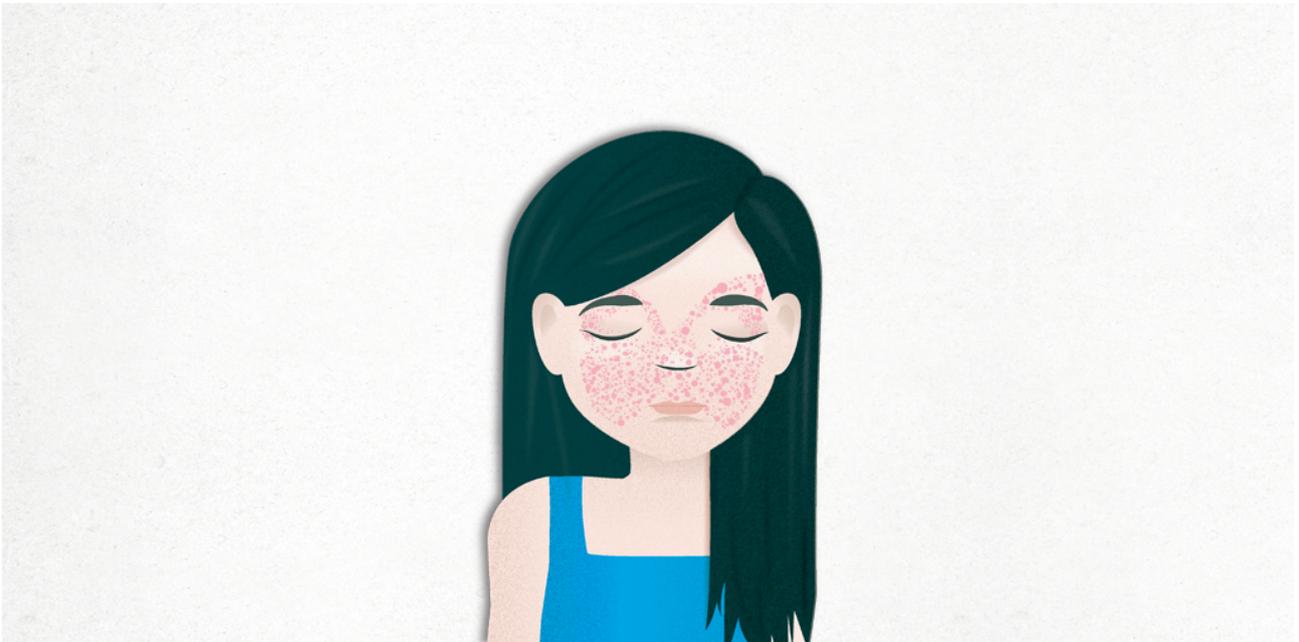


A RESEARCH ON THE IMPLICATIONS OF  
LIVING IN THE UK OR SPAIN AND SUFFERING  
FROM LUPUS DISEASE



## ACKNOWLEDGMENTS

This research project is not just the outcome of my effort and motivation, but also of the guidance and assistance provided by many people, professionally and personally. This is why I would like to take a minute to thank them all.

To begin with, I would like to thank “Fundació Catalunya - La Pedrera”, who gave me the opportunity to be part of the course “Bojos per la Medicina”. Thanks to this course I met Dr. Ricard Cervera, internist and Head of Autoimmune Diseases Department at Hospital Clínic de Barcelona. Dr. Cervera was the first person who talked to me about lupus, and he has been helping with any doubt I have had throughout the making of this project. He also helped me get in touch with Prof. David d’Cruz, rheumatologist and clinical team lead for the Louise Coote Lupus Unit. So I must thank Dr. Cervera for everything.

Prof. d’Cruz has been a participant in one of my interviews, so I want to express my gratitude for being so kind and predisposed to help.

I would also like to thank Pilar Lucas, founder and CEO of “Associació Catalana de Lupus E.G.”, and Chanpreet Walia, Social Media & Projects Officer from Lupus UK. They have both helped me become more familiar with lupus and they shared the polls I had prepared, which are basic for my project, on their social media so that they could be answered by as many people as possible. They also answered an interview each and have guided me all the way.

Succeeding, I want to thank all patients and family members who have answered my interviews and responded my polls. Without them, this project would have not been possible.

Furthermore, I want to thank \_\_\_\_\_ my tutor. In spite of this not being her field of expertise, she has done everything she could and more to guide and assist me at all times. It is undeniable that, without her, this project would not have been the same.

Last but not least, I would like to thank my mum, my dad, my sister and my brother for supporting me whenever I need it and for always being there for me.

To all of these people, thank you very much.

## RESUM

En aquest Treball de Recerca es comparen els aspectes mèdics, humans i socials del lupus, una malaltia autoimmunitària sistèmica, en dos països europeus: Espanya i Regne Unit. Per tal de fer-ho possible s'han realitzat enquestes i entrevistes a pacients de lupus i familiars de pacients, així com també a metges especialistes en la malaltia i a membres de les juntes de les associacions de malalts de lupus.

Les dades obtingudes en aquestes enquestes s'han analitzat a partir de gràfics de barres comparatius entre els dos països. Una de les conclusions més rellevants ha estat que els pacients de lupus residents a Espanya són més propensos a patir afectacions renals com a conseqüència de la malaltia. També s'ha posat de manifest que els pacients britànics pateixen un nombre més elevat de brots i, per tant, prenen més medicació immunosupressora. Així mateix, tot i patir més efectes secundaris, els pacients britànics tenen una adherència al tractament més elevada. Els especialistes entrevistats, creuen però, que el futur del lupus va encaminat cap als tractaments biològics.

D'altra banda, ha quedat reconeguda, en les entrevistes a membres de les juntes de les associacions, la tasca immensa que realitzen aquestes, donant a conèixer la malaltia a la població així com donant suport als malalts i familiars.

A nivell personal, aquest treball m'ha ajudat a reafirmar-me en la meua vocació, les ciències de la salut. Altrament, gràcies a aquest treball he pogut aprofundir en la malaltia del lupus, tant a nivell mèdic com humà.

## RESUMEN

En este trabajo de investigación se comparan los aspectos médicos, humanos y sociales del lupus, una enfermedad autoinmune sistémica, en dos países europeos: España y Reino Unido. Para hacerlo posible se han realizado encuestas y entrevistas a pacientes de lupus y familiares de pacientes, así como también a médicos especialistas en la enfermedad y miembros de las juntas de las asociaciones de enfermos de lupus.

Los datos obtenidos en estas encuestas se han analizado a partir de gráficos de barras comparativos entre los dos estados. Una de las conclusiones más relevantes ha sido que los pacientes de lupus residentes en España son más propensos a sufrir afectaciones renales como consecuencia de la enfermedad. También se ha puesto de manifiesto que los pacientes británicos sufren un mayor número de brotes y, por lo tanto, toman más medicación inmunosupresora. Asimismo, a pesar de sufrir más efectos secundarios, los pacientes británicos tienen una adherencia al tratamiento más elevada. Los especialistas entrevistados, creen, sin embargo, que el futuro del lupus va encaminado hacia los tratamientos biológicos.

Por otra parte, ha quedado reconocida, en las entrevistas a miembros de las juntas de asociaciones, la tarea inmensa que realizan estas, dando a conocer la enfermedad a la población así como apoyando a los enfermos y familiares.

A nivel personal, este trabajo me ha ayudado a reafirmarme en mi vocación, las ciencias de la salud. Además, gracias a este trabajo he podido profundizar en la enfermedad del lupus, tanto a nivel médico como humano.

