vary in severity and can be partially alleviated with medication.

On the whole, users who live with these diseases are characterised by forming fairly goal-oriented or practical communities, using the platform as a strategy to resolve doubts or questions about their illness. They mainly request information 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.

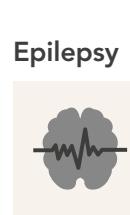
In some of these illnesses, as is the case of arthritis or acute leukaemia, the dimension of the carer takes on a certain importance. In others, such as epilepsy, the level of disability can vary depending on how the disease affects each person in particular (number of seizures and severity thereof).

However, it is true that members are less likely to interact with each other socially or emotionally, probably because this function is already covered by their own environment in the physical world.

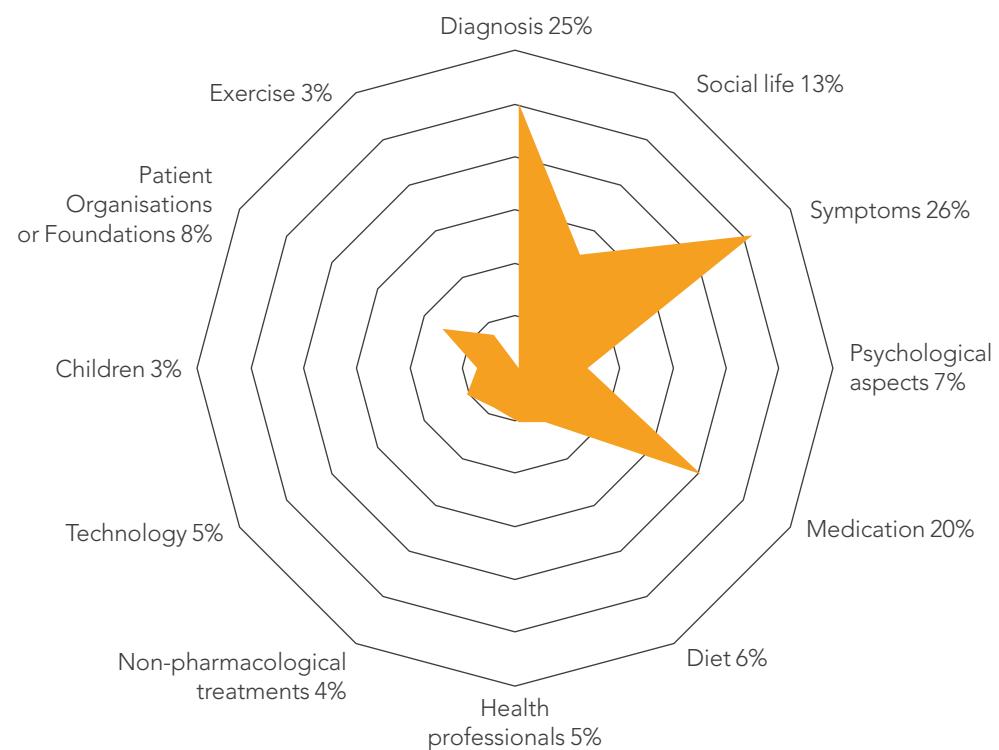
With regard to the interests of the community classified into subject categories, we note that there is a significant presence in the group of conversations about drugs and more medically-focussed issues: diagnosis (25%), symptoms (26%) or medication (20%). Furthermore, concern is also shown around issues relating to healthcare professionals (5%) and, more particularly, patients' organisations (8%), which are more active in this segment than in any other of the five groups of illnesses under analysis.

It is also interesting to note that in more family-related conversations, the recurring theme is that of children, probably due to the influence of diabetes (Type 1) and acute leukaemia. However, we were expecting a much higher figure in the social life category.

Incapacitating illnesses



Themes of conversations on incapacitating illnesses



Suspected (or prevention)

Do I have the illness?

Illnesses: Hepatitis and HPV (Human Papilloma Virus).

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 raise serious doubts.

In an attempt to confirm their suspicions, they usually consult many resources available on the platform and tend to make very specific demands for information related to diagnosis (30%) or symptoms (18%). This behaviour is probably a preliminary stage before going to the doctor.

What is more, these users are not particularly interested in forming closer ties with other members of the community, but instead they use the platform as a tool for resolving doubts

and questions. There seems to be a clear interest in having in-depth knowledge of these illnesses (and their associated characteristics) in order to confirm or dispel their suspicions.

In this group, there is a particular prevalence of users with profiles set as "interested" who, without knowing for sure if they have the illness, need information that answers their questions. Issues such as relationships (6%), due to the importance of sexual practices in this segment, or non-pharmacological treatments (6%) are particularly relevant in this group of illnesses.

There is also a large number of people using the platform as a prevention tool in order to find out how to avoid exposure to the illness. In a way, many members request information as a means of anticipating or preventing something that could happen.

Suspected illnesses

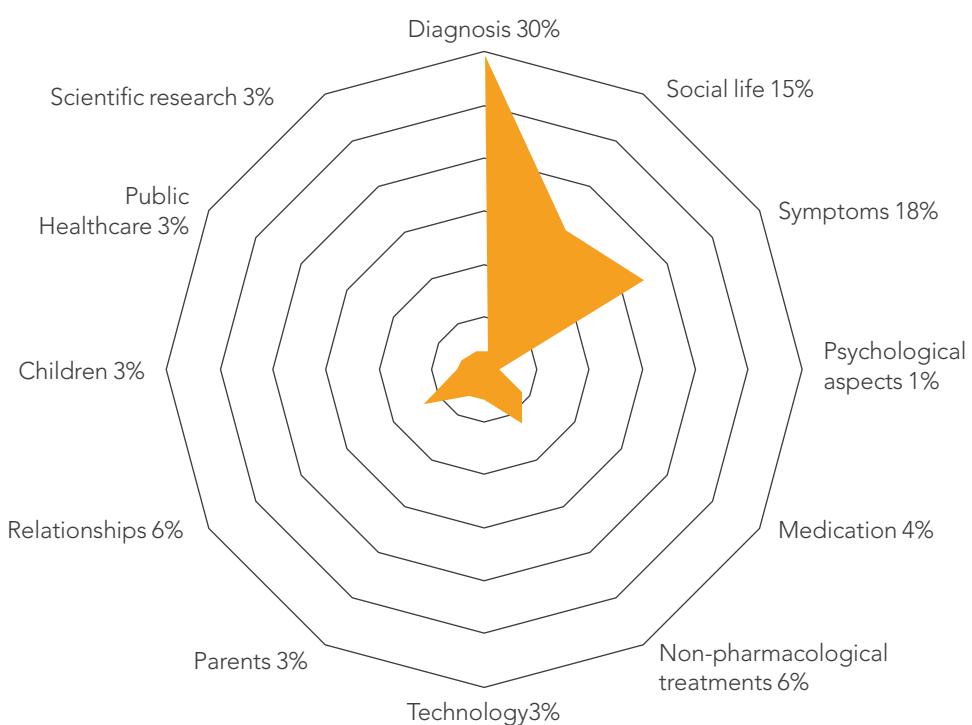
Hepatitis



HPV



Themes of conversations on Suspected illnesses



Under-estimated

Everyday life may seem normal.

Illnesses: Allergies, coeliac disease, depression and obesity.

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

They are medical conditions that have become everyday illnesses commonly found in our surroundings and which in many cases are interpreted more as "setbacks" rather than "major illnesses" due to not being 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 generalisations are often made, devaluing the condition and not giving it the importance due.

However, this clashes with the treatment of these conditions in the media, which is increasingly raising awareness about obesity in Europe or the importance of depression (still considered by many as mere sadness or the patient being oversensitive). Meanwhile, better vaccines and anti-allergy drugs are increasingly available and it is easier to find gluten-free products.

Patients' associations carry some weight in the community and conduct

prevention and visibility campaigns, attempting to highlight the true importance of the illness and make the general public more aware.

Profiles of users suffering from or interested in these illnesses are quite common in our communities. They are people who come to learn and take part in a forum where they can discuss the difficulties they face.

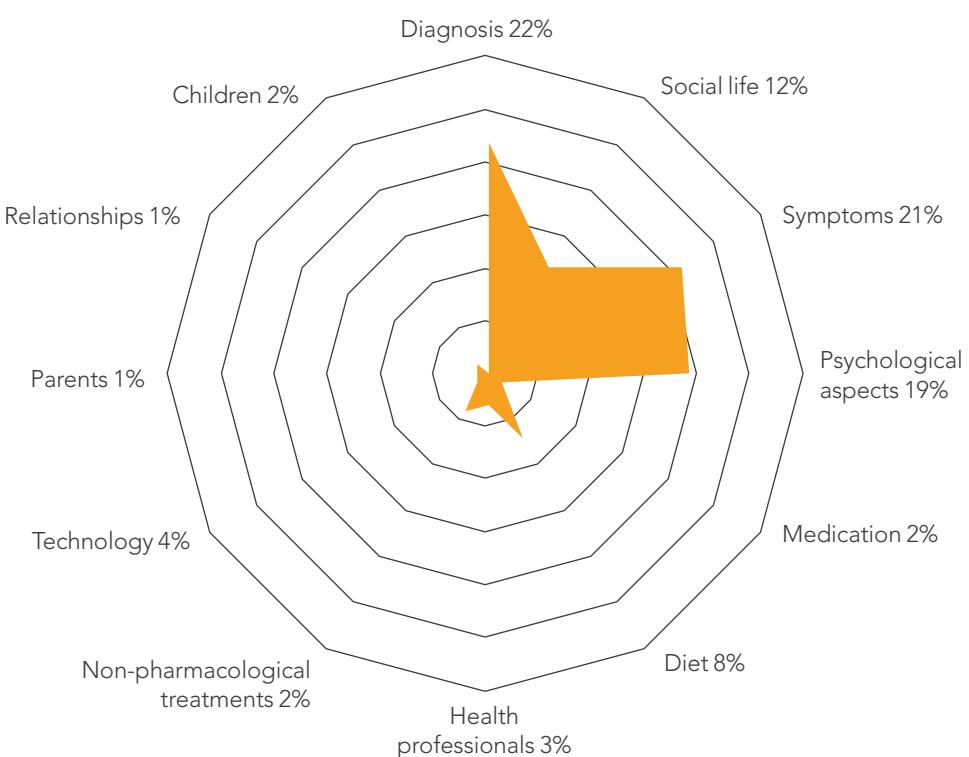
In this group, the interests of the community concern diagnosis (22%) and symptoms (21%), whilst questions such as medication are far less important, with just 2%. The categories of psychological aspects (19%) or diet (8%) take on a very important role, which is mainly due to the effect of illnesses such as depression and obesity, where the patient's emotional dimension is more important than other aspects. Meanwhile, the main concern of coeliac disease, given its characteristics, focusses on questions such as diet.

Although social life accounts for 12% of the comments, this proves that it is a community rather more focussed on practical issues. When personal interactions take place, a deeper and more emotional dimension takes hold, leaving aside superficial issues and questions.

Underestimated illnesses



Themes of conversations on Underestimated illnesses



Age-related illnesses

Where the carer participates more than the patient

Illnesses: Alzheimer's, atrial fibrillation and chronic leukaemia.

The illnesses in this group are those where the carer figure is particularly relevant 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 five countries covered by this study, a higher relative number of carers was detected in this category than in the other two registration profiles (patient and interested party).

The need for assistance and extended care over time is also explained as they are illnesses 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 carer.

The illness in which the carer is more prevalent is Alzheimer's, where the number of registered people actually with the disease is very low (only 3%) and where such registrations relate to people in the early stages of the disease (when they are still very self-sufficient).

Carers are a majority in these communities. Reasons why users access the community range from the search for advice and recommendations for improving care to the need for emotional support for themselves

(given the emergence of the burned-out carer and the major toil taken). As for atrial fibrillation and chronic leukaemia, although these are cases where a higher level of personal autonomy is retained, we are also talking about age-related illnesses with a corresponding need for care.

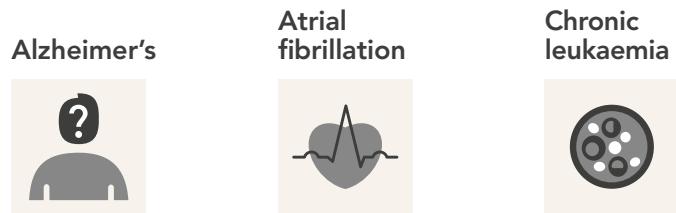
Among the illnesses segmented as "age-related", there is also a prevalence of messages connected to symptoms (21%) and diagnosis (17%).

Compared to other groups, with carer-related illnesses there are some interesting figures regarding psychological aspects (12%), parents who receive care (5%), and non-pharmacological treatments (6%), due to the interest in addressing the illness from all kinds of alternative non-medication strategies.

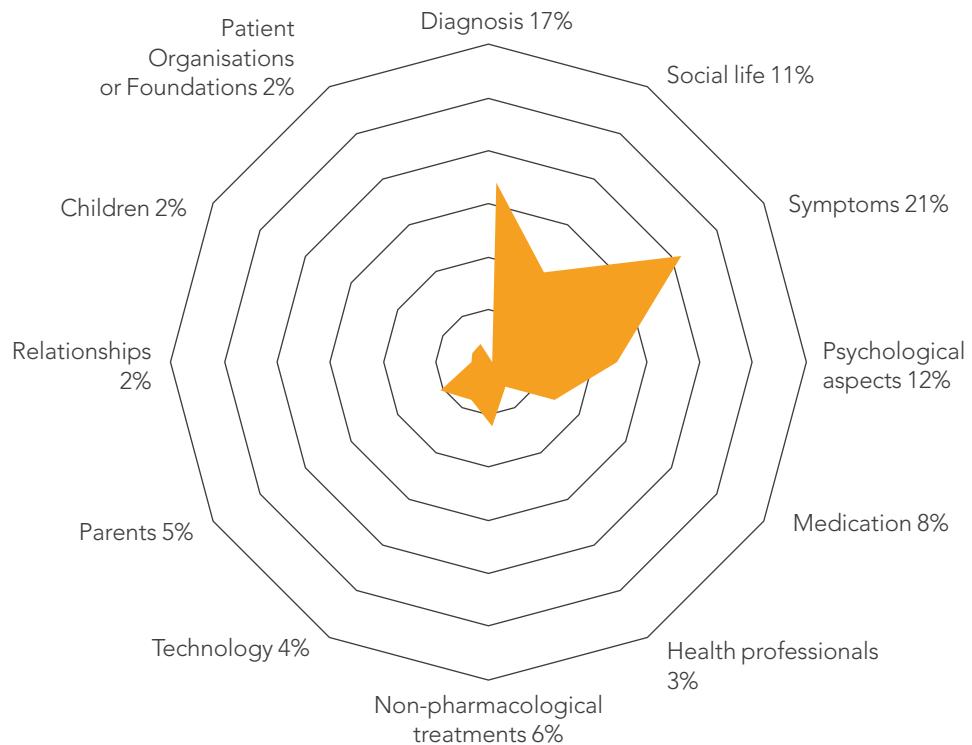
Particularly interesting was the fact that social life (11%) did not feature more strongly, as carers had been expected to share their experiences and observations more, in an attempt to foster a cohesive and mutually-enriching community. However, this failed to happen, resulting in a more goal-oriented profile than had been expected. This is also shown in another somewhat unexpected category which nevertheless received a moderate score: technology (4%). We believe that this also refers to the search for new strategies to tackle the illness of the carers' parents.

Regarding the "burned-out carer" syndrome, we will expand on this in Chapter 4.

Age-related illnesses



Themes of conversations on Age-related illnesses



Conclusions

Having read this far, the reader will have realised that illness from a social point of view, focussing on everyday life with the condition, is far removed from a traditional medical perspective.

Through the types shown, we conducted the proposed analysis methodology to better understand the characteristics of the illness in terms of users' reasons and experiences. While the groups of "suspected" or "incapacitating" illnesses are far more formalised and practical, those enduring prejudice or a degree of social incomprehension ("Under-estimated" and "socially-stigmatised") are much more geared towards social aspects or psychological-emotional support. It seems clear that each of the groups shown requires a particular type of information, management and/or intervention (especially in those where carers take on a leading role).

The groups involved in each segment share many characteristics and experiences that create a strong bond of cohesion among them and, although they are different types of illnesses, the psycho-sociological processes they undergo are similar and relatively comparable (both for the actual patient and for their environment).

User identity is socially constructed through the experiences we have in our daily lives. Aspects such as culture or collective social imagination that are present in online communities end up being internalised and transform us as people, influencing our practices and perceptions (improving our well-being).

The qualitative analysis performed shows that when intimate questions such as personal experiences with an illness become visible and reach the public sphere, society becomes more aware of them and life with the illness is made easier (enhancement of understanding, elimination of prejudices, etc.). Free expression in an e-health community becomes a powerful tool for communication and social awareness.

In any case, it is clearly still necessary to raise social awareness about the reality of the patient and the carer, to dispel current prejudices and to provide tools and information that empower users (bearing in mind that there is still a certain generational digital divide in the access to such technologies). Although there are no prior social types, illness clearly has two distinct aspects: medical and psychosocial.

3 The figure of the carer in online communities

The carer is a key figure in the world of illness.

Therefore, we dedicate this chapter to them. In it, we conduct an overview of the current situation of the non-professional carer in Europe, paying particular attention to the medical and socio-cultural differences between countries.

In addition, we are particularly aware of gender inequality as we have observed that it is still mainly women who take on the work of caring for the sick.

Have you heard of burnout syndrome? We address this term which is increasingly common among carers and ask questions about the role of e-health communities, the challenge to find future solutions and their contribution to creating a more equal and empowered society in terms of health.

An outline of the European carer

Illness is not limited to those who suffer it directly, but also affects the circle of people around it. In this chapter we want to give some additional information on the figure of the carer and explain what characteristics the people who fit this profile share.

Throughout 2015, carers of all illnesses in the five countries have come to represent 28% of the total registered in our platform. This figure indicates, first of all, that the figure of the carer is important and one of the key players on the issue and, secondly, that these are also e-patients, even e-carers, because they are interested in obtaining the best possible information to facilitate their own lives and that of the person in their care.

It is important to note that the carer may be professional or non-professional. The latter refers to those cases in which the family or a member of the family takes it on themselves to look after the patient without receiving a salary.

Individual European countries differ in the ways they deal with public health

greater responsibility, taking care of the patient directly or by providing certain benefits or economic compensations to the family. In other cases, such as in Spain and Italy, it is still mainly the family who cares for the illness, even though there are certain laws and assistance in this regard. In these two countries in particular there is some discomfort with public institutions, leading us to understand that if the family itself is not doing the caring, it is possible that the patient is not receiving sufficient care.

The non-professional carer

The figure of the non-professional carer, to whom we refer in this chapter, has always been present in relation to illness and the family. Traditionally these activities have fallen to women, but as they have entered the job market, the situation has begun to change gradually. The different expectations about who should care for the sick depends largely on the context or the cultural tradition of each particular country (and varies enormously, even between regions). On the other hand, access to specialists, resources and health care differs greatly between rural and urban areas.



"Lately in Italy there has been a lot of talk about the rights of carers, the support they should have from the Italian state and of the need to fight for fundamental rights (e.g., the right to have time off or have a social life). This is why the absence of a law that protects Italian carers has been reported to the European Parliament and to the UN".

care. In the south, this task falls to the family and the close environment, but in the north it is usually the State which adopts a regulations-based role of

Given the widespread availability of services in large cities and metropolitan areas, the most remote and sparsely populated areas are sometimes less

well served as far as health care is concerned (including provisions related to professional patient care). In any case, it is increasingly common for the family to have a professional carer to provide extra help.

In all five countries it is women who mainly assume the charge of caring for the sick. We can see that more than 7 out of 10 carer-users are women, confirming the gender inequality in care. This is the situation in 2015; but what can we do from the online community to suggest future solutions that contribute to creating a more equal and empowered society in healthcare terms?

While women mainly take on the role of carer, they are also the most involved in the community and are more collaborative and communicative. Apart from this, they have a strong presence in social networks, although the trend changes in the section on measures taken to control illness, as we shall see later in Chapter 8.

It should be noted as a specific characteristic of carers that, although they share an average age of around 45 years, the family roles they play are different depending on the illness in question and the age of the patient.

Therefore, when the diagnosis comes at an early age (e.g., during adolescence) it is mainly the mothers who take on the care, administering medication and taking charge of periodic reviews.

However, in other diseases where the patient is older, such as atrial fibrillation or Alzheimer's, it is usually the wives or sisters who take charge of these areas. In general, daughters take on the dominant role when the mother is already too old or has died.

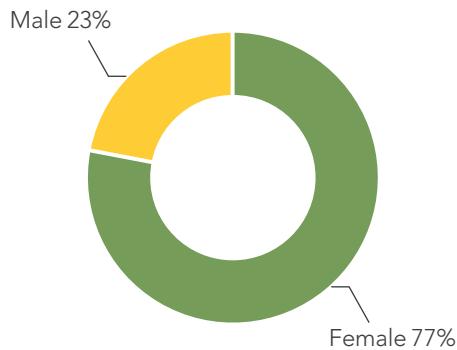
Among the illnesses that have a higher percentage of carers, Alzheimer's is in first place (70% carers) and schizophrenia second, although at a considerable distance (42%), followed by epilepsy (35%) and coeliac disease (35%).

Finally, in the quantitative analysis, according to the phi coefficient there is a slight association (previously found) between sex and type of user where there is a higher probability between being a woman and a carer than being a man and a carer ($\Phi = 0.235, p < 0.01$).

Profile of the European carer

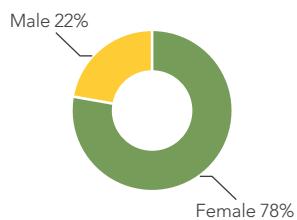
Europe

Average age: 45



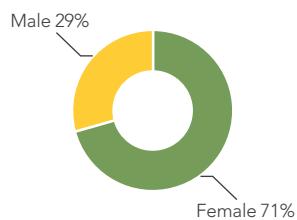
France

Average age: 41



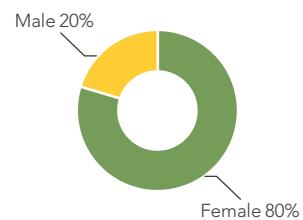
Germany

Average age: 46



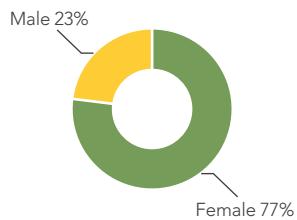
Italy

Average age: 46



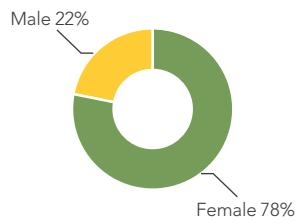
Spain

Average age: 45



United Kingdom

Average age: 44



Caregiver burnout syndrome

What is it?

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

Although in countries like Spain it affects 4 out of 10 carers¹, this figure rises to 85%² in the case of the non-professional carer (family and close environment). The high prevalence of this syndrome is also evident throughout the rest of Europe. Factors such as stress, the time dedicated and the responsibility involved in the task of caring for someone with an illness often mean that people caring for someone have this syndrome.

What are its symptoms?

Often, the time and dedication required in caring exceed the limits of what the carer can endure. This is when the symptoms of this disorder become evident thereby impacting emotional ties and family relationships.

- The person feels completely exhausted and that they do not have the strength to cope with the situations arising from

their work as carer. They now feel unable to take on more responsibilities and are not capable of continuing to take care of the sick person.

- Self-esteem suffers, the carer is more irritable and susceptible than usual and even shows some symptoms of depression. It is also common to suffer problems of anxiety, fatigue and insomnia.
- Social relationships start to become jeopardised. The person stops seeing their friends and family and increasingly becomes more absorbed in their caring role.
- A negative subjective perception is created around the tasks being performed. The carer tends to feel incapable, to think that they are doing everything wrong, that they do not measure up to the task.
- A depersonalisation phenomenon occurs, which in turn generates an emotional disconnection. Often, the carer starts to perform tasks mechanically, without emotional involvement.

Among the carers most engaged in online communities, a large majority (92%) have stated that they have experienced, at some point, one of the symptoms described.



Laura Mata, Psychiatrist
Social Medical
Manager Spain at
Personas Que

“The contribution of the People Who platform both to patients and to relatives of patients diagnosed with a severe mental illness such as schizophrenia is undoubtedly valuable. It entails an innovative and natural approach to these illnesses by providing close support and an improvement of the family-patient-doctor triangle, which in normal clinical practice is at times very tricky to achieve. The success of the platform is based on the possibility of sharing experiences and receiving support, as well as boosting knowledge about the illness and its characteristics, all under the daily supervision of a psychiatrist. This is all achieved thanks to the digital format, which enables patients and relatives to interact whilst avoiding the embarrassment or taboos which these illnesses tend to create. We believe that it is an undeniable advance in such a complicated and unexplored field as mental health”.

¹ Navarro-González D., Ayechu-Díaz A., Huarte-Labiano I. (2015). Prevalence of burnout syndrome and its associated factors in Primary Care staff, SEMERGEN.

² La Caixa Foundation (2010). The care of people. A challenge for the XXI century. Social Studies Collection.

Conclusions

From consolidated communities such as diabetes and Alzheimer's, we have initiated a solid line of research with the premise that patient social networks may be of great help for the patient and carer in living with the disease on a daily basis, as we have tried to demonstrate with the burnout syndrome in the case of Alzheimer's disease (paper presented at the 20th Wonca Europe Conference 2015 Istanbul¹) or with therapeutic compliance in diabetes (paper presented at the 37th National Congress SEMERGEN Valencia²).

Caring for a person can become a closed circuit of increasing absorption. However, the exchange of experiences and emotional support among carers

and community members can help prevent the onset of the disorder and even become a tool for early detection of possible new cases.

This chapter has shown one of the social aspects of illness, closely related to the care and to the daily impact on the patient's environment. While huge gender inequalities in the provision of non-professional care services have been revealed, some changes have occurred, where online communities are a key tool to address the problem and its solutions.

¹Linares, M., Puente, H., García, E., Baonza, E., García, T. (2015). Digital Health Platforms and Burnout Syndrome. A Case Study of People Who Global, WONCA 2015 Europe Conference Istanbul, 22-25 October, 2015.

²Linares, M., Puente, H., García, E. (2015). Las redes sociales y las tecnologías digitales como nuevas herramientas en el manejo de la Diabetes, SEMERGEN National Conference, 14-17 October, Valencia (Spain)

4 Motivations and attitudes

What do e-patients in Europe look for and what are their attitudes? This question starts off this chapter, in which we will categorise and study the comments within our community according to whether they offer or ask for help.

We will then analyse the focus of these comments: whether they are “more humane” questions; whether they are social and emotional statements or experiences about the illness; or whether they are about something more practical, questions about medication, what to do to get help, for example, or advice from doctors.

This is all to answer the question of why patients come to our platform, what they look for and whether we meet their expectations.

What do e-patients look for in a social network?

The reason that prompted us to consider this chapter was to report the different motivations for user engagement. On one hand, looking for information is important for everyone, but so is expressing feelings about everyday life with the illness. Besides this, as it is a community that sets out to foster links, the ongoing relationship between participants requesting and offering support for all illnesses is very important. In the following sections we shall present several maps to clarify the issue and to show the differences between the 5 European countries in a clear and visual way.

Two sides of the same coin: the emotional and the practical.

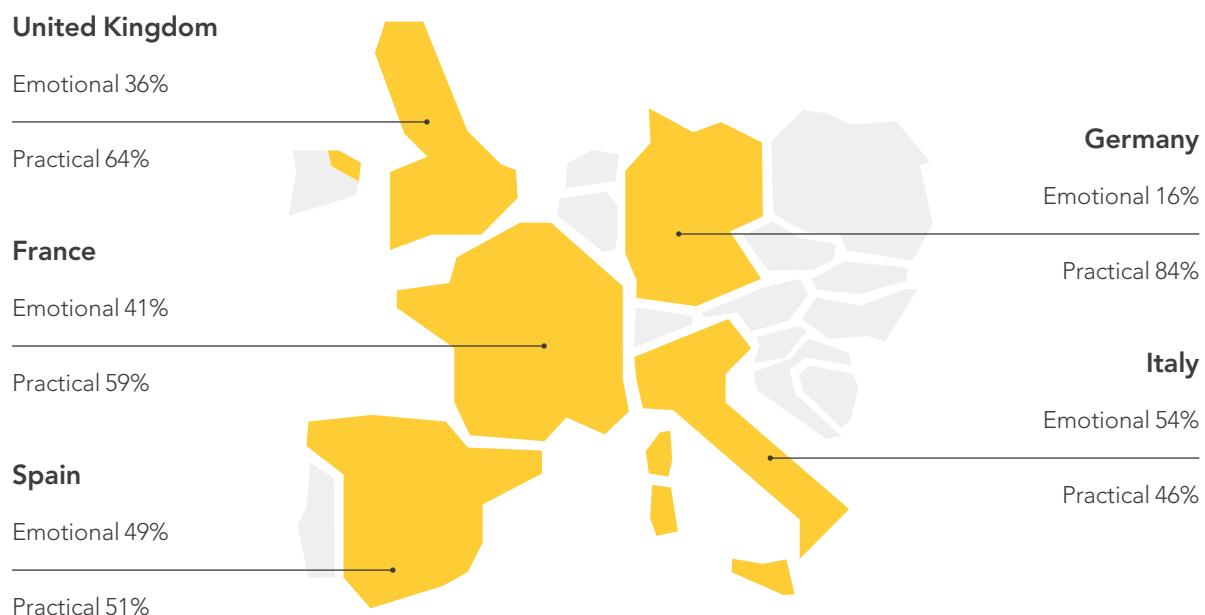
There are clear differences between northern and southern Europe in terms of the motivations of communities when

participating. We have divided the types of interactions at this level into emotional and practical, with the split being when questions or discussions are goal-oriented (such as medication) and when more intimate issues are expressed.

While in southern countries such as Spain and Italy an important part of the questions and discussions have to do with issues from the emotional sphere, leisure and sociability (49% and 54% respectively), the figure is much lower in other countries. By contrast, in northern countries the main motivations for interaction are related to clarifying doubts and to more technical or goal-oriented questions.

France, Germany and the UK use the community in a more goal-oriented purpose of answering questions, without

Map of emotional/practical interactions in Europe



Data obtained from the analysis of comments in communities of all illnesses in 2015.

overly interacting with other users, while Italy and Spain are much more inclined to search for support with the illness.

Two mindsets: to help and to get help in the community.

As referred to in the introduction, we should point out the existence of two distinct roles in users when it comes to help. Some request support or information and others respond to these requests. The data below provide an indicator of the extent to which community members actively show their support when someone poses a problem and how perceptions can be changed about it as a community.

In southern countries up to 37% of the comments offer support and help to other users. Participants engage in conversations, fostering a collective

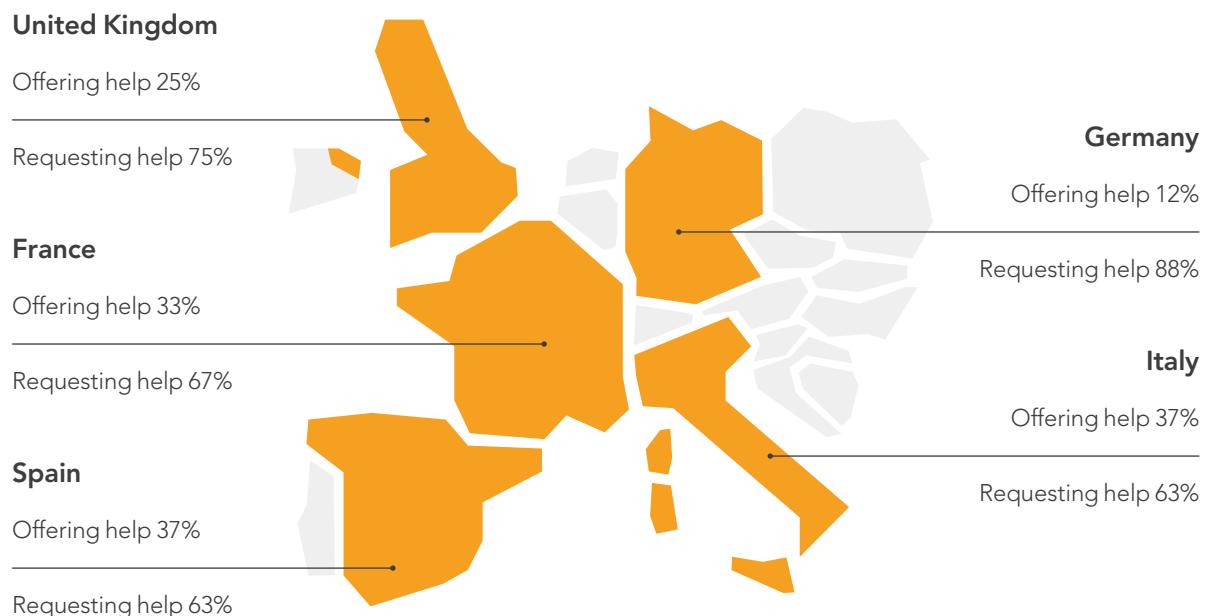
spirit of community. The high numbers of requests for help show that many users in different countries often express themselves literally with formulas such as "I need help" or "How I can do X?", which gives meaning to a subject-based social network like this one.

The case of Germany is particularly interesting, with only 12% of participants answering questions or offering support to others, confirming the inclination of this community more towards looking for information than towards creating social ties or interaction.

But what really attracts patients?

The expectations of people entering the platform seem to be met, as it covers the need to find a place to chat with other people in their situation, in a secure environment and supervised by doctors.

European map on requesting and offering help



Data obtained from the analysis of comments in communities of all illnesses in 2015.

It is not unusual to read comments expressing “happiness at having found such a place” and at having reached out to others experiencing a similar situation (awakening a collective sense of solidarity and mutual understanding), since, depending on the illness, finding people or associations in the same situation can be difficult.

On the one hand, those who have the illness look to resolve specific questions on various topics in all countries. More specifically, newly-diagnosed patients and carers value the opportunity to openly vent and express their frustrations (we shall study the topics discussed by the community in Chapter 6).

The platform includes a practising doctor in each country’s community to moderate the community and answer

For the doctors on the platform, the added value of the community is also interesting, as they can gain first-hand opinions from patients, which helps them to get an idea of how medical practice is developing in places other than the region or community where they practice their profession, off the platform. As well as providing valuable information, given their status as experts, they can encourage other community interactions, although they never act as a substitute for the doctor treating each patient in their country. For this reason, in many cases they find themselves referring a user back to their doctor, but this time armed with some more information about the question that was troubling them.

In particular, they have the advisory role that we talked about earlier, contributing



Chloé Paternotti
Social Community
Manager France at Les
Gens Qui

“When it comes to the user profile, contrary to what we might think at first, the user who plays an intensive and regular part on the platform enters with the aim of offering help, willing to build a community of solidarity. In 2015, the most active community in Les Gens Qui has been the Alzheimer’s one. It managed to structure itself thanks to the active participation of some leading participants, who are key factors in developing a community.”

questions about the illness. Even though he or she never holds surgery, the role of the 2.0 doctor is based on advising and assisting the patient in a slightly more intense way than in the surgery, where there really is not enough time to respond to each person.

their scientific knowledge but also respecting the medical and legal perspective.