## **INDEX**

1. INTRODUCTION	1
2. THE IMMUNE SYSTEM	4
2. 1. IMMUNITY CELLS	4
2. 2. IMMUNE SYSTEM'S BRANCHES	7
3. AUTOIMMUNE DISEASES	9
3. 1. WHO GETS AUTOIMMUNE DISEASES	9
3. 2. CLASSIFICATION	9
3. 3. DIAGNOSTIC PROCESS	10
3. 4. TREATMENT	10
4. LUPUS	11
4. 1. TYPES OF LUPUS	11
4. 2. CAUSES	12
4. 3. SYMPTOMS	12
4. 4. DIAGNOSIS	14
4. 5. TREATMENT	15
5. METHODOLOGY	17
5. 1. POLLING METHODOLOGY	17
5. 1. 1. PATIENTS' POLL STRUCTURE	19
5. 1. 2. FAMILY MEMBERS TO LUPUS PATIENTS' POLL STRUCTURE	19
5. 2. INTERVIEWING METHODOLOGY	20
6. DATA ANALYSIS	21
6. 1. PATIENTS' POLL	21

6. 1. 1. SECTION 1: GENERAL QUESTIONS	21
6. 1. 2. SECTION 2: SYMPTOMS	22
6. 1. 3. SECTION 3: DIAGNOSTIC PROCESS	23
6. 1. 4. SECTION 4: TREATMENT	24
6. 1. 5. SECTION 5: FACTORS THAT MAY LEAD TO SUFFER FROM LUPUS	27
6. 1. 6. SECTION 6: ABOUT LUPUS	28
6. 1. 7. SECTION 7: LIFESTYLE	29
6. 2. FAMILY MEMBERS TO LUPUS PATIENTS' POLL	30
6. 2. 1. SECTION 1: GENERAL QUESTIONS	30
6. 2. 2. SECTION 2: QUESTIONS FOR FAMILY MEMBERS WHO ALREADY LIVED WITH THE PATIENT BEFORE HE/SHE WAS DIAGNOSED	31
6. 2. 3. SECTION 3: QUESTIONS FOR ALL FAMILY MEMBERS	33
7. INTERVIEWS	35
7. 1. INTERVIEW TO LUPUS CHARITIES STAFF MEMBERS	35
7. 2. INTERVIEW TO LUPUS SPECIALISTS	36
8. CONCLUSIONS	37
9. BIBLIOGRAPHY AND WEBLIOGRAPHY	41
9. 1. BIBLIOGRAPHY	41
9. 2. WEBLIOGRAPHY	41
ANNEXES	

## 1. INTRODUCTION

When I started thinking about a topic to do this research project about, there was only one idea that I had very clear in my mind: it was going to be related to health. For as long as I can remember, I have felt very curious about diseases and illnesses. As a young child, I used to enjoy watching TV shows about medicine that my mother, who is a pharmacist, watched. She has often explained to me how, while watching the shows, I would constantly ask her a lot of questions about every disease mentioned.

Another anecdote related to my interest in conditions since being a child is that I have a very clear memory of the first day I heard about ebola. I just started asking myself a lot of questions. I wanted to understand how such a small virus could get into the body, what it did once inside and, most importantly, why it was so hard to cure. It is also very peculiar how I remember very well this feeling of wanting to know more and more about diseases and illnesses. Maybe it is because I still have this feeling nowadays.

Currently, at the age of 15, I can spend endless hours surfing the Internet or reading books learning about all types of conditions, and I am also convinced that, next year, I want to study a health science degree.

Last year, I was selected for “Bojos per la Medicina”, which is a course that gives the opportunity to a total of 25 students from Catalonia who are studying “Batxillerat” to spend 16 Saturday mornings at Hospital Clínic de Barcelona learning about medicine. It is organised by “Fundació Catalunya - La Pedrera”. Thanks to this course I met Dr. Ricard Cervera, internist and Head of Autoimmune Diseases Department at Hospital Clínic de Barcelona. In our first conversation, he explained to me he was specialised in a disease I had never heard about before: lupus. He briefly described autoimmune diseases and lupus, and managed to convey me his interest in them. So, after just one conversation with him, I knew what my research project was going to be about: autoimmune diseases. I have been in contact with Dr. Cervera since the day we met, and he has helped me with any doubt I had for the making of this project, specially when it came to more medical related aspects.

A few weeks after having met Dr. Cervera, I came up with the topic for this research project; I was going to compare how differently a disease like lupus could affect patients from two countries like Spain and the UK. The idea of comparing these two countries came to my mind after a visit to my brother, who is studying in London. Succeeding this visit I asked myself to what extent the same disease could affect distinctly there compared to Spain. Initially, I thought that an autoimmune disease like lupus would not affect any differently in two countries which are geographically close and similar in terms of the economic development. Nevertheless, I still wanted to discover whether this idea was accurate, as these two countries have a very different “modus vivendi” and health system.

This was the project's main aim: to compare the medical, social and human sides of lupus disease between Spain and the UK.

My other main goals for this project were to learn as much as possible about autoimmune diseases and lupus, to understand how research projects are done, and, the most important one, to enjoy the opportunity to profoundly learn about a disease, which passionates me.

When I had finally decided what my research project was going to be about, I contacted Pilar Lucas, who is the founder and CEO of "Associació Catalana de Lupus E.G. (ACLEG)". In our first call, I explained everything about my idea for this research project, and she informed me about what they did as a charity and helped me become even more familiar with lupus. Since then, she has been fundamental to make this project a reality.

At this point, I had decided what my project would be about and I had become familiar with the topic, so I had to start acquiring more knowledge about lupus and autoimmune diseases. In order to do so, I read some books related to autoimmune diseases and lupus and I visited various websites. To assure the websites were reliable I consulted the author, the organisation in charge of the rights and the last update.

Once I considered I had enough knowledge I started creating polls and interviews that I would use as the basis of the project. I decided to create polls for lupus patients and for family members to lupus patients, and interviews to female and male lupus patients, family members to lupus patients, lupus charities staff members and lupus specialists. All the polls and interviews would be done identically twice, as they had to be answered both in Spain and in the UK. I decided to design these polls and interviews because they would help me know about not only the medical side of lupus but also about its social and human sides, which I think are extremely relevant in diseases. While making them, I got in touch with Lupus UK, a lupus charity based in the UK. I emailed the CEO explaining my project and asking him whether they would be able to help me find contacts of people who would answer my polls and interviews. In order for them to be able to help me, my research project had to firstly undergo an ethical approval process. I also had to send him an explanation of how the responders' data would be used, all the questions I would ask and the responders' "right to withdraw". This procedure really surprised me, as nothing similar had to be done in Spain. After all those documents were sent I could finally send him the links to the polls. I also sent them to Pilar Lucas, but I sent her the link to the polls in Spanish and the links to the polls in English to Lupus UK's CEO. Then, both charities shared those links in their social media so all their followers could answer them.

Referring to the interviews, I had initially planned to do all of them face-to-face. However, it was not possible in all the cases due to Covid-19. This meant that I had to find another way of interviewing, and so I

did. Finally, interviews were done via email, phone-call, video phone-call, Instagram Live or, in two occasions, face-to-face. I could contact all the interviewed, with the exception of the specialists, thanks to Pilar Lucas, founder and CEO of “ACLEG”, and Chanpreet Walia, Social Media & Projects Officer from Lupus UK.

Dr. Cervera answered the interview prepared for a Spanish specialist and also sent me Prof. David d’Cruz’s contact, who is the specialist from the UK and who answered the interview I had prepared for a British specialist.

By the time the polls and interviews had been responded, I had to analyse the data obtained. In order to analyse the polls I had to convert the answers into an Excel spreadsheet, and after it was done I could create dynamic comparative graphics. I also had to translate all the Spanish data into English.

Thanks to the interviews to patients and family members I could hear personal stories that really helped me understand the disease’s human side. The interviews to lupus charities staff members helped me understand the social side of lupus and the importance of support for people who suffer from such an unknown illness. The interviews to lupus specialists permitted me discover what research is being done and what the future of lupus might be.

As it happened with the polls, half of these interviews were in Spanish, so I had to translate them into English.

After all the polls’ data was converted into graphics and the interviews had been transcribed, I had to start interpreting the results and reaching conclusions.

This research project is titled: “A research on the implications of living in the UK or Spain and suffering from lupus disease”. I chose this title because I think it describes clearly and briefly what this research project is about. I wanted this project to have a title that expressed its objectivity, so I did not want to give it a title with multiple interpretations. After thinking about it for a few weeks, I came up with this title, and I am very pleased with it.

In this memory I explain the immune system, which is needed to understand autoimmune diseases and lupus. Then I explain the methodology of the making of this project and, succeeding, the data obtained from the polls is analysed in graphics. Subsequently the most relevant interviews are commented. Finally, there is the conclusions part, where I remark the most significant conclusions I have reached and I also evaluate my experience throughout the making of “A research on the implications of living in the UK or Spain and suffering from lupus disease”.

## 2. THE IMMUNE SYSTEM

The immune system's function is to protect the body from invaders such as viruses, bacteria, parasites or cancer cells. So, it means it is our main protection against infections, illnesses and diseases.<sup>1</sup> This system is a vast network of cells, tissues, organs and molecules that is constantly on the lookout for invaders, and once a pathogen<sup>2</sup> is spotted, a complex attack takes place, also called immune response.<sup>3</sup> The immune system also has the ability to memorise, which implies it can respond more rapidly and effectively to pathogens that have previously been encountered. So that, the immune system is able to, first, identify a threat, then, mount an attack and eliminate the pathogen, and finally, remember the offender.