Illnesses with the highest activity in the community.

The illnesses that generate higher levels of participation vary by country and the characteristics of their communities. However, all countries share the idea that the platform provides privacy and gives a space to openly express feelings and concerns, where it is possible to observe deeper interactions than those seen in comments made on social networks like Facebook.

In this sense, Alzheimer's is the most popular in France, where perhaps the emotional dimension of carers and early-stage patients is the greatest stimulus for users to post comments.

In Spain, however, mental illnesses such as schizophrenia and bipolar disorder have the most active communities, and are largely successful because of the very nature of these illnesses. These require the patient to spend a lot of time at home, mostly due to sick leave or disability, and those living with them need to chat, let off steam and share their everyday lives. Other illnesses, such as arthritis, epilepsy, psoriasis and coeliac disease, also generate quite a lot of traffic due to the long process of diagnosis, the need to find appropriate treatment and the monitoring they require.

There is a vital need to show personal progress to the rest of the community and

to collectively share the success stories of other users.

In Italy, the most active communities are Alzheimer's and bipolar disorder. The case of Alzheimer's is especially significant thanks to the support and drive by other social networks that have drawn in visitors who have become permanent and active members of the community, which itself has grown steadily.

Meanwhile, in the UK, the most active illnesses are diabetes, arthritis and bipolar disorder. Here, users look for information about new treatments and solutions to everyday problems about living with the disease. Arthritis in particular has been a very popular subject on social networks and on the community at People Who, with a large number of comments about the perception of arthritis in society and the need for it to be taken more seriously.

Finally, in Germany the most active illnesses are diabetes and depression. The main reason may be that depression is the leading cause of medical consultation in this country. In addition, users like to talk to others about how they feel, looking for support and some relief. Another interesting feature of this platform is that the average age in the latter case is lower. Thus, with it being a younger community, there is greater disinhibition when chatting to other users online about intimate or private subjects.



Erika Garcia, Sociologist
Analyst at People Who
Global

"From our point of view, online methods should be acknowledged as providing solid and valid approaches to issues which, like health from a social point of view, may be sensitive for people who in one way or another are living with an illness. Collective learning among all members of patient communities is one of the most enriching aspects to spring from projects like this, and we hope to have conveyed a little of what we now know thanks to them".

Conclusions

In this chapter we have observed how the existence of anonymity in online communities enables users to address deeper issues, something that could improve life with the illness when adopting specific strategies on a daily basis.

These differences are probably a cultural reflection of the people living in these places, and account for the different perceptions of the illness and the positions taken by different subjects. In some countries, although everyone wants to share their experiences, there are still cultural barriers that make users refrain from joining a conversation as

this may be perceived as invasive. On occasion, and although most people find it comfortable, some do not seem to want to address an issue if not invited to do so and they let the doctors intervene to settle different issues. On the whole, interactions based on respect and education prevail, and the percentages of users requesting and offering help are a sign of their willingness to be part of a group with a certain level of cohesion.

We hope that such barriers will be gradually overcome and tools like the one shown can be used at 100% of their potential.

5 Types of users

To understand a community, you must first understand what kinds of users exist within it. To form an idea of their characteristics, we have analysed the interactions and the roles taken in the community.

We study what kind of interests they have, how they are related or what place they occupy within the social structure of the platform. We encounter Leaders, Socialisers, Observers, Newbies, Professionals and Monitored. A whole cluster of users with different profiles, who enrich and renew the concept of community within the healthcare sector.

Six types of users

Leaders, Socialisers, Observers, Newbies, Professionals and Monitored.

So far we have seen a social segmentation of illnesses through the prism of the five groups presented in Chapter 2, where there was emphasis on the shared characteristics of the diseases. Now we drill down one more level to provide further detail by putting the real players under the spotlight: the platform users. With the preview of this report in October, we already set out the user types and offered some pointers as to their main characteristics. Throughout this section, we will break down the proposed categories and try to explain in more depth each type of e-patient found in People Who.

This categorisation is common to all five countries and, when we created it we used the content of the messages posted by users in the different communities as a way of trying to highlight the shared traits at intragroup level.

However, although the segments are separate from one another, participants can change their behaviour or concerns over time, gradually turning into new types of users with different characteristics to the original. Mobility depends on the learning process, experiences or time spent on social relations on a daily basis. For example, a new user will behave predictably according to expectations for a novice; however, if they strengthen their ties to the community and acquire certain prestige or status, they may end up becoming a respected leader.

Later in this chapter, data on the composition of each platform will be provided by profile, which will account for the way in which e-patient communities for People Who in Europe interact as well as the relative importance of each profile.



Renata Bieber, General Practitioner
Social Medical Manager Germany at Menchen Die

"The role of the doctor on this platform is not just to cover the aspect of clinical or illness-related uncertainties, but also to foster patient interaction in order to generate debate and contribute new points of view amongst all users. Also, the questions we answer on a daily basis in the community give us the big picture about patients' concerns, which are not always so evident and might raise unexpected topics, useful for all of us".

Leaders

Active and influential in the community.

As in any traditional community, in all the illnesses covered on People Who there are certain types of users who are considered a reference or authority because of the way in which they take part. This type of e-participant stands out mainly because of their level of activity, attitude and influence on the rest of the community.

They initiate conversations and their opinions and interventions matter. Other community users often seek their approval and agreement on the different topics of conversation or questions. They are popular and well-known within the community, and this grows the

longer they participate. The leaders' status depends on their charisma and/or the success of their interventions.

However, far from becoming digital 'celebrities' in People Who, the leaders are more committed to doing things for the community by sharing useful content for all, welcoming the newcomers and answering specific questions about how the community operates.

Here is an example of the type of post from this user profile.

Italy: Bipolar disorder. Female, 63, has the illness



Username

15 maggio 2015

A Username, vedo se riesco a dirti cos' è la Mindfulness, io l'ho trovata su internet ma non l'ho mai fatta. E' una tecnica di concentrazione che si può fare da soli e che aiuta in qualsiasi momento a distoglierci da emozioni, giudizi, riflessioni che ci procurano sofferenza, agitazione, ansia. Si basa sull' osservazione pura e semplice della realtà. Magari al mattino mi alzo e dedico la mia attenzione al caffè, mi concentro sul suo colore, sul profumo al sapore, chiudo gli occhi e non penso a niente, do retta solo a ciò che i miei sensi mi trasmettono. In ufficio evito di fissarmi sul fatto che il capo c'è l' ha con me. Lo osservo con distacco, senza emozioni e colgo solo la novità del colore della sua cravatta. Sono momenti di pura oggettività, in cui non ti occupi di giudicare, di emozionanti. Puoi distaccarti dai tuoi pensieri "pericolosi" quando è dove vuoi. Molto insegnano in merito i buddisti e altre tecniche di meditazione più complicate.

Hello Username, let me see if I can explain mindfulness to you. I've seen it on the internet, but I've never practised it. It is a concentration technique that can be done alone and helps us at all times to distance ourselves from emotions, judgements or opinions which might make us suffer. It is based on the observation of reality. When I get up in the morning, I focus on my coffee: its colour, its smell and its taste. I close my eyes and think about nothing; I only think about what my feelings convey. In the office, I avoid taking notice of my boss if he is angry with me. I look at him without emotions and I only look at the colours on his tie. These are purely objective moments, in which I do not judge anybody or get emotional. You can distance yourself from your most dangerous thoughts whenever and wherever you want. Many people also follow Buddhism and more complex forms of meditation.

France: Alzheimer's. Female, 56, taking care of someone with the illness



Username

23 septembre 2015

oui bravo Username de ne pas lâcher, d'être là, mais comme dit Username, il y a des aides, des accompagnants, renseignez vous... alzheimer est reconnu et il y a des prises en charge, ne restez pas isolée dans cette relation qui doit vous dévorer, je vois combien gérer mes parents est épuisant et pourtant je travaille et vois du monde. Faites vous aider, ouvrez vous vers l'extérieur pour trouver un appui à travers des professionnels. Bon courage à vous

Congratulations Username for not giving up, for being here, but as Username says, you could be helped or supported, you should ask for some information... Alzheimer's disease is a recognized disease and you could ask for the intervention of a professional caregiver. Do not stay isolated, I personally know how exhausting it is to take care of my parents even though I work and have a fulfilling social life. Ask for help, open yourself and ask for the support of health professionals. Cheer up!

Spain: Bipolar. Male, 56, has the illness



Username

29 agosto 2015

Convéncete (sin tirar platos, por supuesto) que tiene que ir al especialista por las personas (y perros) que más quiere: Tú y sus hijas. Una de las características del TB es que no se tiene miedo a la muerte, y por eso se le suele perder el respeto a la salud. Me dio hace unos meses un derrame cerebral y no temí por mi vida en ningún momento; pero simultáneamente pensé en el dolor de mis seres queridos por mi ausencia, y sentí como si una fuerza interior me empujara hacia mi total recuperación. Tienes que dejarle claro (con mucho amor y comprensión), que tiene que luchar por estar bien para que sus seres queridos sean un poco más felices. Ánimo Username, piensa que el amor es el sentimiento vital que nos hace mejores personas. Ya nos contarás. SALUD.

Convince him (without throwing plates, of course) that he has to see a specialist for the people (and little dogs) he loves most: you and your daughters. One of the characteristics of BD is not fearing death, and therefore they often lose respect for their health. I had a stroke a few months ago and did not fear for my life at any time; but simultaneously I thought of the pain my loved ones would feel for my absence, and I felt as though an inner force pushed me towards full recovery. You have to make it clear (with a lot of love and understanding), that he has to fight to be well so that his loved ones are a little happier. Cheer up Username, remember that love is the core emotion that makes us better people. Keep us posted. YOUR GOOD HEALTH.

Socialisers

Active in building relationships between members of the community.

This group consists of people who help maintain community ties and are interested in interacting on the platform with other users by sharing their experiences. Although they are quite active, they are not as visible as the leaders, which is not to say that their contributions are less valid.

They try to encourage dialogue and exchange of opinions, asking about the status of other users, resuming old topics that have been discussed previously or proposing all sorts of new topics related to the illness, leisure and entertainment, curious facts, etc. They usually work well in tandem with the leaders when it comes to contributing dynamism to the platform on a daily basis and they have a dynamic and friendly style of writing.

Germany: Atrial Fibrillation. Male, 68, has the illness



Username

10.Februar

Ich leide seit einiger Zeit an Vorhofflimmern und suche einen Austausch mit Betroffenen über ihre Erfahrungen im psychischen Bereich. Ist doch sehr belastend.

I have suffered from atrial fibrillation for a long time now and am looking to exchange experience with other people especially in the psychological sector. It's a burden.

United Kingdom: Depression. Female, 58, has the illness



Username

28 August 2015

Hi Username, just joined the group and read your message. I can fully understand what you're saying. Putting on a face when not feeling sparky is so draining. We do this as people don't understand this illness we have. I have come to realise that if you don't suffer from depression they don't fully understand how we feel. I go through spells of dark days, grey days and beat myself up saying to myself why can't I be normal. We are normal but we have an illness. I can say this to you because you know what I'm talking about and will understand but it's accepting this yourself which is hard all the time. Especially when you feel brighter than the dark cloud comes over for no reason at all. It's good to chat to people like ourselves even if online. Don't beat yourself up, it is an illness xxx

Observers

They are present but do not interact with others.

They are the silent majority, common to many online communities. We know that they are receptive thanks to the number of visits that the articles and different topics on the platform receive, but they are less active as they usually read more than interact. This may be due to a lack of interest in actively writing

(probably because they have different expectations of the platform).

Sometimes they reveal their presence in the community in order to raise some specific issue, but we do not know to what possible extent they are attentive to the contents because they limit themselves to being merely passive spectators.

Spain: Schizophrenia. Male, 31, has the illness



Username

13 diciembre 2015

Hola a todos, aparezco poco por aquí pero os leo todo lo que ponéis de un tirón. Al final me matriculé en la uned y debería ponerme desde ya a estudiar. Hice un taller de 10 días en una asociación y no ha estado mal, trataba sobre autoconocimiento, autoconfianza, autocontrol y algunas cosillas más. Aparte de eso no tengo demasiada vida social, esta misma noche mis amigos están de cena de navidad. Al igual que a otros muchos eventos no voy por tema económico. Pero cada vez tengo menos ganas si pudiera. Hay cosas que no entiendo, si yo tuviese un amigo al que conozco desde siempre y se que no tiene dinero para nada aparte de tabaco... haría una recolecta entre todos para que pudiese ir. No se, quizás piense diferente pero no veo que sea una idea muy disparatada. Son demasiados feos que me han hecho ya desde mi último ingreso. Cada vez soy más consciente de que en esta vida estamos solos, tan sólo nos tenemos los que compartimos enfermedad. Respecto a mi estado de salud me noto más que nada apático, me importa poco lo que me rodea. Es como si estuviese decepcionado con el mundo por cómo me trata. No tengo ganas de navidad, nos juntamos la familia y siempre suele haber peleas... es una pesadilla. En fin, deseo que se me pase rápido. Hasta marzo no tengo cita con mi nuevo psiquiatra, llevo sin ver a uno desde mayo. Un saludo.

Hi everyone, I seldom post here but I read everything that you put in one go. In the end I enrolled at the UNED and I ought to get down and study. I did a 10-day workshop in a group and it was not bad, it was about self-knowledge, self-confidence, self-control and a few other things. Other than that I don't have too much of a social life, tonight my friends are at a Christmas dinner. Like many other events, I can't afford to go. But even if I could, I am increasingly less interested. There are things I do not understand, if I had a friend who I've known for a long time and I know he has no money for anything other than cigarettes ... I would take up a collection so that he could go. I do not know, you might think differently but I don't think it's such a bad idea. Too many bad things have happened to me since my last entry. I am increasingly aware that we are alone in this life, we only have those who share the illness. With regard to my health, I am mostly apathetic, I don't care about what is going on around me. It is as if I was disappointed with how the world treats me. I am not looking forward to Christmas, the family gets together and usually has fights ... it is a nightmare. To be brief, I want to get it over with as soon as possible. I do not have an appointment with my new psychiatrist until March, I have not seen one since May. Best regards.

Newbies

They are new to the community.

As the name suggests, the new users group have just joined the community.

The identifying characteristic is that they themselves indicate their situation when they introduce themselves and write, apologising if they make some mistake due to their limited experience in the community.

This is the most fluid profile of them all and membership of this group is defined according to the time spent actively participating in the community.

Depending on the extent to which they interact with others they can progress to other user profiles. It is, therefore, a more situational than behavioural profile.

The learning curve for new users is quite long. They often ask for help or advice on where to write or how to ask for something they need and are normally grateful. In some way, the knowledge they obtain thanks to the help from other users they then give back to the community when they return to help others.

United Kingdom: Diabetes. Female, 28, has the illness (type 1)



Username

9 April 2015

Hi all, I am new here so thought id introduce myself...My name is Username and I have had type 1 diabetes for 17 yrs this year, im almost 27. I joined this site in hope of meeting people my age who live with type 1, as I do not have any friends or family members who have it...sometimes I feel so alone!!

Germany: Depression. Female, 47, has the illness



Username

9 April 2015

Hallo, nach langem Überlegen habe ich mich hier angemeldet. Seit März 2014 weiss ich, das ich an Depressionen erkrankt bin. Habe lange gebraucht, damit ich das Wort Depressionen sagen konnte. Habe 2 Akutkliniken Aufenthalt und 6 Wochen Reha hinter mir. Zur Zeit ziehe ich mich wieder zurück und gehe wieder an meine Grenzen. Weiss auch nicht mehr, wem ich vertrauen kann. Weiss auch als nicht, was ich sagen soll, wenn ich gefragt werde. Den gut fühle ich mich nicht. Aber zweifle an mir, ob ich das nur einbilde. Würde am liebsten den Koffer packen und mich vom Alltag zurückziehen. Das ist doch kein Leben. Nehme über den Tag 300 mg Venlafaxin. Wer hat Tipps um wieder richtig am Leben teilnehmen. Danke im voraus.

Hello, after thinking about this a long time, I have finally created a profile and signed up on here. In March 2014, I was diagnosed with a depression. It took me quite a long time to be able to use the expression depression. Since then, I have been taken to hospital twice and been sent to rehab for 6 weeks. At the moment I am not having an active life and have withdrawn from everything, pushing myself to my limits again. I have doubts about whom to trust and don't know what to say when I am being asked. The truth is I don't feel very well. But I am not sure whether I am just imagining this. I would love to just pack my bag and escape from reality and my everyday life. No one can tell me that is a normal life. I am taking 300mg Venlafaxine per day. Does anyone have some advice how to enjoy life again? Thanks for your help.

Professionals

People Who team and volunteers.

This group is made up of doctors and moderators from the People Who team along with other people related to the professional healthcare field¹ who actively participate in the community on a voluntary basis (nutritionists, therapists, hygienists, psychologists, physical trainers, professional carers ...).

This profile is easy to identify as they are often experts who help with advice

and technical recommendations to other members of the community. They are involved in helping others or disseminating information and they usually resolve goal-oriented issues. They are of great value to the communities where there are a lot of these kinds of questions.

Spain: Bipolar disorder. Male, 45, taking care of someone with the illness. Volunteer



Username

7 diciembre 2015

Un psiquiatra ideal no existe, pero sí tienes derecho a buscar uno que te dedique tiempo para escucharte y conocerte. Los que sólo se fijan en síntomas y medicación son buenos para las crisis agudas, pero para la estabilización y seguimiento es mejor tener a alguien que pueda dedicar al menos 30 minutos en una consulta.

There is no ideal psychiatrist, but you do have the right to look for one who will take the time to listen to you and get to know you. Those who only look at symptoms and medication are good for acute crises, but it is better to have someone who can devote at least 30 minutes in a consultation for stabilisation and follow-up.

United Kingdom: Alzheimer's. Female, 59, interested in the illness. Professional volunteer



Username

30 November 2015

I am a dental hygienist and I do training for care home staff in dementia homes. I would make sure that the toothbrush and toothpaste are the same as he has always used. If he doesn't want to do it first thing in the morning or last thing at night it really doesn't matter too much. As long as once a day you or he gets in with a toothbrush. Even if the top are done one day and the bottom the next day. Try and find a time in the day when he is more relaxed. Guiding with your hand over his works quite well for some people. You could try and involve your local community dental service.

¹ People Who is a place for patients and their immediate environment. Therefore other doctors who are not from the same team are not encouraged to be there. It is a platform where no consultation takes place and where we also avoid commercial activities. We are working on a version of People Who for health professionals in order to connect patients and doctors for other purposes.

France: Allergies. Social Medical Manager in France, People Who professional



Dr Notari

5 octobre 2015

Bonjour Username,

En effet, il est tout à fait possible de sortir de l'obésité et de l'hyperphagie sans avoir recours à la chirurgie.

Dans un premier temps, le médecin généraliste peut s'occuper de vous. La stratégie est de définir des objectifs personnalisés accessibles, d'accroître le niveau d'activité physique, d'améliorer les habitudes alimentaires, d'évaluer les risques/complications de l'obésité et de mettre en place une approche psychologique.

Si les objectifs thérapeutiques ne sont pas atteints, au bout de 6 mois à un an, le médecin peut faire appel à d'autres professionnels tout en continuant à vous suivre (diététicien ou médecin spécialisé en nutrition, psychologue et/ou psychiatre, professionnels en activités physiques adaptées)

La chirurgie bariatrique est envisagée après échec d'un traitement médical, nutritionnel, diététique et psychothérapeutique bien conduit pendant 6-12 mois (pas de perte de poids suffisante ou absence de maintien de la perte de poids).

Elle est proposée aux gens qui ont un IMC = 40 kg/m² ou un IMC = 35 kg/m² associé à au moins une maladie susceptible d'être améliorée après la chirurgie (hypertension artérielle, syndrome d'apnées du sommeil et autres maladie respiratoires sévères, diabète de type 2, maladies ostéo-articulaires invalidantes, stéatohépatite non alcoolique)

La personne doit être bien informée au préalable et doit avoir compris et accepté la nécessité d'un suivi médical et chirurgical à long terme.

L'intervention ne sera bien entendu réalisée qu'après une évaluation et une prise en charge préopératoires pluridisciplinaires et si le risque opératoire est acceptable.

"Hello Username,

It is, indeed, absolutely possible to overcome obesity and hyperphagia without the help of surgery.

At first, your GP can take care of you. The strategy is to define some personalised and realistic objectives, to increase physical activity, to improve food habits, to evaluate the risks/complications of obesity and to put in place a psychological approach.

If the therapeutic objectives are not reached after 6 months to 1 year, your GP may ask other health professionals to intervene (a nutritionist or a doctor specialised in nutrition, psychologist or psychiatrist, coach for physical activities).

Bariatric surgery is to be considered only if a 6 to 12 months medical, dietetic and psychotherapeutic treatment has failed –without any loss of weight or a loss of weight that was not maintained.

Bariatric surgery is offered to people with a BMI = 40kg/m² or a BMI of 35 40kg/m² associated with at least one illness that could be improved by the surgery (atrial hypertension, sleep apnoea or other respiratory illness, diabetes type 2, disabling osteoarticular problems, non-alcoholic steatohepatitis).

The patient must first be well informed and accept the necessity of a long-term and surgical follow-up.

The surgery will –of course– be programmed after a complete evaluation and a multidisciplinary preoperative preparation, if the surgical risk is acceptable"

Monitored

These are users who due to their performance in the community are identified and monitored to ensure that their performance always comes under the community usage rules. We have identified two types of monitored users: those who generate negative controversy in the community by putting the social relations of other users at risk (Controversial) or those who have promotional purposes and appear in the community for this reason (Spammers).

Controversial

Users thus classified generate negative controversy in the different communities, due to the topics discussed or how they discuss them.

They normally display provocative behaviour that can make the other readers uncomfortable. They resemble internet 'trolls' and may require a rap on the knuckles from the moderator. At other times, they are also socially penalised by the other users owing to the unease that certain comments generate. Nevertheless, some become quite popular.

As a community that is actively moderated by the People Who team, there are not many users who fall within this category, but sometimes

these behaviours produce friction or disagreements among different users. All comments that violate the codes of conduct and respect in the community are deleted.

Spammers

They are users with very specific interests regarding the community. They normally interact with other people in order to seek self-promotion, obtain some benefit or advertise third party content. They are not looking to find people in the same situation or to answer questions as occurs with the other members of the community. Their aim is to find an audience in the community in order to advertise their own or third party content that can attract people from within the community.

These kinds of users normally share many links or information about something specific, seeking visits to an external content on the web (website of another association, a private service, a blog, a survey, a product, etc.)

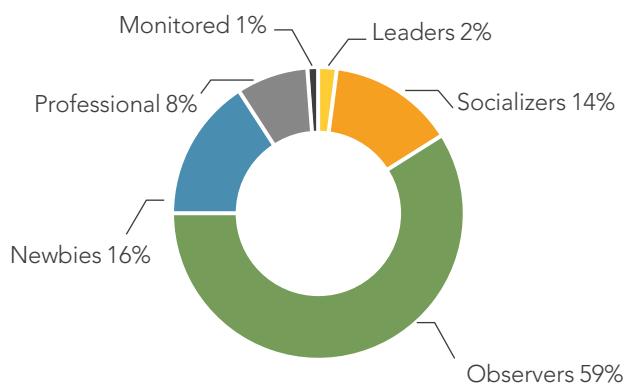
Social Community Managers are the people in charge of monitoring this type of user to block comments or users breaching the platform's terms of use.

Distribution of user profiles

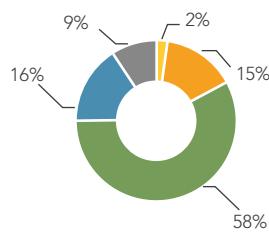
The most common profile: Observers. As it is a social network focused on health, the way in which users interact is exactly the opposite of on other social networks such as Facebook, for example. At first, all users are unknown to one another.

The circle of interest is slowly formed and relations are gradually built. The types of users in a community frequently change with time, depending on how long the illness has been online and the number of users it has.

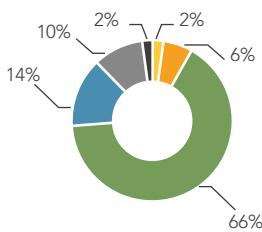
Europe



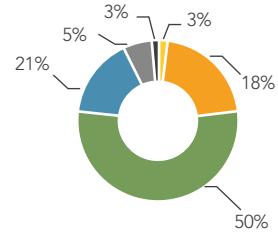
France



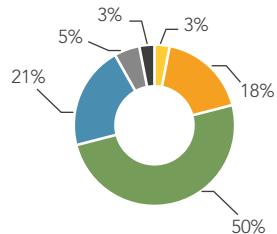
Germany



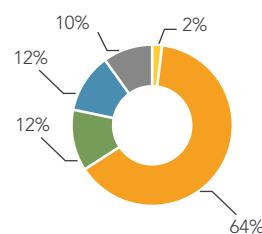
Italy



Spain



United Kingdom



- Socializers
- Leaders
- Monitored
- Professional
- Newbies
- Observers

Conclusions

The observer profile dominates in the community, as there is a significant number of users whose main aim is to seek information and/or documentation without showing a special interest in the exchange of opinions or social interaction.

The group of leaders is limited because it is a select elite and few people meet the characteristics or conditions required to be recognised in this position.

The country that has the largest proportion of new users is Spain, where 21% of the messages have these characteristics. As we have previously stated, as time passes and these users benefit from collective learning, they move into different profiles.

The weight of professional comments is higher in the UK and Germany, which indicates that in many instances direct intervention is requested from them, as they are mentioned in order to mediate on questions or because they are asked direct questions where other people do not intervene. However, in Spain they only account for 5%, probably because the community is more likely to seek emotional support from other users and answer their own questions collectively without having to resort to an expert.

6 Concerns under discussion

What users talk about. It's as simple and important as that. In this chapter we focus on the main concerns that users have when interacting in the community with other members. What they discuss, what do they look for in the answers from other users and what are their questions.

We created a series of XY axis graphs where the weight of each topic is positioned and quantified (a total of 18 tags) from all the comments, questions and answers from registered users.

This chapter enables us to compare the different styles of interaction per country and learn more about what kind of issues the e-patients discuss.

Classification by topic

At People Who we have made a classification by subject in order to gather statistics and better understand the concerns of those living with an illness. While our Social Community Managers monitor the communities from each country, they classify the discussions with these 18 tags and with the frequency of these tags we can map these concerns. This allows us to better understand what it is that concerns those who have the illness, care for others or are interested in it.

Thematic tags

Social life

This is the most varied category. It includes the activities mainly aimed at getting users to socialise: from commenting on daily life, talking about leisure preferences and opinions to get feedback.

Psychological aspects

This tag contains everything that has to do with emotions, different attitudes regarding the illness and what this entails.

Work

The comments under this title are work-related, questions are almost always asked about what impact the illness will have on doing their work, if they are able to apply for help, or questions about everyday life in the workplace. It usually comes up in the illnesses that in one way or another render people unable to work.

Children

The comments under this tag talk about topics primarily related to the children of users, almost always due to the fact

that they are affected by the illnesses and the father/mother/family is the carer. It occurs, for example, in the case of diabetes, with parents who have children with diabetes.

Parents

Family issues are important when living with an illness and the discussions about family are very different depending on whether they are about parents or children. With the increase in life expectancy in Europe, illnesses in elderly people where the children care or help their parents are more common. This is the case in Alzheimer's, with a significant presence on this tag.

Relationships

It refers to aspects related to the couple, either because the couple is affected, or because the affected person reports problems or needs some information to help improve their relationship. In many cases the diagnosis affects the couple's relationship and even the medication in certain treatments.

Patient organisations

Patient organisations are welcome and their discussions and interactions with other users are identified with this tag and allow us to assess their presence.

Diet

With this tag we designate the issue of nutrition, diet, food properties and food-related habits. We clearly see that although proper nutrition should be important in all instances, there are illnesses such as diabetes in which the frequency of this tag is high, whereas it is hardly present in mental disorders.

Non-pharmacological treatments

Unlike medication, they concern products or procedures that are not exactly medicines but may play some part in improving the illness, whether they are natural products, specific practices, etc.

Exercise

This is related to users' physical activity: types of sports, recommended exercises and queries on these issues about whether someone may or may not continue with a particular activity.

Symptoms

In this tag we collect everything related to the symptoms of various illnesses, especially practical matters and queries, how to differentiate one from the other and what these symptoms lead to.

Health professionals

This concerns messages that contain references to healthcare staff and health-related fields.

Diagnosis

This has to do with medical issues, especially comments on the diagnosis received or expected, specifically whether a doctor is present who answers queries and clarify issues around it. In many cases, a commonly-discussed topic is on viral diseases where there is still no diagnosis but a suspicion about the possibility of having the disease.

Medication

This is everything medication-related. Under this tag we specifically find comments shared about whether an

active ingredient and opinions in that regard work or otherwise, what they are specifically taking, whether there have been any bad experiences, etc.

Scientific research

This covers the whole topic from a more academic-scientific perspective. Usually the comments we see here are about news items relating to issues that have been discovered about a disease, informative articles on it and information on the issue.

Public healthcare

It allows us to identify when there are discussions on treatment-related issues that public health currently deals with or otherwise.

Private healthcare

This has to do with private health, income, care, procedures, etc. For the time being, the frequency of this tag is minimal.

Technology

Here we can give an account of various topics, whether they are applications related to the disease, devices or programs used, news that is in some way related, or queries on the issue.

User concerns

Grouping topics

On the positioning maps, we depict the frequency of 18 tags explained previously in three categories that we identify in colours to have a quicker overview on the charts.

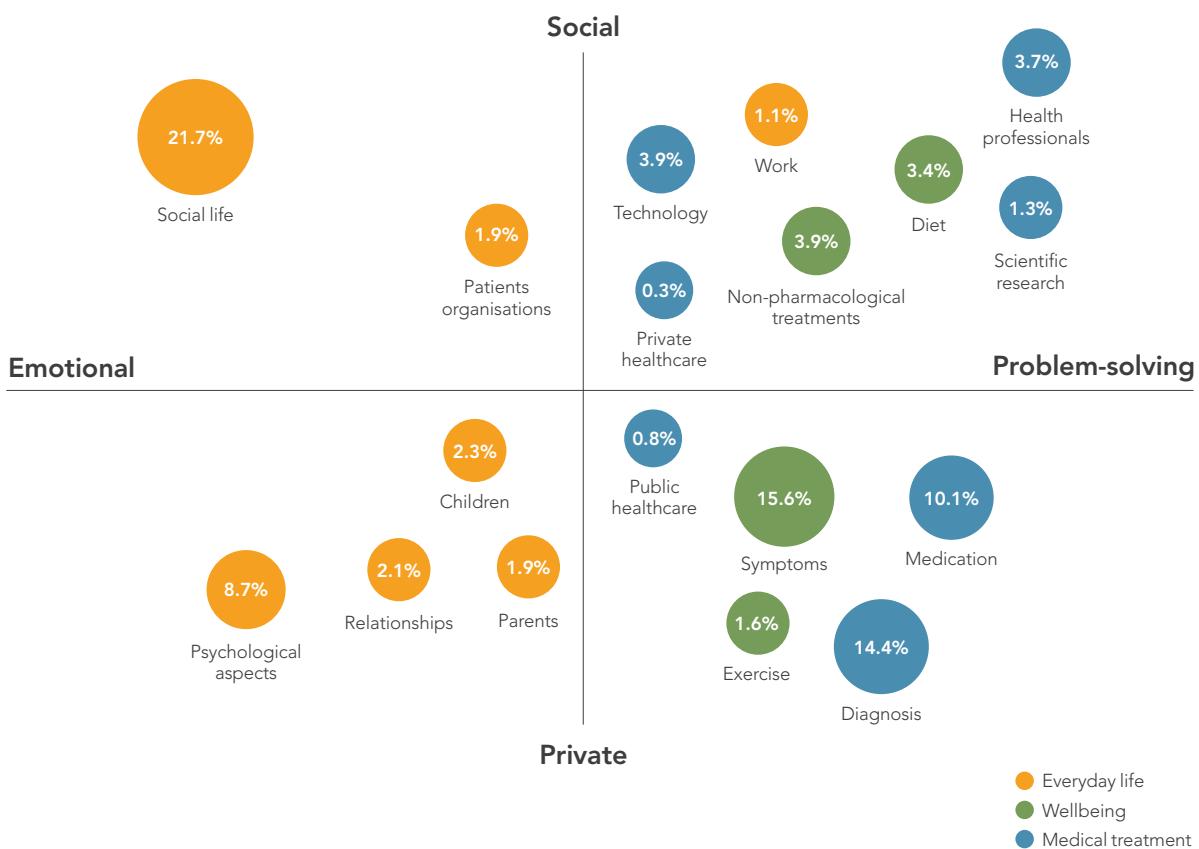
- Everyday life: Social life, Work, Children, Parents, Relationships, Psychological aspects and Patients organisations.

- Wellbeing: Exercise, Symptoms, Diet, Non-pharmacological treatments

- Medical treatment: Private healthcare, Medication, Diagnosis, Technology, Public healthcare, Health professionals, Scientific research.

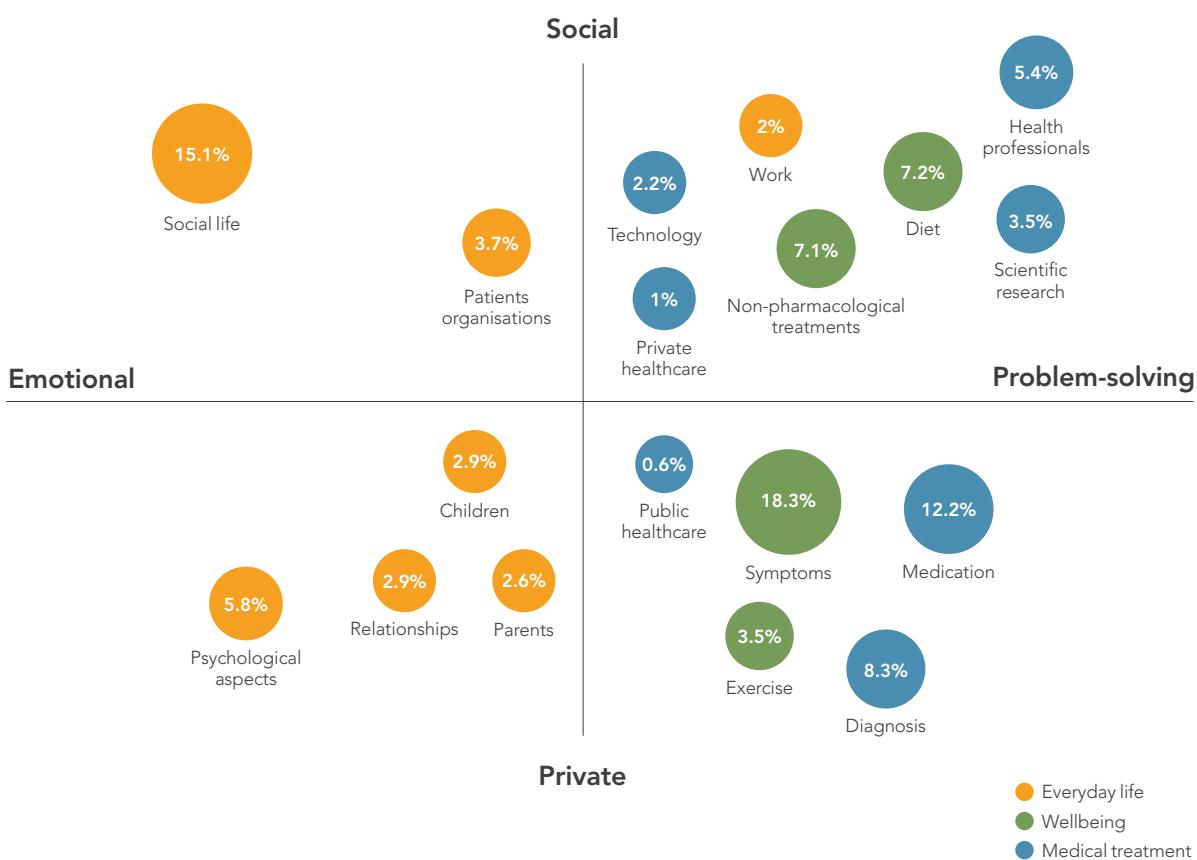
Europe

Discussions tagged per topic, all the disease communities in the 5 European countries.