### 2. 1. IMMUNITY CELLS

The main characters in the immune system are the following:

- White blood cells: also called leukocytes. Hematopoiesis is the process of forming white blood cells, as well as red blood cells and platelets. Hematopoiesis starts with a multipotent hematopoietic stem cell which can develop into various cell types — its future is undecided. White blood cells are constantly looking for pathogens and, when they find one, they begin to multiply and send signals out to other cell types. There are between 4.000 and 11.000 leukocytes in every microlitre of blood.<sup>4</sup>

Our white blood cells are stored in different places in the body, which are referred to as lymphoid organs. These include the thymus, spleen, bone marrow, lymph nodes, adenoids, tonsils and Peyer's patches.<sup>4</sup> (*see ANNEX I, 1. 1. where a drawing and explanation of these organs appears*)

We can classify leukocytes into:

- Myeloid progenitor cells: they are all part of the innate immune response and can be found in the blood as well as in the tissues. We can identify the following:

- Granulocytes: group of cells with dense granules (which contain proteins) in their cytoplasm.

Granulocytes include these different types of cells:

- Neutrophils: during the immune response the bone marrow produces mainly neutrophils. Neutrophils use a process called phagocytosis. Phagocytosis is when they arrive close to a pathogen and surround it with their cytoplasm to "swallow" it whole, so that it ends up in a phagosome. This phagosome proceeds to fuse with a lysosome, becoming a "phagolysosome".

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/>

<sup>2</sup> Biological agent that can cause disease.

<sup>3</sup> <https://www.medicalnewstoday.com/>

<sup>4</sup> <https://www.hopkinsmedicine.org/>

Then the phagolysosome lowers the pH to break its contents down and once the contents have been neutralised, the phagolysosome forms a residual body that contains waste products from the phagolysosome. This process ends up killing the neutrophil, but each neutrophil takes out a lot of pathogens with it.

- Eosinophils: they are also phagocytic<sup>5</sup> and they are best known for fighting large and unwieldy parasites, because eosinophils are much larger than neutrophils and have receptors that are specific for parasites.<sup>6</sup>
- Basophils: these cells are also much less common than neutrophils and they are not phagocytic. They are most commonly produced in response to infections caused by parasites.<sup>7</sup>
- Mast cells: non-phagocytic cells which are involved in asthma and allergic responses. However, they also play an important defensive role, being intimately involved in wound healing, angiogenesis, immune tolerance, defence against pathogens, and vascular permeability in brain tumours. As with the other leukocytes we have seen, mast cells originate in the bone marrow.
- Monocytes: phagocytes found in the bloodstream. They circulate around the body, and when a tissue is infected or inflamed they may leave the bloodstream and enter the tissue. Once they enter the tissue they become macrophages or dendritic cells. Monocytes are the largest type of phagocyte, with a kidney-bean-shaped nucleus.
- Macrophages: leukocytes formed in response to an infection or to an accumulation of damaged or dead cells. They derive from monocytes and they are found in the tissue. Macrophages are large, specialised cells that recognise, engulf and destroy target cells. In addition, they can also present antigens<sup>8</sup> to T cells and initiate inflammation by releasing molecules (known as cytokines) that activate other cells.
- Dendritic cells: antigen-presenting cells that form an important role in the adaptive immune system. Dendritic cells can be found in the lymph, blood and tissue. When dendritic cells are young and immature, they are excellent at phagocytosis, constantly eating large amounts of proteins found in

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<sup>5</sup> undergoes phagocytosis

<sup>6</sup> <https://medlineplus.gov/>

<sup>7</sup> <https://www.verywellhealth.com/>

<sup>8</sup> Any foreign substance to the body that evokes an immune response.

the interstitial fluid<sup>9</sup>. However, mature dendritic cells will destroy the pathogen and divide its proteins into short amino acid chains. Dendritic cells then move through the lymph to the nearest lymph node and they perform an antigen presentation, which is where they present those amino acid chains, which are antigens to T cells.

Now, only T cells with a receptor that can bind to the specific shape of the antigen will be activated. However, T-cells can only see their antigen if it is presented to them on a silver platter, and on a molecular level that platter is the Major Histocompatibility complex or MHC for short. So, the antigen presenting cell will load the antigen onto an MHC molecule and display it to T cells, and when the right T cell comes along, it binds.

All cells that undergo phagocytosis are also referred to as phagocytes.<sup>10</sup>

*(see ANNEX I, 1. 2. where a representation of each myeloid progenitor cell appears)*

- Lymphoid progenitor cells: they are the T-cells, B-cells and Natural Killer cells. B cells and T cells form the adaptive immune system, while Natural Killer cells are part of the innate immune system. Between 20-40% of leukocytes in our body are lymphocytes. All lymphocytes are able to travel in and out of tissue and the bloodstream. The lymphoid progenitor cells are:
  - T lymphocytes (T cells): T cells are produced in the bone marrow and they later move to the thymus where they mature. They participate in the cell-mediated immune response, which is an immune response that does not involve antibodies. There are two types of T-cells:
    - Helper T-cells: they are activated by macrophages or dendritic cells and provide help to other cells in the immune response by recognising foreign antigens and secreting substances called cytokines that activate cytotoxic T cells and B cells<sup>11</sup>. Helper T-cells have receptors on their surface which are very specific, and they get activated when they bind to an MHC class II molecule presented by macrophages or dendritic cells.
    - Cytotoxic T cells: these cells present T cell receptors that recognise specific antigens, and once an antigen is recognised they can directly kill intracellular pathogens and eliminate mutated and cancerous cells.
  - B lymphocytes (B cells): B cells, like T cells, have receptors on their surface that allow them to only bind to an antigen that has a very specific shape. The main difference is that B cells do not need

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<sup>9</sup> Interstitial fluid is a thin layer of fluid which surrounds the body's cells.

<sup>10</sup> <https://www.youtube.com/osmosis>

<sup>11</sup> <https://www.medicinenet.com/>

antigens to be presented to them on an MHC molecule, they can simply bind to an antigen directly. Once B cells are activated by helper T cells, they start to divide in order to produce clones of themselves. During this process two new types of cells are created, plasma cells and memory B cells.

- Plasma cells: they produce proteins called antibodies, also referred to as immunoglobulins, which seek out the infected cells and help destroy them. Antibodies attack antigens by binding to them. It is also important to remark the fact that they are very specific. Typically, it takes a few weeks for antibody levels to peak. Antibodies are just the B cell receptor in a secreted form, so they can circulate through the serum, which is the non-cellular part of blood, attaching to pathogens and tagging them for destruction. As antibodies are not bound to cells and float freely in the blood, this is considered humoral immunity (“humors” refers to body fluids)
- Memory B cells: these cells have a prolonged lifespan and can remember specific intruders. If the host is re-exposed to the same antigen, these cells rapidly divide with the assistance of T cells and produce more B cells capable of producing specific antibodies to the pathogen. This often means that the pathogen can be dealt with before the infection takes hold.<sup>12</sup>
- Natural Killer cells (NK cells): they are large lymphocytes with granules, and they target cells infected with intracellular organisms, like viruses, as well as cells that pose a threat, like cancer cells. NK cells kill their target cells by releasing cytotoxic granules in their cytoplasm directly into the target cell. These granules contain some molecules that punch holes in the target cells membranes by binding directly to the phospholipids and creating pores.<sup>13</sup>

Now that we know what the immune system is made out of, we should see how it works.

*(see ANNEX I, 1. 3 where a representation of each lymphoid progenitor cell appears)*

## 2. 2. IMMUNE SYSTEM'S BRANCHES

The immune system can be divided into:

- Innate immunity: it is the body's first line of immune defence. It responds the same way to all invaders, which is why it is sometimes referred to as the “nonspecific” immunity.

It is also called innate immunity because we are born with it. The innate immune system can be subdivided into:

- Barriers: they prevent most of the pathogens to enter our body. There are two type of barriers:
  - Physical barriers: such as skin, eyelashes, mucous lining of all our organs, etc.

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<sup>12</sup> <https://teachmephysiology.com/>

<sup>13</sup> <https://www.youtube.com/osmosis>

- Chemical barriers: lysosomes in the tears, acid in the stomach, bile, etc.
- Inflammatory response: it is initiated by mast cells. These cells are constantly searching for suspicious invaders in the body, and when they find one, they release a signal in the form of histamine molecules. These alert the body, and blood is rushed to the problem area. This is what causes inflammation, and it also brings leukocytes. Once they get to the suspicious invader, all the harmful substances are destroyed. Leukocytes, as we have previously seen, come in many types, but those that belong to the innate immune system are phagocytes. These cells can either patrol the body or they can stay in certain places and wait for their cue.<sup>14</sup>

In summary, the main purpose of the innate immune response is to immediately prevent the spread and movement of foreign pathogens throughout the body.

Leukocytes of the innate immune system include: mast cells, macrophages, neutrophils, eosinophils, basophils, NK cells and dendritic cells. Dendritic cells and, less commonly, macrophages are the link between the innate and adaptive immunity, as they are responsible for the activation of lymphocytes, the adaptive immunity cells.

- Adaptive (acquired) immunity: it is also called “specific” immunity, as it is highly specific for each invader. The cells of the adaptive immune response have receptors that differentiate one pathogen from another by their antigens. T lymphocytes, B lymphocytes and a few other antigen presenting cells make up the adaptive immune system. Adaptive immunity is not present since birth, and it is created as we are exposed to foreign substances.

The adaptive immune system starts working when the innate immune system has not been able to destroy a pathogen. If it is the first time that a certain pathogen invades our body, the adaptive immune response is minimal, as it is unable to recognise it yet. Nevertheless, if it is not the first time that a kind of pathogen invades our body, as the adaptive immune system has the ability to memorise, it acts very effectively in a very short amount of time.<sup>15</sup>

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<sup>14</sup> <https://www.youtube.com/ScienceABC>

<sup>15</sup> <https://www.khanacademy.org/>

### 3. AUTOIMMUNE DISEASES

An autoimmune disease occurs when the body's immune system attacks and destroys healthy body tissue by mistake.<sup>16</sup> As we have seen earlier, the immune system can usually tell the difference between foreign cells and its own cells. However, in an autoimmune disease, the immune system mistakes part of the body, like the joints or skin, as foreign. The body parts that are affected depend on the type of autoimmune disease. There are more than 80 known types.<sup>17</sup>

#### 3. 1. WHO GETS AUTOIMMUNE DISEASES

Autoimmune diseases can affect anyone, yet certain people are at greater risk, including:

- Women at childbearing age: autoimmune diseases mainly affect women who are between the age of 15-45.
- People with a family history: some autoimmune diseases tend to run in families. It is also common for different types of autoimmune diseases to affect different members of a single family.
- People who are surrounded by certain aspects related to the environment: sunlight, chemicals called solvents, and viral and bacterial infections are linked to many autoimmune diseases.
- People of certain races or ethnic backgrounds: some autoimmune diseases tend to affect more people from a specific ethnicity or race. For example, the autoimmune disease type 1 diabetes affects mainly white people.<sup>18</sup>

#### 3. 2. CLASSIFICATION

There are two different ways of classifying autoimmune diseases, which are the following:

- Whether they are caused by autoantibodies or by T-cells. Some examples of autoimmune diseases caused by autoantibodies are: Rheumatoid Arthritis, Chronic Autoimmune Hepatitis and Primary Biliary Cirrhosis. In contrast, some examples of autoimmune diseases caused by T-cells include: Type 1 diabetes, Hypothyroidism and Addison's disease.
- Whether they affect only one organ (organ-specific) or more than one organ (systemic). Examples of organ-specific autoimmune diseases are: Graves Disease, Vitiligo, Hashimoto Thyroiditis... On the other hand, examples of systemic autoimmune diseases include: Systemic Lupus Erythematosus, Myasthenia Gravis and Multiple Sclerosis.<sup>25</sup>

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<sup>16</sup> <https://medlineplus.gov/>

<sup>17</sup> <https://www.womenshealth.gov/>

<sup>18</sup> Enfermedades Autoinmunes, El Enemigo Interior. Professor Yehuda Shoenfeld, Professor Luis Javier Jara & Professor Ricard Cervera.

### 3. 3. DIAGNOSTIC PROCESS

Autoimmune disorders can be difficult to recognise and diagnose. Autoimmune diseases affecting multiple organs can lead to highly variable signs and symptoms that can change in severity over time. Vague and slow to develop signs and symptoms may be present and can be misleading during diagnosis. Some of the most common symptoms of autoimmune disorders include fatigue, general feeling of being unwell (malaise), dizziness, joint pain, rash, and low grade fever.<sup>19</sup>

There are many tests that may be done to diagnose an autoimmune disease, and those include: antinuclear antibody tests (ANA), autoantibody tests, CBC, C-reactive protein, urinalysis, and many others. However, one of the most important points in the diagnosis of an autoimmune disease is the family medical history, as autoimmune diseases tend to run in families.<sup>20</sup>

### 3. 4. TREATMENT

Although there is no permanent cure for autoimmune diseases, standard treatments aim at reducing the signs and symptoms of the disease and restrict the autoimmune processes. In order to reduce the intensity of damage caused by abnormal immune system functioning, doctors often prescribe immunosuppressive medicines, such as corticosteroids. Pain-relieving medicines are also effective in reducing bone, joint, or muscular pain. Autoimmune disorders associated with inflammation can be treated with drugs that target those proteins responsible for joint inflammation, such as TNF blockers. If the autoimmune disorder causes a reduction in important cellular components, such as thyroid hormone, insulin, or vitamin B12, doctors might prescribe supplements to replenish them. In the case of mobility-related problems, physical therapies may be useful.<sup>21</sup>

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<sup>19</sup> <https://labtestsonline.org/>

<sup>20</sup> <https://medlineplus.gov/>

<sup>21</sup> <https://www.news-medical.net/>

## 4. LUPUS

Lupus is a systemic autoimmune disease that can affect many organs. People with lupus present numerous autoantibodies in their bloodstream, which bind to their own antigens forming immune complexes that are the ones that cause inflammation and tissue damage.<sup>22</sup> Lupus lasts for a long period of time or even all life. However, lupus is manifested by combining periods of increased activity or flares (exacerbation) with periods of inactivity (remission).<sup>23</sup> With a good treatment and doctor supervision, more than 90% of people with lupus have a normal life expectancy.

Lupus can affect anyone, although some people are in higher risk of suffering it than others. Lupus affects more women than men (9 out of 10 lupus patients are women), and even though it can appear at any age, it usually manifests between the ages of 15-44. Lupus is also much more common in Latin Americans, African Americans and Asians.

In the world there are about 5 million people with lupus, 50,000 of which are in Spain. In Catalonia, there are about 7,000 lupus patients. Approximately 1 out of 1000 people suffers from lupus.<sup>30</sup>

### 4. 1. TYPES OF LUPUS

There are four main types of lupus:

- Systemic Lupus Erythematosus (SLE): it is the most common type of lupus and it can affect many parts of the body. It can be difficult to diagnose, as there are no two patients who present exactly the same complaints. Also, its symptoms may be confused with those of another disease.
- Cutaneous Lupus (Lupus limited to the skin): it only affects the skin and it is characterised by rashes in the face, legs and arms. The rash appears in clearly defined areas and it can protrude from the surface of the skin. 5-12% of those who have cutaneous lupus may end up having systemic lupus erythematosus.
- Drug-induced lupus (DILE): it only represents 10% of all cases of lupus. It occurs as a reaction to determined types of drugs. Its symptoms are similar to those of the SLE, although they are usually milder and they go on remission when the medication is discontinued.
- Neonatal Lupus: unusual type of lupus that can only affect newborns. It can be developed in children whose mothers suffer from lupus, as the mother's antibodies are present in the newborn. Symptoms usually disappear after 6-8 months, coinciding with the complete elimination of maternal antibodies.<sup>24</sup>

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<sup>22</sup> Lupus. Guia pràctica per a pacients de lupus. Laia Feliu.