France

Discussions tagged per topic, all disease communities in France.

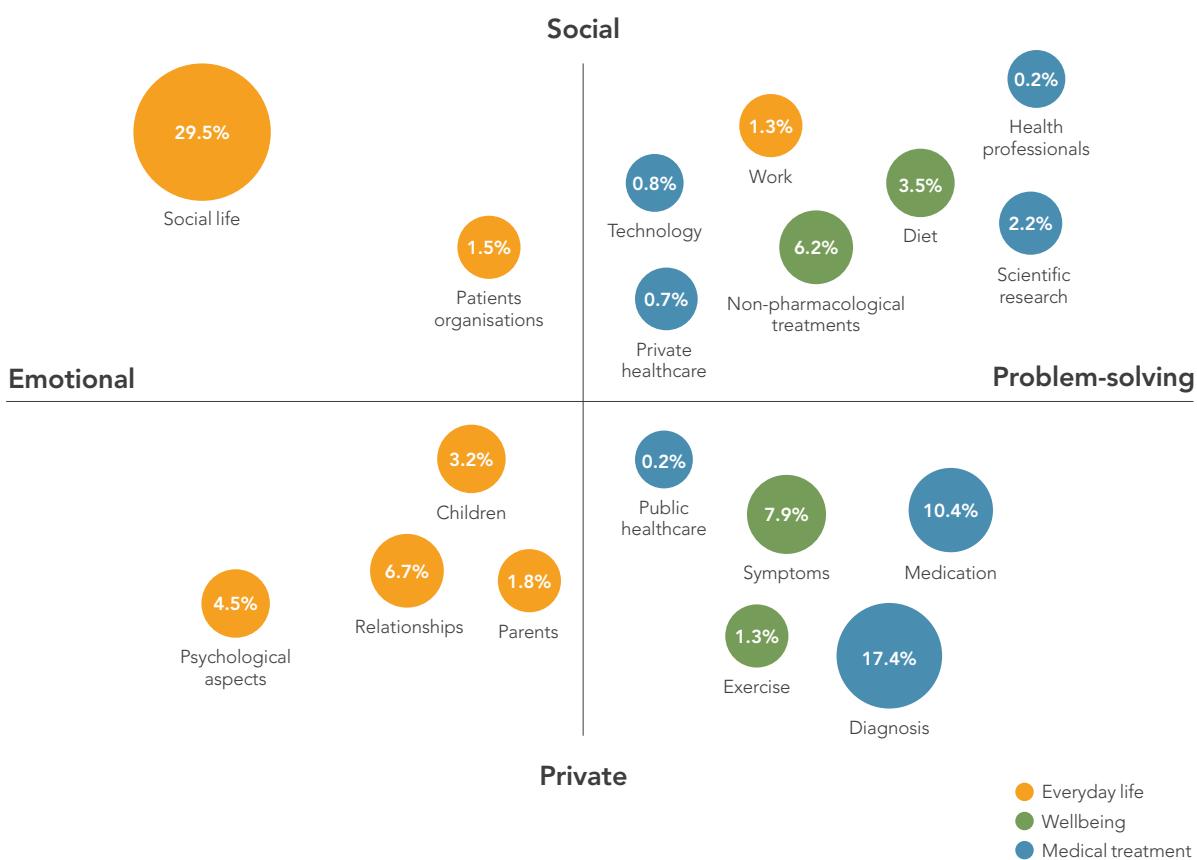


Marc-Antoine Notari,
General Practitioner
Social Medical
Manager France at
Les Gens Qui

“During 2015, the French platform Les Gens Qui got off to a good start. My interventions as the doctor of the platform have enabled me to chart three main categories of preoccupation by e-patients. First the diagnosis, often associated with the anxiety of the patient when confronted to the illness; the treatment (whether pharmaceutical or not); and finally the scientific knowledge about physiopathology and treatment. As a contributing doctor to the communities the main difficulty is to respect deontological ethics and medical-legal risk. The role of the Social Medical Manager tends to develop into the role of an advisor, consulted to improve the information the patient already has, but doesn’t – and shouldn’t – substitute the GP’s work in the doctor’s surgery”.

Germany

Discussions tagged per topic, all disease communities in Germany.

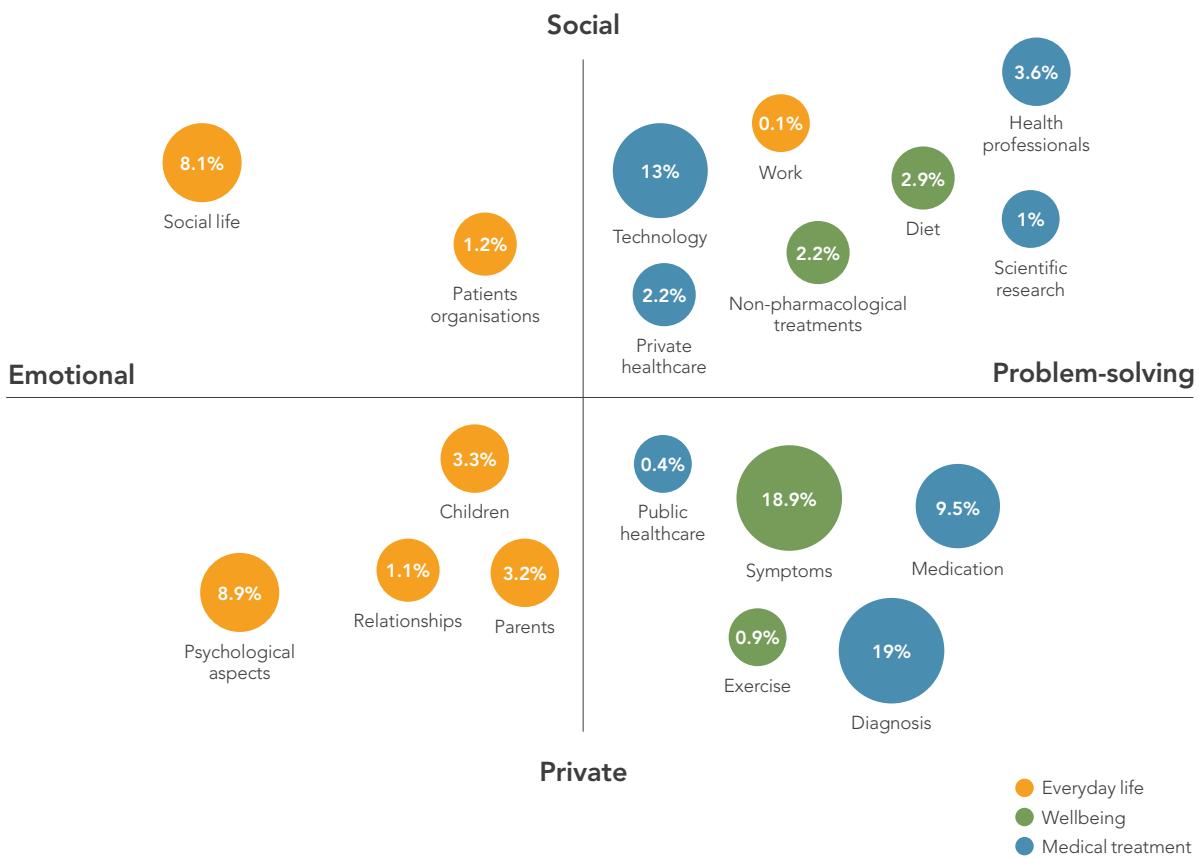


Charlayne Iwanczuk,
Social Community
Manager Germany at
Menschen Die

"The most active illness communities on Menschen Die are diabetes and depression. The number of interactions between users is the highest. One of the main reasons for this may be on the one hand that depression is reported to be one of the most frequent reasons why people in Germany see their GP and, on the other hand, being a mental illness, people like to talk about their feelings and thoughts with others. For both illnesses, diabetes and depression, it has also been noted that the average age of a user on Menschen Die is lower than in other illnesses, which also shows that our younger users are more technically versatile, digital-minded and generally spend more time on the internet than the older generation".

Italy

Discussions tagged per topic, all disease communities in Italy.

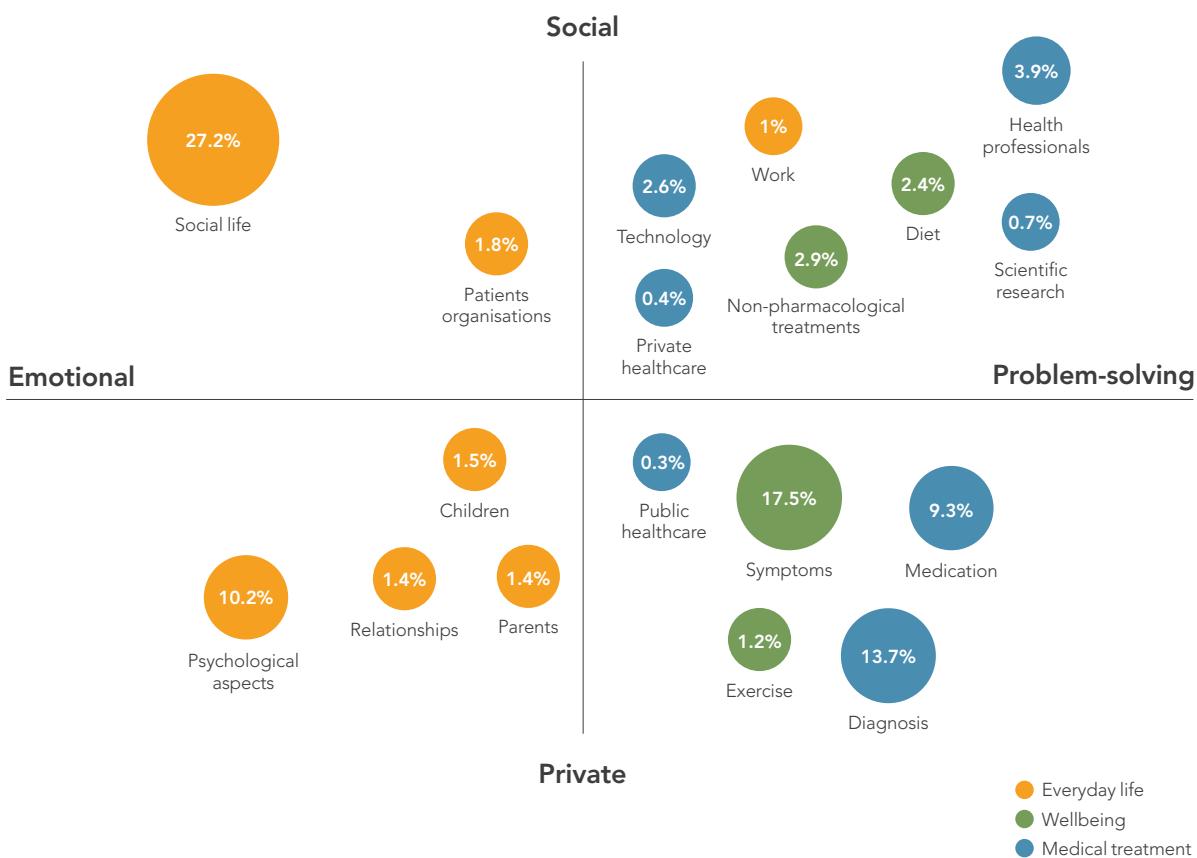


Marco Bongiovanni,
General Practitioner
Social Medical
Manager Italy at
Persone Che

“I believe that the number of e-patients will increase in the near future; a lot of patients in the last few years have been looking for clinical information about their therapy or their symptoms on the web. Unfortunately many websites give partial or unverified information, without any scientific moderation or without a direct contact with a medical doctor”.

Spain

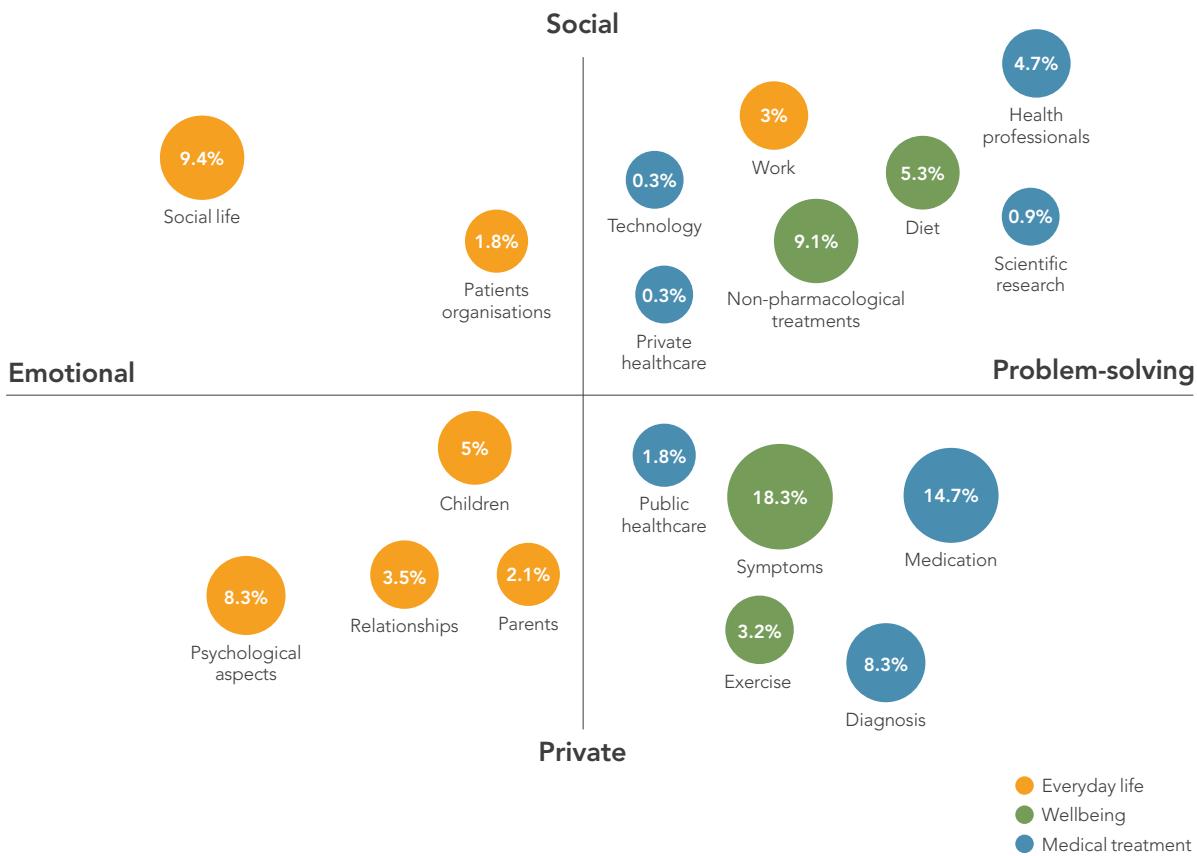
Discussions tagged per topic, all disease communities in Spain.



"Overall, there are a lot more positive opinions. People are happy to have found such a site on the internet. It gives the impression that they have really found the place they were looking for, specific to their illness, with people experiencing the same as them. They often post appreciative comments for making such a space available".

United Kingdom

Discussions tagged per topic, all the disease communities in the United Kingdom.



Aida Oates, General Practitioner
Social Medical Manager UK at People Who

"I feel that the UK community may differ from the mediterranean ones, like Spain or Italy in as much as, people in the UK are very reserved about personal or medical matters, and tend to keep illnesses and treatments confidential. I've found that most e-patients were either seeking empathy from other users and sharing their positive or negative experiences, or looking for medical answers regarding treatments side effects, efficacy etc , alternative therapies etc. Some were even trying to get a second opinion or double checking that what their doctor was doing was appropriate. And a few are looking for advice on more personal matters. I can definitely see future in e-health communities. As the majority of the population becomes access to IT and gets familiar with this new way of getting medical advice , e-health will become more widely used".

Conclusions

The positioning maps shown have revealed great differences between the countries in regard to the levels of interest generated by the different diseases. Even though it was expected, the symptom (15.6%), diagnosis (14.4%) and medication (10.1%) categories have a substantial weight in every health community; sociability-related issues (21.7%), psychological aspects (8.7%), family relationships (6.3%), technology (3.9%) and diet (3.4%) also figure prominently.

A relevant example is in relation to non-pharmacological treatments, where the willingness to try alternative therapies differs greatly according to the country. While in the communities in the United Kingdom (9.1%), Germany (6.2%) and

France (7.1%), these types of treatments have gained great popularity in recent years, they have not aroused as much interest in Spain (2.9%) or Italy (2.2%), or the patients are more conservative when trying them.