<sup>23</sup> <https://www.clinicbarcelona.org/>

<sup>24</sup> <https://www.lupusuk.org.uk/>

## 4. 2. CAUSES

The origin of lupus is multifactorial, that is, there are several factors that influence its development. Research suggests that genetics play an important role, although it is not absolutely determinative. There are several autoimmune genes that will make a person more likely to have the disease, but this person will not necessarily develop it. There are other factors that influence and contribute to the onset of lupus, such as hormonal or environmental factors. For example oestrogen, infections, emotional and physical stress, pregnancy, various drugs and ultraviolet light from solar radiation can trigger lupus activity and the onset of symptoms.<sup>25</sup>

## 4. 3. SYMPTOMS

Lupus symptoms vary enormously depending on the person and the way lupus presents itself. Nevertheless, the most frequent symptoms and signs are:

- Muscle pain: it affects most people with lupus. Common areas for muscle pain include the neck, thighs, shoulders, and upper arms.
- Pain or swelling in the joints: 95% of lupus patients report joint pain, and for this reason it is considered the most frequent symptom for this disease. The joint condition is usually symmetrical and most commonly affects the small joints. These symptoms last between 12 to 48 hours, although they sometimes last up to 7 or 10 days, and resolve without leaving any sequelae. The lupus joint disease differs from Rheumatoid Arthritis in a very important aspect: in lupus it is very rare for the joints to be damaged. (*see ANNEX II where a representation of this symptom appears*)
- Fever: a fever higher than 37.5°C affects many lupus patients. The fever is often caused by inflammation or infection. Lupus medicine can help manage and prevent fever.
- Rashes: they appear due to inflammation in small blood vessels of the skin, which cause a variety of reddish rashes, most often on the cheeks. (*see ANNEX II where a representation of this symptom appears*)
- Chest pain: lupus sometimes causes inflammation in the heart lining membranes (the pericardium) and in the lung lining membranes (the pleura), which originates pericarditis and pleurisy. Both have very similar symptoms: chest pain and sometimes fever. In general, they do not usually pose any major problem and respond well to simple medical treatments.
- Hair loss: patchy or bald spots are common. Hair loss could also be caused by some medicines or infection. It usually only appears during a flare, and when the patient is in remission the hair grows again.

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<sup>25</sup> Lupus. Guia pràctica per a pacients de lupus. Laia Feliu.

- Sensitivity to sunlight or fluorescent light: most people with lupus have a very sensitive skin, which makes them sensitive to light, a condition called photosensitivity. Prolonged exposure to the sun can trigger a flare. For this reason, lupus patients need to use sunscreen very often and cover as many parts of their skin as possible.
- Renal disorders: the kidney frequently becomes ill in lupus. The most frequent kidney disorder is its inflammation (lupus nephritis), which sometimes causes the kidney to be unable to properly remove waste from the body. Then, this waste accumulates in the blood. Occasionally and due to inflammation, the kidney is unable to retain substances as important as proteins, which leads to them being excreted in the urine. It also leads to the swelling of the face and legs. Finally, in other cases, the kidney injury causes a rise in blood pressures.

Lupus patients need to know that all of these renal disorders do not cause any symptoms, which is why it is very important for them to take routine medical exams to check up their kidneys.

- Mouth sores: also called ulcers, these sores usually appear on the roof of the mouth, but they can also appear on the gums, inside the cheeks, and on the lips. They may be painless, or may present soreness and a dry mouth.
- Extreme or prolonged fatigue: lupus patients usually feel tired or exhausted even when they get enough sleep.
- Haematological abnormalities: haemolytic anaemia (destruction of red blood cells), leukopenia, lymphopenia, and thrombocytopenia, i.e., decrease in white blood cells, lymphocytes, and platelets, are diagnostic criteria for lupus. For this reason it is very important that lupus patients undergo blood tests periodically in order to control the disease.
- Eye dryness or inflammation: lupus can affect any structure of the eye, so retinal vascular manifestations are the most common form of ophthalmologic involvement in these patients. In most cases, they do not cause loss of visual acuity. Very often, people with lupus also suffer from another autoimmune disease called Sjögren's syndrome, which is a condition in which the exocrine glands that produce tears and saliva are attacked and destroyed by the immune system.
- Clots: in lupus patients there is a higher risk of blood clotting. This can cause blood clots in the legs or lungs, stroke, heart attack, or repeated miscarriages.
- Leg swelling: leg swelling is usually due to all the kidney problems, which cause an accumulation of liquids in the body that sometimes end up in the legs, causing the swelling. (*see ANNEX II where a representation of this symptom appears*)

- Pale or purple fingers or toes: patients with lupus may develop Raynaud syndrome, which is the tendency of the fingers or toes to become numb and white when exposed to cold. (*see ANNEX II where a representation of this symptom appears*)
- Headaches: between 50-90% of lupus patients suffer from headaches.
- Depression/Anxiety: although they might be caused by a mild inflammation of the brain due to lupus, they might also be caused by any other circumstance. In addition, many lupus patients suffer from anxiety and depression as a consequence of knowing that they have lupus, but not as a cause of lupus itself.
- Weight loss: lupus may be associated with unhealthy weight loss, so eating to achieve a healthy weight is very important. Weight loss is due to the loss of appetite that lupus causes, although it can also be due to medication and mouth sores (which make eating painful).<sup>26 27</sup>

Occasionally, lupus overlaps with other diseases such as: Celiac disease, Myasthenia Gravis, Rheumatoid Arthritis, Sjögren's syndrome, Osteoporosis, Type 1 diabetes, Hypertension or others. These might be caused by medication or can simply appear to lupus patients for no apparent reason. Sometimes they can also be caused by lupus itself.

#### 4. 4. DIAGNOSIS

There is no specific test to diagnose lupus and it can take months or years to detect it. However, for its diagnosis, three essential steps are required:

1. A detailed overview of the patient's symptoms and past medical history
2. A detailed physical examination
3. Tests: mostly blood tests, but this may also involve other tests such as biopsy of affected organs

The most common tests for diagnosis include:

- Blood tests for autoimmune diseases: lupus patients have several autoantibodies and other immunologic disorders that are monitored by blood tests:
  - Anti-nuclear antibody test (ANA): very common test for all autoimmune diseases. In lupus, levels are usually very high. This test detects a group of autoantibodies directed against components of the nucleus of the cell, such as DNA and ribonucleoproteins<sup>28</sup>.
  - Double-stranded DNA test: for some unknown reason, the presence of autoantibodies against double-stranded DNA is the hallmark of lupus, although it is not specific for it.

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<sup>26</sup> <https://www.womenshealth.gov/>

<sup>27</sup> Lupus. Guia pràctica per a pacients de lupus. Laia Feliu.

<sup>28</sup> a substance composed of RNA in close association with protein.

- Anti-Sm antibodies test: anti-Sm antibodies only appear in lupus patients. Nevertheless, only 10% of lupus patients present them.
- Anti-Ro, anti-La and anti-RNP antibodies test: these antibodies appear in some lupus patients, although they also appear in people who suffer from another autoimmune diseases.
- Antiphospholipid antibodies test: this test is used to detect an autoimmune disease called antiphospholipid antibody syndrome (APS) which often affects lupus patients as well.<sup>29</sup>
- Biopsies: a biopsy is a minor surgery to remove a sample of tissue. The tissue is then viewed under a microscope. The biopsies which are usually done in order to diagnose lupus are:
  - Skin biopsy: samples of skin tissue are analysed and professionals can observe the aspect of a rash. Thanks to this, physicians get to know whether the skin injuries are a sign of lupus or not.
  - Kidney biopsy: in patients who might suffer from lupus nephritis, renal biopsy allows to know the severity of the inflammation, the extension of the scars and it enables doctors to know which is the best treatment for the patient.<sup>30</sup>
- Urine tests: urine tests can help to diagnose and monitor the effects of lupus on the kidneys. The presence of protein, red blood cells, white blood cells, and cellular casts can all help to show how well the kidneys are working. As commented earlier, the kidneys can often be affected in lupus patients.<sup>31</sup>
- Other tests such as x-rays or electrocardiograms can also be performed throughout the diagnostic process.

#### 4. 5. TREATMENT

There is currently no cure for lupus, but pharmacologic and non-pharmacologic treatments can help lupus patients feel better by improving their symptoms. The treatment is different for every lupus patient, as it depends on the symptoms and the individual needs. The goals of treatment are to: prevent flares, treat symptoms when they happen and reduce organ damage<sup>32</sup>

The most used types of treatment are:

- Non-steroidal anti-inflammatory drugs (NSAIDS): used by patients who suffer from joint and muscle pain. They reduce pain which is due to inflammation. Examples of NSAIDS: ibuprofen, naproxen... It can cause kidney disorders, so it should be avoided in lupus patients who already have kidney involvement.

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<sup>29</sup> <https://www.medicalnewstoday.com/>

<sup>30</sup> <https://www.medicalnewstoday.com/>

<sup>31</sup> <https://www.clinicbarcelona.org/>

<sup>32</sup> <https://www.womenshealth.gov/>

- Antithrombotic drugs: medicines which prevent and treat clots that can appear in lupus patients. For example: acetylsalicylic acid, acenocoumarol, etc.
- Antimalarial drugs: these drugs were developed to cure malaria. However, most patients with lupus are treated with antimalarial drugs, as they reduce joint pain due to inflammation, improve rashes, improve mouth sores and reduce fatigue. The most commonly used are hydroxychloroquine and chloroquine.
- Corticosteroid drugs: very effective to reduce lupus activity. Due to its numerous side effects, doses must be very low and they should not be used for a long period of time. Doses depend on how severe symptoms are, and, if the disease is controlled, they should decrease until the patient does not take any at all. An example of a corticosteroid medicine is prednisolone.
- Immunosuppressants: used when lupus manifestations are more serious, like when lupus affects the brain or the kidney. They act by dampening down the immune system. Most commonly used immunosuppressants: methotrexate and azathioprine.
- Biological therapies: created from human proteins or living cells. Currently, they are used for severe cases that do not respond to conventional treatment. The most commonly used are belimumab and rituximab. The future of lupus treatments is geared towards biological therapies.<sup>33 34</sup>

#### Non-pharmacologic lupus treatment:

- Walking, swimming or riding bike: it is advisable to perform this types of activities to prevent muscle weakness caused by fatigue and alternate it with rest periods.
- Avoid direct sun exposure and other light sources: especially in patients with photosensitivity, as it might make the rashes worse or even cause a lupus flare.
- Balanced diet: it is advisable to eat food with low levels of fats, salt and sugar, and with high levels of fibre.
- No smoking: smoking can make symptoms worse in lupus patients.<sup>35</sup>

As lupus affects many different parts of the body, lupus patients usually visit more than one doctor at a time. The most common types of doctors who treat lupus include: internists, rheumatologists, nephrologists, dermatologists, pulmonologists, neurologists and cardiologists.

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<sup>33</sup> Lupus. Guia pràctica per a pacients de lupus. Laia Feliu.

<sup>34</sup> <https://www.lupusuk.org.uk/>

<sup>35</sup> <https://www.clinicbarcelona.org/>

## 5. METHODOLOGY

This research project is based on the comparison of lupus between Spain and the UK. The main analysed lupus related traits are: diagnostic process, treatment, lifestyle, factors that increase the risk of having lupus, family members' role, scientific research done and the role lupus charities have. In order to make it possible, polls and interviews have been carried out. The performed polls were the following:

- Poll to lupus patients from Spain and from the UK
- Poll to family members to lupus patients from Spain and from the UK

And the interviews made were:

- Interviews to a Spanish and a British female lupus patient
- Interviews to a Spanish and a British male lupus patient
- Interview to a family member to a Spanish lupus patient and to a British lupus patient
- Interviews to a staff member from a lupus charity from the UK and from a lupus charity from Spain
- Interviews to a lupus specialist from Spain and a lupus specialist from the UK

### 5. 1. POLLING METHODOLOGY

The polls carried out for this project were done using Google Forms, a survey administration software. For the design of these polls, firstly, I informed myself about the immune system, autoimmune diseases and lupus. Then, I thought of the most suitable questions to ask that could be comparable between the two countries, and created the polls. Polls to lupus patients and relatives are identical in Spanish and in English.

In order to reach as many people as possible, I contacted Lupus UK and “Associació Catalana de Lupus E.G. (ACLEG)”. Both charities replied expressing their willingness to help me, although the process I followed to share the polls was very different in each country due to their idiosyncrasy. After explaining my project to Pilar Lucas, founder and CEO of ACLEG, she was disposed to help me throughout the making of this project. Once the polls were ready, I sent her the link and she shared them in ACLEG's social media.

To share the polls in the UK, a different process took place. At first, I emailed the CEO of Lupus UK explaining my project. When the polls were prepared I communicated with him again, and he explained to me that, in the UK, when polling people for a research project, there are a few steps to be taken before the polls are shared. These steps consisted in sending him all the polls' questions, the participants' “right to withdraw”, an explanation of how the data would be used and proof of ethical approval (*see ANNEX III where the required documents appear*).

Succeeding, the Lupus UK CEO put me in contact with Chanpreet Walia, Social Media & Projects Officer at Lupus UK. The upcoming steps were the same procedure as that in Spain. I attached the link to the polls in

an email and she then shared it in the Lupus UK's social media. This is how I managed to make the polls reach so many people.

More than two weeks after the polls had been opened to responses, I closed the Google Forms, which means no more answers were accepted, and started processing the data. Firstly, the Google Forms responses, which were all anonymous, were exported to a CSV file in order to be able to treat the data in an Excel spreadsheet. This was done for every poll, so a total of four times.

Then, I selected the responses that were going to be used for the project. The poll to Spanish lupus patients was responded by 185 patients. However, only 158 would be useful for this project, as some responders did not meet the requirements. The poll to English lupus patients was answered by 243 patients. Nevertheless, only 158 were taken into account. The responses from the UK which did not meet the requirements were also eliminated from the database that was going to be used for the comparison. Reached that point, the number of responses was still greater than 158, so other responses were not taken into account, chosen at random. The exact same number of responses from the UK and from Spain were used for this project so that the data was completely comparable.

The family members' polls data was processed the same way. In the poll to Spanish relatives' there were 60 responses, and the English family members' poll had 37 answers. As all of the responses from the UK met the requirements, a total of 37 responses per country were used for the project. The Spanish relatives' poll had more responses, so some had to be eliminated randomly. The eliminated responses, however, were not removed from the general database, they were simply not used when it came to the comparisons.

Once the responses I was going to use for the project were selected, the data that would be used from each poll was copied into another spreadsheet. Nevertheless, this time, the data from the Spanish patients' poll and the data from the British patients' poll was put into the same spreadsheet, and the same with the family members' polls data. This means that, at this point, I had two spreadsheets with all the data that was going to be used for the project.

These spreadsheets had all the responses to each question asked in the four polls, although I had to take into account that half of the responses from these spreadsheets were in Spanish, so I translated them into English. By the time this was done, I had to compare the data, which is what my project is about. In order to do so, I converted the data into dynamic tables and dynamic graphics. The answers to each questions were compared according to the country of residence from each responder.

*(see ANNEX IV where the Excel books with all the spreadsheets used for this project appear)*

### 5. 1. 1. PATIENTS' POLL STRUCTURE

The patients' poll is structured in 7 sections:

- General questions: this section consists of questions like: sex, country of residence, type of lupus, etc., as they are interesting to consider and gave me an idea of the profile of a lupus patient.
- Symptoms: questions about the first symptoms patients had, age of appearance of these first symptoms, the most frequent symptoms and lupus flares.
- Diagnostic process: it gives an idea of the usual tests performed to diagnose lupus, period of time since the appearance of the first symptoms until the final diagnosis, specialists who diagnose lupus, etc.
- Treatment: this section englobes questions about which medical specialist lupus patients visit more often, what drugs they are taking nowadays, which symptoms have improved or been eradicated with treatment, alternative therapies, etc.
- Factors that may lead to suffer from lupus: questions in this section are about whether they have any family member with lupus or any other autoimmune disease.
- About lupus: short section about knowing if the patient also suffers from any other disease and if they had any child who has suffered from neonatal lupus.
- Lifestyle: questions are not related to the disease directly, but they are about many traits of their lifestyle and how lupus affects their life. There are also some questions about lupus charities and how important the respondents think they are.

In total, the poll has 48 questions (*see ANNEX V where the complete survey appears*).

### 5. 1. 2. FAMILY MEMBERS TO LUPUS PATIENTS' POLL STRUCTURE

The relatives' poll is made up of 4 sections:

- General questions part 1: short section to know what kind of relationship the relatives have with the lupus patient, their country of residence, sex and year of birth.
- General questions part 2: section to get to know the relative better. Questions include: time they have been cohabiting with the patient, the knowledge they had of lupus before the diagnosis and whether they had been cohabiting with the patient or not when he or she was diagnosed.
- Questions for family members who already lived with the patient when s/he was diagnosed: this questions aim to know how much the mood and lifestyle of the patient changed during the diagnostic process.
- Questions for all family members: this section aims to know about the role family members have in lupus patients' life. Questions are about how much their lives have changed, which symptoms of their relatives' disease affects them the most, if they foresee when their family member is going to have a lupus flare, etc.