With regard to eating habits, there is less concern in the Mediterranean countries about these issues (diet and nutrition). Probably the presence of more balanced diets (with fewer associated problems) makes these kinds of topics less recurrent. On the contrary, food still arouses more than double the interest in the north (specially in France) than it does with its neighbours in the south.

7 Interest in content

What is the content and for what disease is it of most interest? What articles do users look for and read? In this chapter we conduct an analysis of the main concerns of users when consulting the content published in our online magazine.

An interest in health information that varies by country and disease. We know that e-patients are empowered patients seeking online information but now finally we know specifically what content they are really interested in.

Content classification

The data shown below contain information extracted only from visitors to the People Who magazine. As the published contents are grouped under different categories, all the data have been weighted to avoid statistical distortions. Thus, the graphs show the real interest of each country by subject category. If a category does not appear in the graph of a country, it means that no content was published in the study period it refers to. Grouping by category is as follows:

Diagnosis

General information about the disease, terms and definitions. Specially designed for newly diagnosed people.

Opinion

Professional opinion about the disease. It may be a doctor, a surgeon, a scientist or even a lawyer who, for example, deals with the legality of an illness.

Treatment

Contents updated on drug treatments and how the medication for each illness acts on the body.

Wellbeing

Content on psychological aspects, tips and tricks for a healthy life covering topics such as physical activity, nutrition and family and personal relationships.

Experiences

Stories of people who have experience with the disease as this may help other people also living with this disease (UGC, User Generated Content supervised before publication).

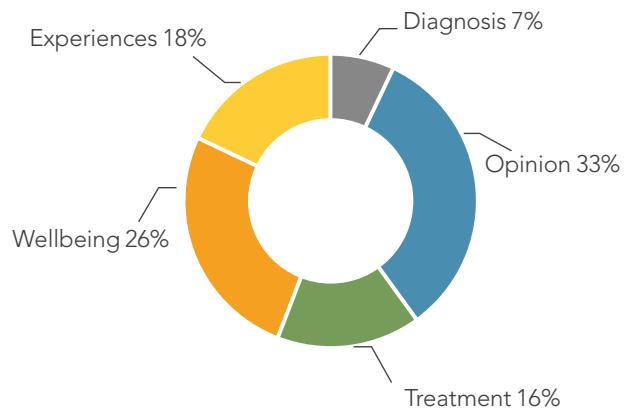
Overall, the most visited content in Europe is related to expert healthcare opinions (33%). Opinions of professionals on issues affecting the disease, such as the latest scientific developments, new therapies, expectations for improvement or recommendations for better living are what attract most interest.

Issues related to wellness are also very attractive to e-patients (26%). Aspects such as maintaining good habits, nutritional advice, physical activity or emotional balance feature among the most popular content. This category is particularly relevant to those illnesses that carry a social stigma, as has already been discussed in Chapter 2, where we not only face the physical barriers caused by the disease but also social ones.

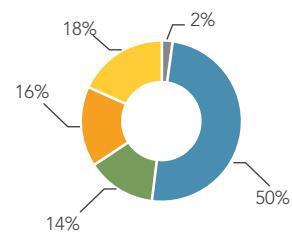
Treatments and medications account for 16% of visits and interest in health content. While drugs or therapies represent a large part of user interest, the percentage is lower than expected and contrasts with the view of society. When it comes to more general information about the disease (like terms and definitions), content dealing with basic information (7%) did not seem to be very popular with empowered patients. Probably this information is not relevant to a user who is characterised by being relatively well informed, very active on the internet and already engaged in those issues that have to do with daily life with their disease.

Interest in content: By country

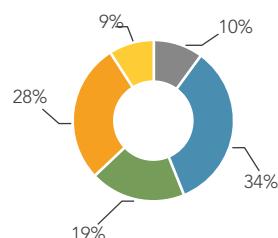
Europe



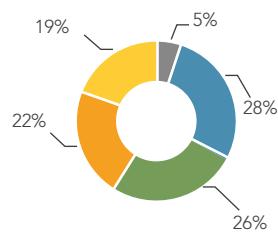
France



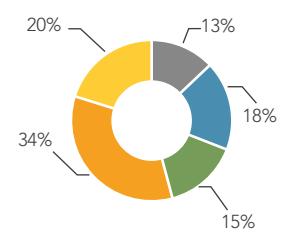
Germany



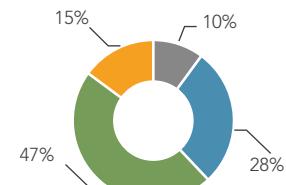
Italy



Spain



United Kingdom



- Diagnosis
- Opinion
- Treatment
- Wellbeing
- Experiences

Interest in content: By illness

The most popular content also varies considerably depending on the diseases with which users are living, which creates a series of priorities depending on the e-patient's situation. While diagnosis-related issues are very important in diseases such as HPV (40%), allergies (35%) and ovarian cancer (35%), the diagnosis does not seem so relevant for more controlled diseases such as mental issues (schizophrenia and bipolar disorder), diabetes, infertility or psoriasis.

There are situations where, once the diagnosis is known, attention tends to focus more on treatment, as in the case of arthritis (31%) or cancers, where there is a special interest in new therapies.

Moreover, issues related to well-being arouse much interest in diseases such as coeliac disease (51%), bipolar disorder (40%) or Alzheimer's (34%).

Finally, diseases where the interest is more focused on experiences coincide with illnesses that carry the greatest stigma, such as HIV (60%), bipolar disorder (25%) and infertility (25%), as we defined in the chapter on social aspects of an illness. Reading about how someone else has overcome a difficulty or what they are doing to overcome it, helps people to keep a more positive outlook and serves as encouragement and motivation for community members.

Allergies



- 35% Diagnosis
- 52% Treatment
- 13% Experiences

Alzheimer's



- 9% Diagnosis
- 31% Opinion
- 11% Treatment
- 34% Wellbeing
- 15% Experiences

Arthritis



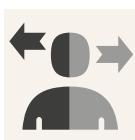
- 20% Diagnosis
- 15% Opinion
- 31% Treatment
- 19% Wellbeing
- 15% Experiences

Atrial fibrillation



- 21% Diagnosis
- 41% Opinion
- 15% Treatment
- 7% Wellbeing
- 16% Experiences

Bipolar disorder



- 7% Diagnosis
- 15% Opinion
- 13% Treatment
- 40% Wellbeing
- 25% Experiences

Coeliac disease



- 23% Diagnosis
- 16% Treatment
- 51% Wellbeing
- 10% Experiences

Depression



- 26% Diagnosis
- 16% Opinion
- 12% Treatment
- 22% Wellbeing
- 24% Experiences

Diabetes



- 7% Diagnosis
- 25% Opinion
- 26% Treatment
- 34% Wellbeing
- 8% Experiences

Epilepsy



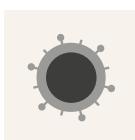
- 16% Diagnosis
- 39% Opinion
- 27% Treatment
- 12% Wellbeing
- 6% Experiences

Hepatitis



- 51% Diagnosis
- 49% Treatment

HIV



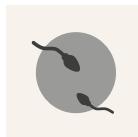
- 12% Diagnosis
- 9% Treatment
- 19% Wellbeing
- 60% Experiences

HPV



- 40% Diagnosis
- 56% Treatment
- 4% Experiences

Infertility



- 9% Diagnosis
- 46% Treatment
- 20% Wellbeing
- 25% Experiences

Acute leukaemia



- 14% Diagnosis
- 61% Opinion
- 18% Treatment
- 3% Wellbeing
- 4% Experiences

Chronic leukaemia



- 15% Diagnosis
- 26% Opinion
- 42% Treatment
- 6% Wellbeing
- 11% Experiences

Obesity



- 29% Diagnosis
- 33% Treatment
- 25% Wellbeing
- 13% Experiences

Ovarian cancer



- 35% Diagnosis
- 29% Treatment
- 13% Wellbeing
- 23% Experiences

Psoriasis



- 9% Diagnosis
- 34% Opinion
- 15% Treatment
- 21% Wellbeing
- 21% Experiences

Schizophrenia



- 7% Diagnosis
- 33% Opinion
- 19% Treatment
- 17% Wellbeing
- 24% Experiences

Skin cancer



- 16% Diagnosis
- 39% Opinion
- 21% Treatment
- 13% Wellbeing
- 11% Experiences

Transplants



- 18% Diagnosis
- 44% Opinion
- 21% Treatment
- 11% Wellbeing
- 6% Experiences

Conclusions

Despite the existence of a user profile looking for basic or essential information about the disease, the data collected seem to indicate that the user profile looking for reliable information about health is relatively well informed (empowered patient) and is more interested in specialised content (generally requiring a high level of knowledge about the illness).

In contrast to popular belief, the main concerns of e-patients seeking information are not symptoms or

treatment, rather the opinion and advice of experts and personal well-being are of greater importance for the person living with an illness. Once again, it appears that these people are more interested in human concerns and distance themselves from more purely medical issues. Therefore, viewing health from a broader perspective that also incorporates social aspects seems a much more productive strategy for approaching the e-patient.

8 Monitoring the illness

The e-patient is identified as someone who uses their initiative and monitors their illness. Therefore, we shall dedicate this chapter to issues such as the tools used for monitoring the variables affecting each illness.

On our platform, we can better understand the user profile using the Control section, that is designed to keep track of the illness.

And not only for understanding the user profile, but also to confirm the unequal rates of access by age and gender (despite being a majority on the platform, women use these devices less).

Daily monitoring of the illness

Keeping track of the illness plays a central role in the life of an empowered patient. Not only does the e-patient want to gather information, but also to monitor and handle their own details. Since the rise of phenomena such as big data and the emergence of new technological devices such as health apps, wearables and e-health communities, accessing and creating personalised information is no longer something alien to the average user. Data on medication, side effects, nutrition, physical activity and regular checks are becoming everyday monitoring measures for the patient and their close environment. Both play a pivotal role in the relation with the illness they are living with.

In the case of users of the Control section for diabetes, there are more men (56%)

than women (44%), reversing the trend found on the platform where females are the clear majority (7 out of 10 registered members of People Who are women). Also, the average user of the data centre is younger (40 years old) than the general profile found in the community of the platform (46 years old). The use of monitoring and tracking tools seems to confirm the existence of a clear generational and gender-based digital divide in favour of groups of younger men (greater access by these groups).

In this chapter we will show some data collected in the field of diabetes monitoring in Spain, but first we shall review the context of diabetes in Europe.

User profile in diabetes, Europe

To contextualise the data in the illness we have chosen, it is necessary to know about the structure of the illness. The data below refers to the total of diabetes

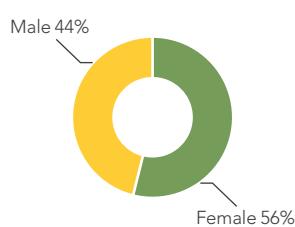
users in Europe, whilst subsequent data correspond to people in the diabetes community who monitor their illness in the Control section of Personas Que (diabetes in Spain).

Diabetes Europe

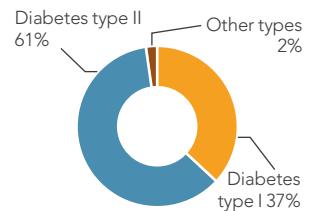
Average age: 50



Diabetes: Gender



Diabetes: Types



Diabetes: Relation with the illness



- 67% have diabetes
- 22% take care
- 11% interested

Diabetes: Interest in content



- 7% Diagnosis
- 25% Opinion
- 26% Treatment
- 34% Wellbeing
- 8% Experiences

User profile

Gender and type of diabetes, Spain

Of all registered users in diabetes in Spain, 12% use tools to monitor the illness. The profile of these people using the Control section is mostly male (56%).

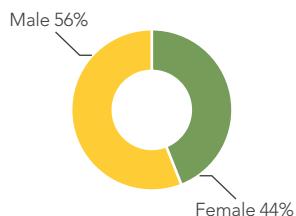
The data below only applies to people who actively use this section, not to the total number of users in diabetes.

Spain Diabetes Users of Control section

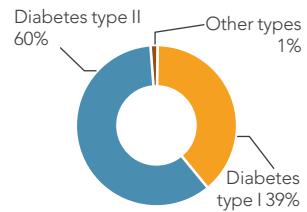
Average age: 47



Diabetes: Gender



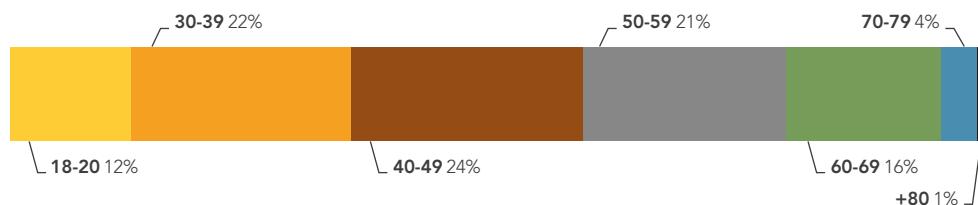
Diabetes: Types



Age, Spain

The age of the people using the Control section is quite varied if we look at the age ranges in decades. By age groups, 45% of the people who monitor diabetes are

between 40 and 59 years old. Although 80% of users are under 60, people aged between 60 and 69 years account for 16%, a high figure considering the digital divide that is common in over-60s.



Medication

It is extremely interesting from a medical point of view to see how the different diabetes treatments are distributed in the diabetes monitoring section.

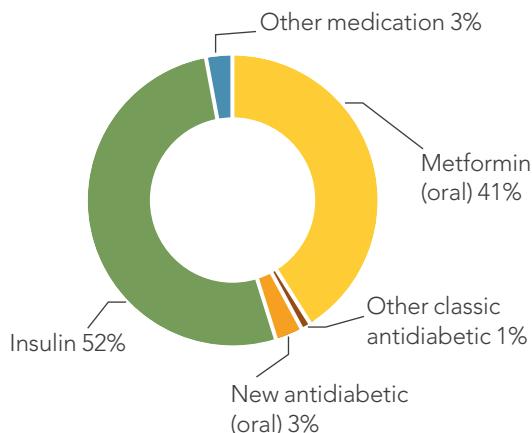
This allows us to analyse the role and importance among users of the different types of insulin, the importance of tried-and-tested oral medication or new oral antidiabetics that have appeared on the market in recent years.

This gives us a snapshot of what the treatments of the group are like at each point in time. For example, we can see how the new molecules are gradually gaining ground on the classic metformin. This certainly provides an opportunity when it comes to planning public information and training needs within the community or anticipating the future expectations of our e-patient.

Drug database used, Spain: Vademeum.

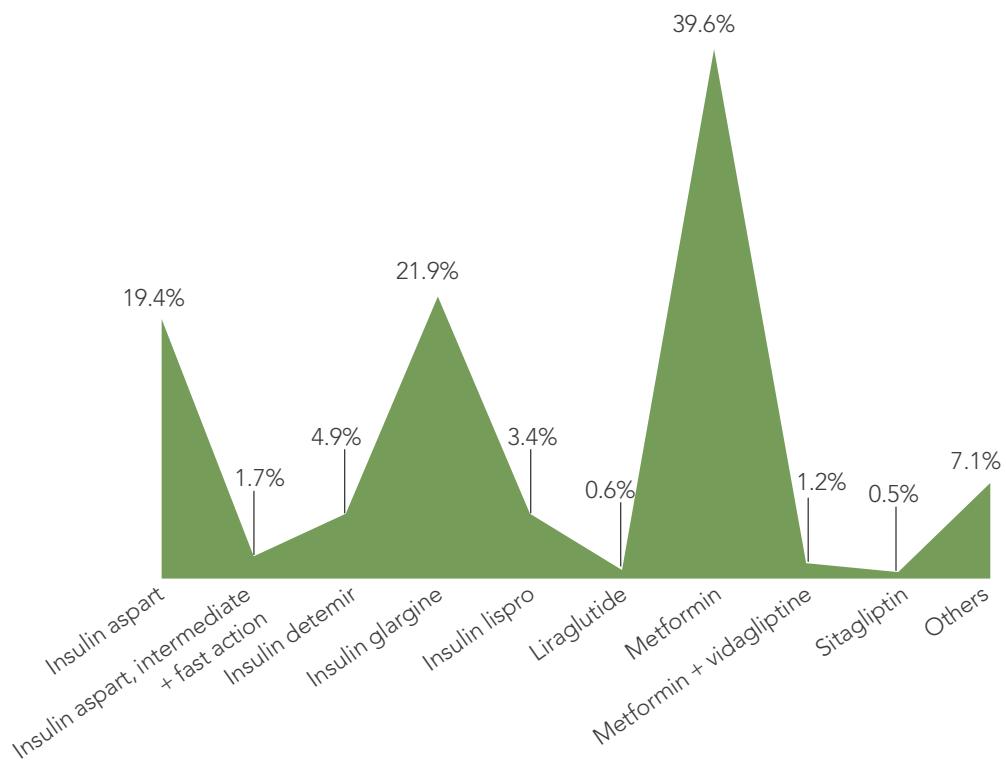
Spain Diabetes

Distribution by type of medication



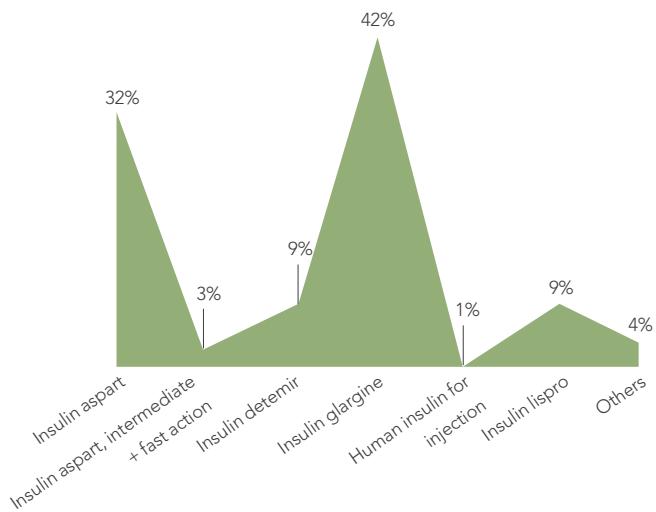
Distribution of medication (insulins + oral antidiabetics): Diabetes, Spain

The 12 most common drugs taken by Personas Que diabetes users (Spain). Frequency of drugs registered by diabetes users in the Control section. Bear in mind that one person can take more than one drug as part of a treatment.