The poll has a total of 21 questions (*see ANNEX VI where the complete survey appears*).

## 5. 2. INTERVIEWING METHODOLOGY

For this research project, I have carried out a total of 10 interviews. The interviews to lupus patients and family members have been performed with the aim to learn more about how lupus affects them. Thanks to the polls I could get a general idea of it, although I thought it would be very interesting to hear about some personal experiences related to lupus. Personally, I have found it very enriching to talk with lupus patients and family members, as I have been able to discover stories full of strength and hope. The interviews have been made to a Spanish and a British female with lupus, a Spanish and a British male with lupus and a relative to a lupus patient from Spain and one from the UK. The differentiation between lupus patients who are male and female is important because, as mentioned earlier, 9 out of 10 lupus patients are women. I managed to contact all the interviewed thanks to both charities, Lupus UK and ACLEG, who facilitated all contacts. (*See ANNEX VII to read these six interviews*)

The other interviews that I have carried out have been to lupus charities staff members and to lupus specialists. Pilar Lucas, ACLEG's founder and CEO, and Chanpreet Walia, Social Media & Projects Officer from Lupus UK, kindly answered the interview I had prepared for a lupus charity staff member. These interviews were performed with the aim to know the role lupus charities have. They do not only help lupus patients and help raise funds, but they also help people who, like me, are trying to learn more about lupus. After conversing with them I realised how important their job is and how many people do not know about it. The final two interviews have been to Dr. Ricard Cervera, internist and Head of Autoimmune Diseases Department at Hospital Clínic de Barcelona, and to Prof. David d'Cruz, rheumatologist and clinical team lead for the Louise Coote Lupus Unit. With these interviews I have been informed about what is being researched and investigated about lupus. I met Dr. Ricard Cervera thanks to the course I was a member of, which is "Bojos per la Medicina". Throughout the making of this project I have been in contact with him, and apart from offering to answer my interview, he also sent me Prof. D'Cruz's email address.

All of these interviews had been planned with the idea of being face-to-face. Unluckily, due to Covid-19 this has not been possible for most of the interviews, and only two of them could be done that way. Nevertheless, I could still do all of them, and I used different methods. Four interviews were done via email, one via phone-call, two via video conference, one via *Instagram Live*, with many people being able to see it, and, as already said, two were face-to-face.

## 6. DATA ANALYSIS

In this chapter I will be analysing the data obtained from the polls using the dynamic graphics made for the comparison of each question.

### 6. 1. PATIENTS' POLL

Firs of all, the data obtained from the patients' poll will be analysed, and, in order to do so, the graphics will be separated into sections, following the structure of the poll.

#### 6. 1. 1. SECTION 1: GENERAL QUESTIONS

This first section, which is referred to as “general questions”, includes the information about the patient related to: sex, number of children, environment they live in and the type of lupus they have.

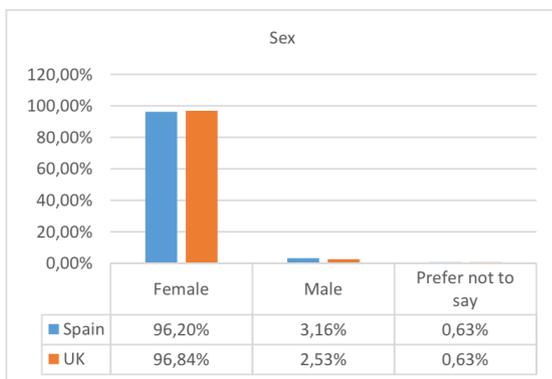


Fig 1. 1. Graphic representing the responders' sex

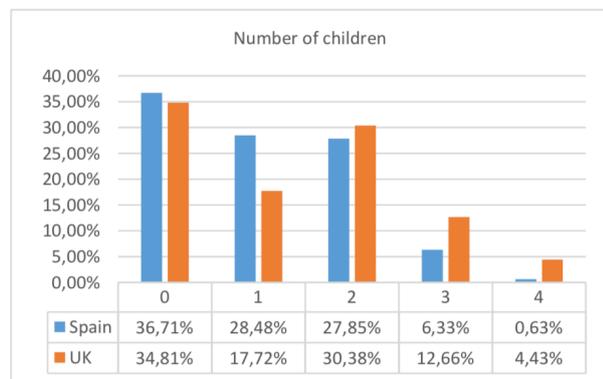


Fig. 1. 2. Graphic representing the responders' num. of children

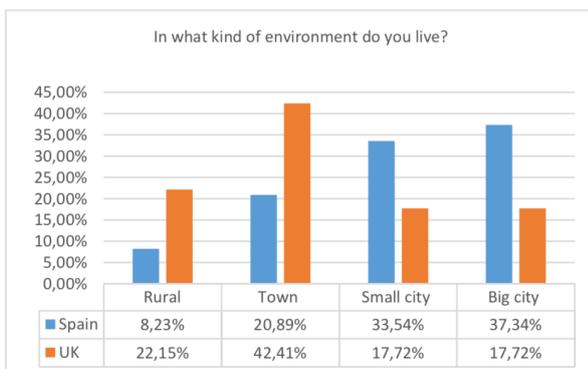


Fig 1. 3. Graphic representing in what kind of environment the responders live in

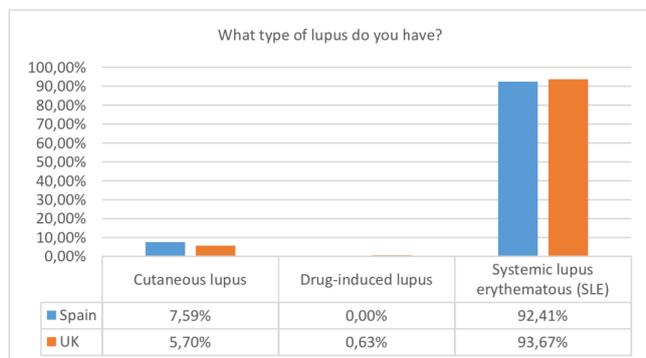


Fig. 1. 4. Graphic representing the type of lupus responders have

From these graphics we can observe there is no relevant difference between the UK and Spain when it comes to the sex of the patient (more than 96% are women in both countries), number of children and type of lupus (more than 92% of patients from both countries suffer from SLE). We can only observe a difference between both countries in Fig. 1. 3. However, I do not consider it pertinent, as I consider it a trait of the “modus vivendi” of each country (in the UK most citizens live in towns or rural surroundings).

## 6. 1. 2. SECTION 2: SYMPTOMS

In this section the analysed data is about: first symptoms, frequents symptoms and lupus flares.

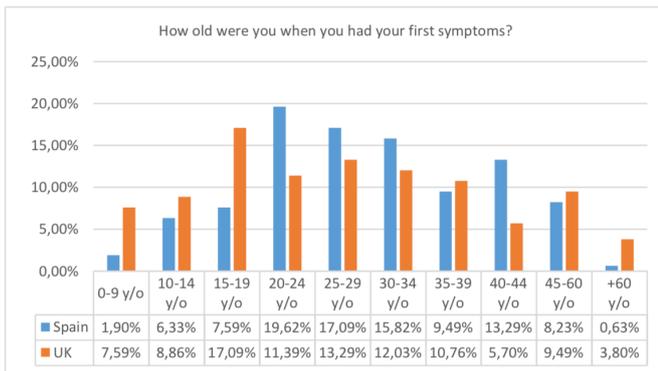


Fig. 2. 1. Graphic representing the responders' age of appearance of their first symptoms