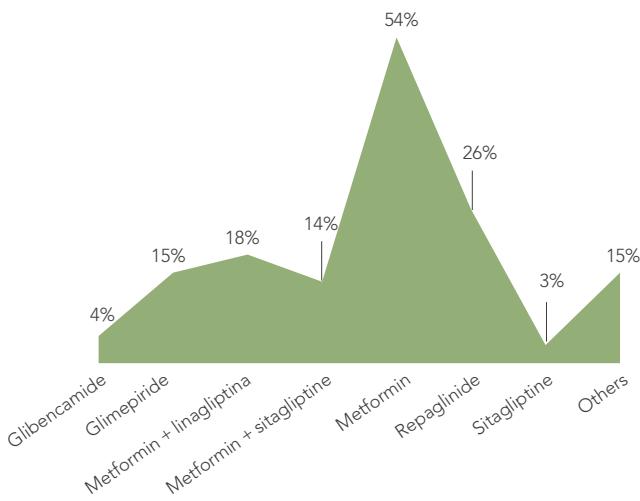
Diabetes, Spain: Insulins

Use of insulin types as registered by diabetes users in the Control section.



Diabetes, Spain: Oral antidiabetics

Frequency of oral antidiabetics registered by diabetes users in the Control section.



Exercise

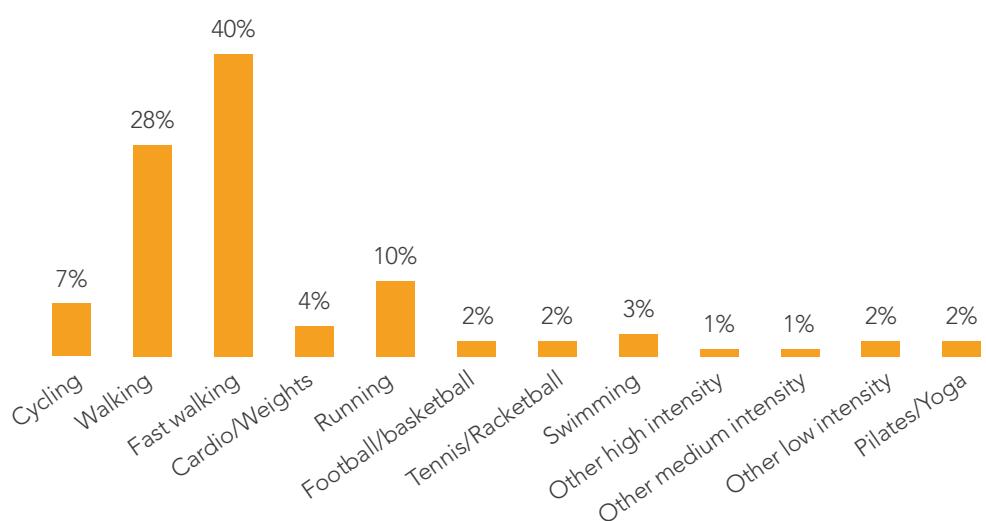
Distribution by type of exercise: Diabetes, Spain

As for the exercise that users do, walking and running (at different intensities) are the activities to which people monitoring their physical activity in the Control section devote most of their time (78%). Cycling also seems to be a relatively

common choice among users (7%), as is cardio exercise (aerobics, workouts, etc.) and other typical gym-based activities such as lifting weights (4%). Swimming (3%), racket sports (2%) or team games such as football or basketball (2%) are, however, less popular choices.

Diabetes, Spain: Exercise

Frequency of types of exercise registered by diabetes users in the Control section.



Conclusions

The production of large amounts of data on health has not only attracted interest from organisations and specialised institutions (pharma industry, research institutes, hospitals, etc.), but has also attracted the attention of the patient, giving them the power to decide, understand and live better with the illness. Accessing and managing health-related information is a hallmark of patient empowerment. The change seems to be here to stay (52% increase in users of the monitoring tool in 2015).

Despite being a majority in the community, the go-to rate of the monitoring tool is lower among women than men. Broadening the use of these technological devices among groups with lower access rates is essential if we aim to achieve an equally-balanced society when it comes to patient empowerment.

9 Social media and content

We cannot ignore one of the scenarios in which illnesses are “shared”: social media. In our final chapter, we analyse country-by-country social media behaviour in terms of the interaction of followers (“Likes”, followers, comments, shares, etc.) and the content that works best on each network. To do this, we shall provide an example, by country, of posts from our magazine which have performed the best on the social network par excellence, Facebook.

Information, essential for e-patients

One of the essential characteristics of the empowered patient is that he or she is an informed patient, a patient who takes a pro-active role in the healthcare world, who engages and who chooses to take ownership in fighting for their well-being. This e-patient is actively involved throughout the process of their illness and wants to know the experiences of other people in the same situation. Online spaces and communities can help them to take possession of that leading role, giving them a place to share information and generate knowledge.

Meanwhile, the fusion between healthcare and the internet makes it easier to create links between people who share a particular illness, which in turn satisfies the e-patient's need to support and be supported by others

going through similar circumstances. However, general social networks do not offer the privacy or the reliability that healthcare demands. And although major social networks like Facebook have many more users, communities specifically designed for illness and patients, offering anonymity and reliability, are beginning to take hold.

This chapter examines the behaviour of social networks and how posts with health-related content function in the different countries where People Who is present. In addition, we will give examples of some of the best-performing social media posts.



Purificación Salgado
Content Manager at
People Who Global

"Within the three years of life of Personas Que in Spain, 18 months of Menschen Die in Germany and Persone Che in Italy, 10 months of People Who in the UK and Les Gens Qui in France, content posted on corporate social networks has become one of the best ways of raising awareness about the platform and gaining new users. The following pages provide analysis of how contents vary in the various social media in those countries where People Who operates".

France

Les Gens Qui on social media

Bearing in mind that social media has managed to replace traditional media in a very short space of time, the aim of such platforms on which Les Gens Qui is present is to make it easier for patients to access information that may be of interest, as well as letting them know that there is a space which can help them better manage their illness.

On the social networks in which Les Gens Qui is present, the illnesses which create the most interaction are Alzheimer's and depression. When content related to these conditions is posted, it is common to see how followers are encouraged to share their experience, with most interactions involving solidarity and emotional support.

As for the most successful type of content, this involves any type of post on the occasion of a 'World Day' (on the whole, any article on a trending topic tends to get a large number of "Likes" and is shared by many followers). However, apart from these cases, the reality of the Les Gens Qui social networks is that they are home to relatively discreet users who reveal their preferences more through their "Likes" than through their comments.

Meanwhile, given that 85% of Facebook fans of Les Gens Qui are women, the most active user profile not surprisingly is that of a woman aged around 45. It could be said that the use of social media in France by Les Gens Qui is mostly limited to communication efforts. Therefore, whenever the country community manager detects a user with a need which they believe could be addressed by using the platform, he or she tells them how to sign up, explaining that on Les Gens Qui they will find services that can really help them to improve their health.

Most popular: Diabetes, "The relationship between diabetes and hypertension"

Diabetes is an illness that affects a large proportion of the population in France and is a real health problem in the country. Therefore, it is not surprising that an article dealing with one of the most common complications associated with this illness is the most popular on the Les Gens Qui social networks. The viral nature of this type of content highlights the important role of social media in creating greater awareness about the illness.



Relation entre diabète et hypertension



Quels sont les symptômes de l'hypertension ? Comment la contrôler ? Quelle influence a l'hypertension sur le diabète ?

5 Octobre 2015. Diabète, Diagnostic

Vivre avec le diabète est possible, mais ce que nous souhaitons tous, c'est vivre bien, sans trop de problèmes, ni de préoccupations. Il est donc important de contrôler sa glycémie pour éviter les maladies associées au diabète qui peuvent occasionner de séries complications. L'une des plus courantes et qui n'est pas à prendre à la légère, c'est l'hypertension. L'hypertension est l'augmentation de la force avec laquelle le sang circule dans les artères. Elle affecte le cerveau, le cœur, les poumons, les reins et les yeux. Mais savez-vous qu'elle est le lien entre diabète et hypertension ? Savez-vous comment l'hypertension influe sur votre état de santé général ? Cet article vous en dit plus afin que vous mettiez toutes les chances de votre côté d'avoir un futur en pleine santé.

Qu'est-ce qui provoque l'hypertension ?

Le diabète est un des facteurs déclenchant de l'hypertension. Si vous avez du diabète, vous avez donc plus de risques de souffrir d'hypertension mais il existe bien d'autres facteurs qui influent sur une pression élevée :

- **l'héritage génétique.** Dans le cas de la pression artérielle, il existe une relation directe entre la présence d'une tension élevée chez les membres au premier degré d'une famille, et un développement ultérieur de niveaux de tension artérielle au-dessus de la normale.
- **l'obésité.** C'est pour cela qu'il est aussi important de combattre le sédentarisme et de pratiquer une activité physique régulière, cela vous permet de perdre ces kilos en trop et d'éviter l'hypertension.
- une **alimentation** peu équilibrée. Un régime alimentaire peu sain, riche en sel et en graisses saturées n'est pas le meilleur allié de notre santé.
- le **tabagisme.** Le tabac augmente considérablement les dommages provoqués sur les vaisseaux. Une raison de plus pour arrêter de fumer !
- la consommation d'**alcool**. Ce qui est mauvais pour la santé, c'est l'excès, une consommation journalière supérieure à 40 grammes d'alcool peut provoquer une augmentation de votre pression artérielle
- la nervosité ou le **stress**. Bien plus souvent que ce qu'on ne croit, le stress est l'élément déclencheur de l'hypertension.

Quels sont les symptômes de l'hypertension ?

Les Gens Qui
18 octobre 2015

#DIABÈTE

Diabète et #hypertension vont souvent de pair. Vous voulez éviter cette complication ? Apprenez à repérer les symptômes et à la contrôler. Retrouvez tout ce qu'il faut savoir sur le diabète dans notre Magazine. Abonnez-vous gratuitement !

Relation entre diabète et hypertension

Vivre avec le diabète est possible, mais ce que nous souhaitons tous, c'est vivre bien, sans trop de problèmes, ni de préoccupations. Il est donc important de contrôler sa glycémie pour éviter...

LEGENSQUI.FR

33 335 personnes atteintes

J'aime Commenter Partager

Username 1, Username 3, Username 3 et 503 autres personnes aiment ça.

324 partages 33 commentaires

Germany

Menschen Die on social media

Although the Menschen Die uses social media to disseminate information and to publicise the existence of the platform itself, they also actually play a role in linking together people with the same illness. In Germany, greater interaction was detected with content in interview format and with articles offering different tips.

As for the most successful illnesses, depression leads the way, with content usually gaining a great deal of comments (mainly from people looking to motivate and support others who are not faring well).

The Menschen Die social media user profile corresponds to a woman between 35 and 55 years old. These are people who have been living with their illness for a long time and have no qualms in sharing their experience if they believe this can help other users.

Meanwhile, it should be noted that the social networks do not set out in any way to create debate. On the contrary, the aim is for people to share their experiences in the Menschen Die

community, which is why the interactions sought by the community manager are to inform followers about a space where they will find others in the same situation and where they can gain control of their illness, which obviously they cannot do in other open and more general social networks such as Facebook.

Most popular: Depression, "A story with depression"

As pointed out above, some of the most successful content on the Menschen Die social networks deals with depression, especially posts which do so from a personal point of view. In this sense, it is not surprising that this experience is one of the most popular Facebook posts. Given that mental illnesses are still a source of stigma and incomprehension, it is easy to understand that in an online environment this type of content garners so much feedback.



Es war mehr als nur Traurigkeit, es war Depression

07.Juli 2015. [Depression](#), [Erfahrungen](#)

Ich kenne die Depression bereits sehr gut, da meine Mutter daran litt. Ich erinnere mich noch aus meiner frühen Kindheit, dass meine Mutter sehr oft weinte und immer traurig war, es gab keinen Trost für sie. Für uns alle war das sehr frustrierend, weil wir nichts für sie tun konnten; alles schien nutzlos zu sein. Ich bin die Älteste von 9 Geschwistern, und wir waren eine sehr glückliche Familie, aber der Schatten meiner Mutter war immer da.

Bevor ich weiterschreibe möchte ich den Jüngeren erklären, wie es war, vor 40 Jahren mit dieser Krankheit zu leben, es ist nicht zu vergleichen mit dem, wie es heute ist. Heute weiß man, dass die Depression eine Krankheit ist, die man behandeln kann, und dass jemand, der sie hat, sehr wahrscheinlich ein Leben wie alle anderen führen kann, bei angemessener Behandlung. Früher war das nicht so, man glaubte, dass Menschen mit Depression einfach nur eine schlimme Zeit durchlebten, traurige Menschen waren... und dass sie die „Pflicht“ hatten, mit ihrer Traurigkeit leben zu lernen.

Auf diese Weise verbrachte meine Mutter fast ihr ganzes Leben: sie lernte, mit ihrer Traurigkeit zu leben, so gut sie konnte. Mit so vielen Kindern hatte sie immer viel zu tun, und wenn sie sich auch nie beklagte, habe ich immer vermutet, dass es zu viel für sie war. So vergingen die Jahre, bis meine Mutter anfing, krank zu werden. Immer häufiger blieb sie in ihrem Zimmer und zog sich allmählich von uns allen zurück. Sie verlor viel Gewicht, und man wusste nicht, was sie hatte. Wir machten uns große Sorgen. Mein Vater spielte eine Schlüsselrolle in all diesen Monaten, er liebte meine Mutter, und es schmerzte ihn sehr, sie in diesem Zustand zu sehen. Er bat einen befreundeten Arzt, sie zu Hause aufzusuchen, da sie nicht ins Krankenhaus gehen wollte. Gott sei Dank fand der es heraus: Meine Mutter hatte Depression, sie wurde körperlich krank auf Grund ihres psychischen und emotionalen Zustands.

Dieser Arzt, dem ich ewig dankbar sein werde, verschrieb meiner Mutter eine Behandlung – endlich, nachdem sie ihr Leben lang von einem Arzt zum anderen gegangen war, ohne eine klare Diagnose. Am Anfang weigerte sie sich, und es dauerte monatelang, aber sie verstand es allmählich, dass sie entweder die Medikamente nehmen muss oder den Rest ihres Lebens so traurig bleiben wird. Es dauerte lange, bis man irgendeine Veränderung merkte; am Anfang war die Kombination der Medikamente nicht optimal, und der Arzt entschloss die Medikamente mehrmals zu ändern. Allmählich aber ging es ihr besser, und nach einigen Monaten fing sie an auszugehen, zu kochen, mit ihren Enkeln zu spielen... Sie entschloss sich neue Hobbies wie das Nähen und Stricken auszuprobieren und schaffte es so die schlechten Gedanken aus ihrem Kopf zu bekommen.

 **Menschen Die**
9. Oktober 2015 

#DEPRESSION
"Es war mehr als nur Traurigkeit... Es war eine Depression"
Marta lebt mit Depression, genau wie ihre Mutter damals auch. Der einzige Unterschied ist, dass wir heute die Krankheit besser verstehen, und so gelernt haben, damit umzugehen. Depression kann heute mit einer richtigen Behandlung geheilt werden. Lesen Sie hier den Erfahrungsbericht von Marta.



Ein Erfahrungsbericht über Depression
Ich kenne die Depression bereits sehr gut, da meine Mutter daran litt. Ich erinnere mich noch aus meiner frühen Kindheit, dass meine Mutter sehr oft weinte und immer traurig war, es gab keinen Trost...
MENSCHENDIE.DE

50.310 erreichte Personen

 Gefällt mir  Kommentieren  Tellen

Username 1, Username 3, Username 3 und 254 anderen gefällt das.

88 Mal geteilt 7 Kommentare

Italy

Persone Che on social media

Italy is a good example of how patients today wish to play an increasingly important role in their relationship with the illness. Therefore, this country stands out as one of the most engaged in this new scenario for the field of health, with a wealth of spaces and communities welcoming people who share a common health condition.

The illness which gains the most interactions on Persone Che social media is Alzheimer's. As a result, it is common to find a large number of followers sharing their experiences on issues such as medication or everyday life with people affected by this illness. They are mostly carers, which also coincides with the profile of most active social media user: a 50-year-old woman who is caring for someone with a chronic condition or dementia.

In the case of Italy, it has been observed that the Persone Che social networks help create links between people who need help, resulting in deeper connections than those usually seen in this type of space.

However, considering that the platform that can really help improve the health of these people is Persone Che, the community manager always tries to divert social media users to the community, explaining that there they will find a place, control tools and other people in the same situation that will help them to cope better with their illness.

Most popular: Alzheimer's, "Why only her?"

If Alzheimer's is the illness with the content that creates the most interactions on the Persone Che social networks, success multiplies when this is also in an experience-based format. Given that the people connected to this disease as carers are really interested in tips that others in the same situation can give them, this type of content always secures a large number of visitors.



Perchè proprio a lei!

11 Giugno 2015. [Alzheimer. Esperienza](#)

Ho un dolore nel cuore: non aver capito che mamma si stava ammalando. Ci sono malattie la cui esistenza l'affronti quando invade la tua vita o quella dei tuoi cari. Non ne conoscevo l'esistenza... per questo la vivo come un tradimento! Ripenso alle volte in cui mamma scriveva le ricette di pietanze cucinate migliaia di volte: "Perchè... come si fanno??" e credevo le piacessero le nostre "versioni". Oppure quando su di un quadernetto scriveva: "Dove ho posato la chiave del cassetto...", "Il compleanno di è...." o, ancora: "I miei nonni si chiamavano...". Non sapevo! Ripenso a quella volta che uscì per andare in una cittadina distante da casa a fare la spesa e... lasciò la porta d'entrata completamente spalancata; la richiuse suo fratello, ma che disperazione per un'azione che non riusciva ad accettare. Perchè è successo a lei? Quanti sacrifici ha fatto! Quante rinunce per non farci mancare nulla! Ed ho un dolore immenso nel cuore e lacrime che rigano il mio volto. Mi ritrovo a pensare a lei, a parlare di lei come fosse ormai morta... io non esisto più nella sua quotidianità. E' atroce per una figlia vedere la propria madre piangere perché le manchi, essere là, dire: "Sono qui con te, vicino a te..." e non essere riconosciuta. Cantarle infinite volte le melodie di un tempo troppo lontano anche per la mia memoria e vederla confusa: lei che era un usignolo dalla voce melodiosa, intonatissima. Non aveva altro orgoglio che questo... e io canto... canto per lei canzoni senza tempo che non riesce più a ripetere: "Mamma son tanto felice perché ritorno da te... Mamma, solo per te la mia canzone vola..." Voi che vivete questo dramma mi potete capire! E dramma nel dramma... io sono terrorizzata dal pensiero che possa accadermi lo stesso: non riconoscere più mio marito, i miei figli... le persone che amo. Non riconoscere più il mio volto riflesso nello specchio: essere una sconosciuta a me stessa. Ho vissuto questa angoscia con la mia mamma. Se tutte le malattie sono angoscianti... questa è atroce. Ti isola, ti annienta, ti porta in una dimensione dove conservi tutto ma non hai più nulla. Alzheimer, se ti potessi materializzare saresti un orrido BUCO NERO in una galassia di stelle e di astri! TI ODIO.

[Diagnose, Psychologische Aspekte, Soziales, Beziehungen, Kinder, Eltern](#)

Personne Che
12 ottobre 2015

#ALZHEIMER
Gilda ha un grande dolore nel cuore: non aver capito che la sua mamma si stava ammalando. Da un giorno all'altro si è trovata ad affrontare la malattia di Alzheimer. Non ne conosceva quasi l'esistenza...! Leggi la sua storia e registrati al nostro Magazine.



Perchè proprio a lei!
Ho un dolore nel cuore: non aver capito che mamma si stava ammalando. Ci sono malattie la cui esistenza l'affronti quando invade la tua vita o quella dei tuoi cari. Non ne conoscevo l'esistenza...
PERSONECEHE.IT

82.983 persone raggiunte

Mi piace Commenta Condividi

Piace a Username 1, Username 3, Username 3 e altri 700.

323 condivisioni Commenti: 65

Spain

Personas Que on social media

The Spanish experience has shown that health-related social networks are the perfect setting for raising awareness. The natural and participative treatment of illnesses can prove to be of great benefit when it comes to increasing awareness about the illness and even to tackling stigma.

Depression, schizophrenia, Alzheimer's or arthritis are the illnesses that create the most interest among Personas Que social media users. Content dealing with scientific advances and new treatments in relation to any of these illnesses tends to receive the most interactions, often causing a flurry of comments in which users share their personal experiences (usually related to a particular treatment). In this sense, social media is valued as a completely open space where people can express themselves freely, and it is often observed that the comments in these spaces are more impulsive and spontaneous than those, for example, on the actual Personas Que platform. In the latter it is common to find longer and more thought-out comments than those found on any of the more general social networks.

The profile of the Personas Que social media user corresponds to a woman between 45 and 60 who is either living with arthritis or caring for someone with a chronic condition (typically diabetes) or a degenerative illness (Alzheimer's).

Most popular: HPV, "What is human papillomavirus?"

The success of content of this type shows that health-related social networks play a key role in disseminating information on illnesses, especially in relation to those that today are still a focus of ignorance. In the case of human papillomavirus, ignorance remains so great that people need to be informed via these platforms about what the illness actually entails.



¿Qué es el Virus del Papiloma Humano?

¿Qué es el virus del papiloma humano? ¿A quién afecta? Te explicamos todo aquí.

17 agosto. VPH, Diagnóstico

Conforman un grupo de más de 100 virus relacionados, de los cuales más de 40 pueden transmitirse muy fácilmente por contacto sexual directo (vaginal, anal y oral). También existen otros tipos de virus del papiloma humano que son responsables de verrugas no genitales y que no se transmiten sexualmente. En la actualidad, el virus del papiloma humano representa una de las enfermedades de transmisión sexual más comunes, algo que nos obliga a tomar conciencia de su existencia, a informarnos sobre los riesgos que entraña para nuestra salud, y a aprender a prevenirlo. De todo esto vamos a hablar en este artículo.

¿Qué tipos de VPH se transmiten sexualmente?

Concretamente son dos las categorías de virus que pueden transmitirse por contacto sexual:

- **Los VPH de bajo riesgo**, los cuales no causan cáncer pero pueden originar verrugas en la piel de los genitales, del ano, la boca o la garganta (técnicamente denominadas como condylomata acuminata). Son los tipos 6 y 11 de los VPH los que causan el 90% de las verrugas genitales, además de ser los responsables de la papilomatosis respiratoria recurrente, una enfermedad menos común en la que tumores benignos crecen en las vías respiratorias que van de la nariz y la boca a los pulmones.
- **Los VPH de alto riesgo**, que sí que pueden causar cáncer. Entre los VPH de alto riesgo, se han identificado cerca de una docena de tipos, de los cuales los tipos 16 y 18 son los responsables de la mayoría de cánceres de cuello de útero.

¿Qué síntomas presenta?

El virus del papiloma humano puede no manifestar ningún síntoma, y muchas veces, no llega a causar tampoco problemas de salud al ser eliminado por el sistema inmune. Sin embargo, cuando esta infección no se cura, y dependiendo del tipo de virus que la haya causado, pueden aparecer desde verrugas genitales hasta enfermedades graves, como diferentes tipos de cáncer.

Cuando aparecen verrugas genitales como producto de esta infección, estas suelen ser de diversos tamaños (planas o elevadas). Son lesiones que pueden desaparecer sin tratamiento, permanecer inalterables o crecer y multiplicarse.

Personas Que
19 de agosto de 2015

#VPH

Seguro que has oido hablar de él un montón de veces, y es que cada día parece afectar a más personas. Es el virus del papiloma humano, ¿sabes lo que es exactamente? Regístrate a nuestra Revista y ¡mantente informado!



Virus del papiloma humano, ¿qué es exactamente?
Conforman un grupo de más de 100 virus relacionados, de los cuales más de 40 pueden transmitirse muy fácilmente por contacto sexual directo (vaginal, anal y oral). También existen otros tipos de vi...
PERSONASQUE.ES

98 600 personas alcanzadas

Me gusta Comentar Compartir

Username 1, Username 3, Username 3 y a otras 483 personas les gusta esta publicación.

311 veces compartido Comentarios: 18

9 | Social media and content

87

United Kingdom

People Who on social media

People who have lived through certain aspects of an illness can help others with their experience, and this can also be done through social networks. In the case of the UK, spaces such as the People Who Facebook page bring together individuals who share the same condition, enabling the creation of a link between them which, although it is harder to achieve in more exclusive spaces such as the actual People Who platform, is by no means impossible. On the contrary, this country is a clear example of this happening.

The illness which creates the most interactions in the UK is arthritis, posts about which are usually very well received and generate a significant number of comments. In general, and surprisingly, these tend to have a more emotional and personal tone than on the platform itself, where interventions tend to show a more practical aspect.

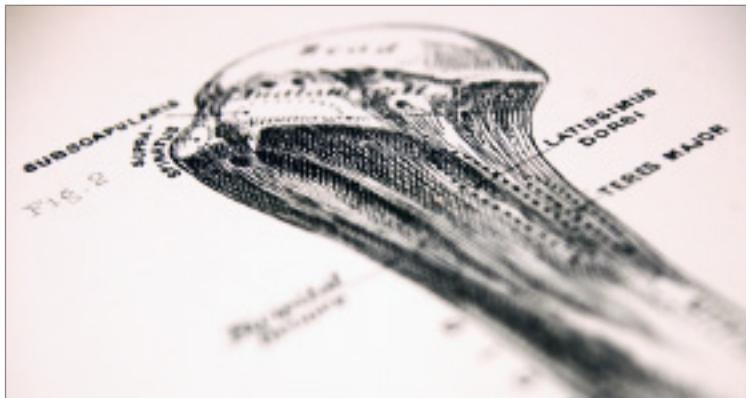
Despite this, and as in other cases, social networks function more as an awareness-raising tool than as an instrument for improving health. This is demonstrated by the fact that very often followers comment to corroborate

that, even though they know the information, they appreciate that it is being disseminated to help create greater awareness about the illness.

In order to show social media followers in the UK that there is a more exclusive space strictly made up of people in the same situation, the community manager is responsible for explaining the benefits obtained by signing up to the platform.

Most popular: Arthritis, "Types of arthritis beyond rheumatoid and osteoarthritis?"

In this case we have content purely for information purposes which, although not new, may be very useful for people recently diagnosed with any type of arthritis recognised today. Fulfilling the platform's role as a distributor and creator of awareness, People Who social media users have taken charge of sharing content, which has attracted a significant number of readers to the platform.



Types of arthritis beyond rheumatoid and osteoarthritis

Rheumatoid arthritis and osteoarthritis might be the most famous, but there are over 100 types of arthritis, from psoriatic to septic.

30 March 2015. [Arthritis](#), [Diagnosis](#)

When it comes to Arthritis, you almost certainly know about osteoarthritis, the most common form. You've probably also at least heard the name rheumatoid arthritis (and if you haven't, you should read our article 'Rheumatoid arthritis - an illness that affects more than just your joints'. But did you know that there are actually over 100 different forms of this illness? Given that they strike in different locations, for different amounts of time, and have different treatment options, it's important to inform ourselves as well as we can about the different forms. Here's a guide to some of these less well-known types of arthritis.

The universal characteristics

Before we get into the details of these forms, the question comes up: what, exactly, do they all have in common? Well, in reality, when we talk about arthritis we're not talking about a single condition. Instead, it's a range of different illnesses with different causes, symptoms and treatments. But what they all have in common is that they all involve inflammation of the joints: in fact, the name "arthritis" comes from the Greek "arthron", meaning joint, and the Latin "itis", signifying inflammation. The clue's in the name!

Now that we know this, it's time to take a look at some of the less famous forms of arthritis.

Psoriatic arthritis

Psoriatic arthritis is a form of the illness that generally affects people who live with psoriasis, a skin condition involving itchy skin lesions. Up to 30% of people living with psoriasis will develop psoriatic arthritis. Even though psoriasis can develop at any point in life, psoriatic arthritis generally only affects adults. It can affect any part of the body, but most typically causes problems in the elbows, back, knees, hands and feet. The treatment may involve NSAIDs, DMARDs, steroids or biologics.

Gout

Gout is a form of arthritis which frequently affects the big toe and other joints. In the past, Gout was famous as a "rich man's disease", associated with indulgent

 People Who UK
6 October 2015 

#ARTRITIS

Sadly, arthritis is an illness which is not well understood. We'd like to introduce you to some of the less well-known forms: spread the word, and let's build a society which lives better with arthritis. Want to keep up-to-date with our latest articles? Subscribe to our free Magazine.



Arthritis beyond rheumatoid and osteoarthritis

When it comes to Arthritis, you almost certainly know about osteoarthritis, the most common form. You've probably also at least heard the name rheumatoid arthritis (and if you haven't, you should ...)

PEOPLEWHO.CO.UK

38,915 people reached

 Like  Comment  Share

Username 1, Username 3, Username 3 and 467 other people like this post.

228 Shares 41 Comments

Conclusions

To understand the information above, it is necessary to know the context of People Who platforms in different countries, some just a few months old and others with several years of experience: 3 years online in Spain, 18 months online in Germany and Italy, 10 months online in UK and France.

Data from all 5 People Who countries in Europe collected in 2015 shows that content posted on Facebook has reached almost 20 million people (19,456,500 people reached), has been shared around 150,000 times and has generated over 18,000 comments on this social network.

Undoubtedly, social media not only functions as a forum for the exchange of information and the creation of shared knowledge, but also as a way of fostering the engagement and empowerment of the patient in their search for well-being. Active participation in health is no longer the exclusive preserve of the doctor's surgery; it is now online and in our daily lives. The empowered patient, as we have shown, is here to stay.

10 Scope and methodology

Country

France: www.lesgensqui.fr
Germany: www.menschendie.de
Italy: www.personeche.it
Spain: www.personasque.es
United Kingdom: www.peoplewho.co.uk

Illnesses

Allergies, Alzheimer's, arthritis, atrial fibrillation, bipolar disorder, coeliac disease, depression, diabetes, epilepsy, hepatitis, HIV, HPV, infertility, acute leukaemia, chronic leukaemia, obesity, ovarian cancer, psoriasis, schizophrenia, skin cancer and transplants.

Type of study

Annual report

Publication date

April 2016

Field study period

12 months

January 2015 – December 2015

Subject/Group analysed

Users of People Who European platforms (profiles, interests, motivations and positions).

Context details

Pages visited/month, Oct 2015: 316,200
Unique users/months, Oct 2015: 192,041
Registered users, Dec 2015: 31,323
Facebook followers, Dec 2015: 201,112

Methodology

We are presenting a case study on e-patient communities in five European countries (France, Germany, Italy, Spain and the UK). Thanks to a methodology combining qualitative and quantitative tools and techniques (triangulation of methods), a comparative analysis was performed to explore the profiles, behaviour and main interests of platform users. The users can sign up to one or more of the illnesses that we cover online. The time during which one illness has been active differs from others and between countries.

Data and scientific methodology

All the data used in the study comes from internal sources and therefore the conclusions are restricted to the sample group of users registered on the platform (People Who internal databases). All the authors included in the document have signed the company's ethical code of conduct, committing to values such as transparency, anonymity and independence. In addition, study authors include doctors whose ethical code obliges them to follow best practices of scientific methodology.

Quantitative methods

Data mining of the internal database combined with data on traffic, social media profiles and user browsing habits.

Qualitative methods

Textual analysis of users' social interactions (comments, questions, groups, etc.)

N= Users of People Who Global platforms. n= 31,323 registered users.

Please note that the aforementioned data refers to users registered on our five European platforms. This analysis includes all registered users, so the sample size (n=31,323) refers to the entire group (N). As for statistical representation, all the data refers to e-patients registered on People Who, in other words, it is not possible to transfer this data to other communities or other populations.

People Who

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

The e-patient observatory sets out to study the e-patient in depth and to provide this knowledge to all companies and institutions that advocate a society in which life with an illness should be better.

Anonymity

No names or surnames: At People Who the user will never be asked to provide personal data such as their name or surname. We act as a virtual profile and we recommend that no personal data

such as real names or email addresses are posted in the community. To contact other users in private, the private message feature can be used.

No photos of people: We want to make sure that user privacy is always protected. For this reason, the use of a facial photo as a profile picture is forbidden and we offer a selection of avatars (images).

No brand names of drugs

Health is a delicate matter and the prescribing drugs is the job of doctors in their surgeries. We want to avoid inappropriate prescriptions or business transactions. If users post brand names of drugs, they will be replaced by their active substance.

No medical consultations

People Who is an online platform dedicated to the everyday life of the patient. It sets out to complement the doctor's work in the surgery, never to replace it. The People Who doctors that interact on the platform do so in a monitoring and community support role. Under no circumstances are medical consultations given on People Who.

European e-Patient Report

This is our 2015 European e-Patient Report in which we have compiled all the data about comments, interactions, interests, habits and needs of the users registered on our platform. It is a comprehensive study which gives us in-depth knowledge about e-patient profiles on a European level, with data from Spain, France, the UK, Germany and Italy, that we will carry out and share on an annual basis.

11 Glossary of terms

Digital divide

Inequality of access to information and communication technologies (ICT) because of gender, age or other significant variables.

E-patient: At the end of the 70s, before the internet changed our society, Dr Ferguson coined the term "e-patient", inviting all patients to involve themselves in their treatment. The "e" refers to 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.
- engaged in their own care.

Collective imaginary

Set of cultural beliefs, customs, values and symbols that operates like a collective social mind, influencing individuals' actions and motivations.

Social interaction

All the social exchanges between people and/or groups that involve a reciprocal social influence.

Goal-oriented actions

Interactions oriented at targets or practical goals that are neither social nor emotional.

Sample

Subset of elements in a population or universe. Normally the aim is to make the sample representative of the universe to which it belongs.

Phi coefficient

A measure of the degree of association between two binary variables (such as gender or the condition of being a carer). If p-value is less than 0.05 it means there is a statistically significant association between two variables.

Representativeness

The capacity to reproduce on a small scale the characteristics of the population being studied.

Segmentation

Division of a set into smaller groups with similar characteristics (intragroup uniformity).

Universe

Set of elements that comprise the population being studied.

Visibility

Bring to light or make visible a social reality or issue.

People Who is an online platform dedicated to the everyday lives of people who live with an illness. A place for patients, carers and healthcare organisations. Together, we want to build a society which lives a little better with illness.

People Who in Europe:

www.lesgensqui.fr

www.menschendie.de

www.peoplewho.co.uk

www.personasque.es

www.personeche.it

Information about the product:

www.peoplewho.com

Information about the company:

www.peoplewhoglobal.com

Do you want to talk with us?

Do you want to work with us?

hello@peoplewhoglobal.com



PEOPLE WHO

live with an illness