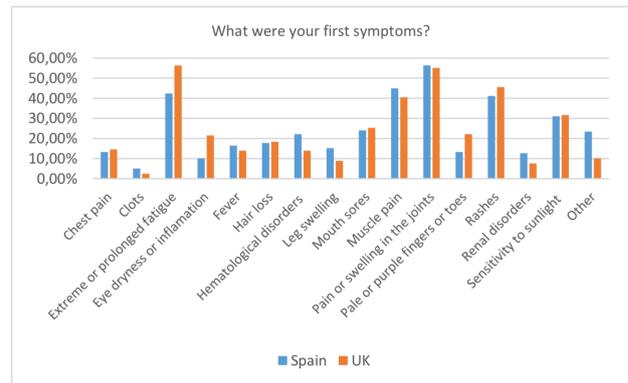


Fig. 2. 2. Graphic representing the responders' first symptoms

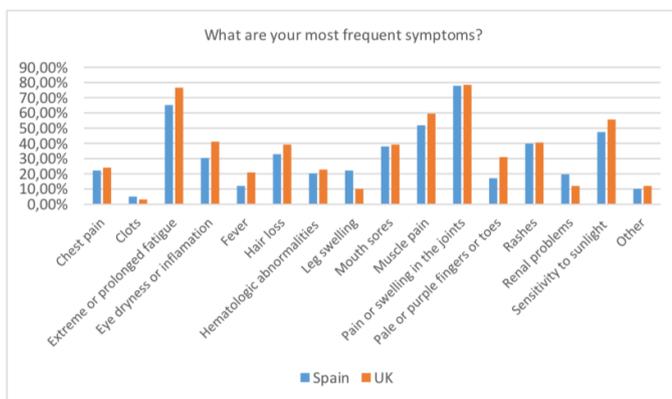


Fig. 2. 3. Graphic representing the responders' most frequent symptoms

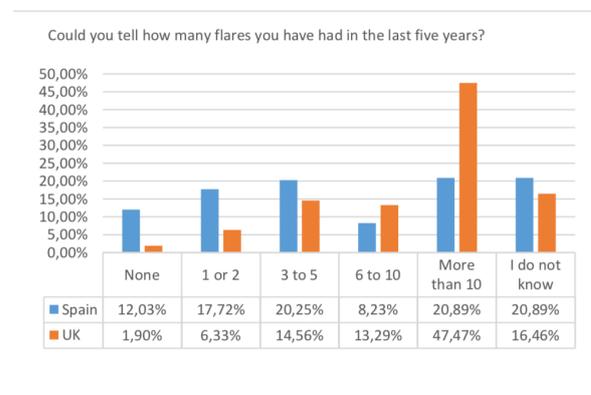


Fig. 2. 4. Graphic representing the responders' num. of flares in the last five years

With these graphics we can identify how there are some differences between each country when it comes to aspects related to the symptoms. From Fig. 2. 1. we notice how, in the UK, the first symptoms appear before the age of 20 in a lot more patients than in Spain. A total of 33.54% of British patients have their first symptoms before the age of 20, whereas only 15.82% of Spanish patients have symptoms before their twenties. Looking at Fig. 2. 2. we do not detect big differences between the two countries. Nevertheless, if we look at it closely, we can see how clots, leg swelling and renal disorders appear as one of the first symptoms in Spanish patients twice as often as they do in British patients. We can also observe how extreme and prolonged fatigue and pain or swelling in the joints are the most common first symptoms in both countries. From Fig 2. 3. we can observe it is very similar to Fig. 2. 2, which means the most frequent symptoms are usually the same as the first symptoms they experience. Finally, looking at Fig. 2. 4. we can detect a very clear difference. Nearly 50% of British patients have experienced more than 10 lupus flares in the last 5 years, although only 20.89% of Spanish patients have.

### 6. 1. 3. SECTION 3: DIAGNOSTIC PROCESS

In this section, aspects related to the diagnostic process have been analysed. They include: tests used to diagnose lupus, time of diagnostic process, medical specialist who confirmed the diagnosis and any mistake there could have been during this process.

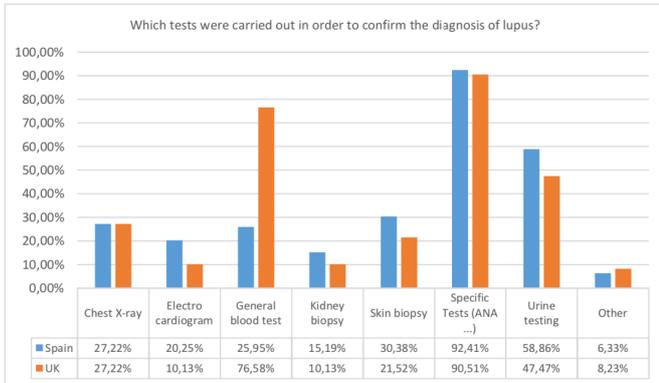


Fig. 3. 1. Graphic representing the tests carried out in order to confirm the responders' diagnosis of lupus

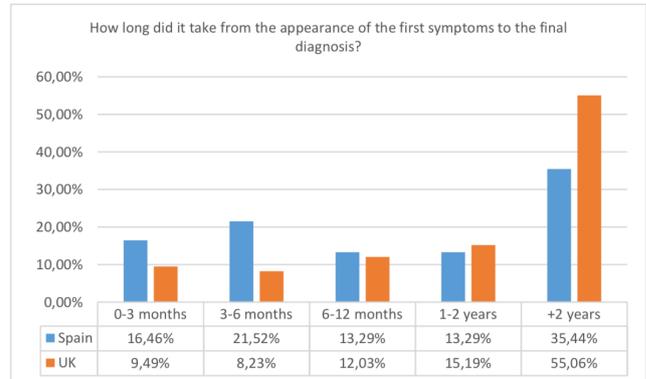


Fig. 3. 2. Graphic representing how long it was the responders' diagnostic process

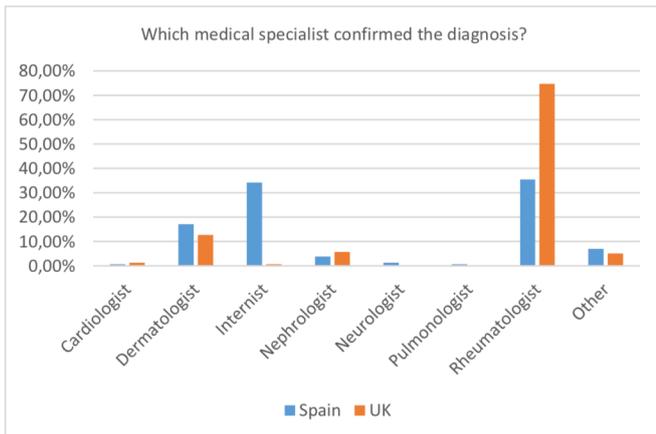


Fig. 3. 3. Graphic representing which specialist confirmed the responders' diagnosis

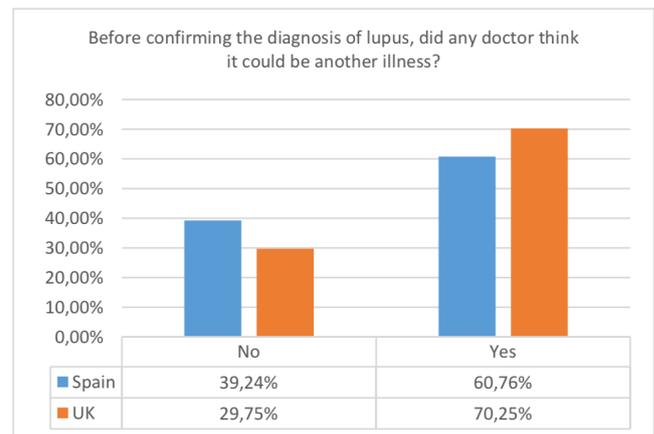


Fig. 3. 4. Graphic representing how many of the responders' lupus was mistaken for another illness

From this graphics various information can be extracted. From Fig. 3. 1. we can see how the general blood test, which is used to diagnose lupus in the UK in 76.58% of the cases, is only used in Spain in 35.95% of the cases. We can also identify how electrocardiograms, skin biopsies, kidney biopsies and urine tests are slightly more common in Spain than in the UK. However, both countries mainly use specific tests like the ANA to diagnose lupus. Over 90% of lupus patients had a specific test done to confirm their diagnosis.

The second graphic we see (Fig. 3. 2.) is about how much time passed for the responders since the appearance of their first symptoms until the final diagnosis. This graphic shows us how lupus is diagnosed in a least amount of time in Spain than in the UK. Lupus was diagnosed in 1 year or less in 51.27% of Spanish lupus patients and in 29.75% of British lupus patients.

Fig. 3. 3. shows some differences between each country. We can observe how most percentages are very similar, although when it comes to the internists and rheumatologists we do detect a big difference. We see how, in Spain, more than 34% of lupus patients were diagnosed by internists, but less than 1% of British patients were diagnosed by them. And if we look at rheumatologists we see how, in the UK, more than 74% of patients were diagnosed by them, whereas in Spain the percentage is much lower, being just a little more than 35%.

Eventually, looking at Fig. 3. 4. we detect how, in most cases, lupus is mistaken with another illness by doctors. In Spain, 60.76% of lupus patients' doctors mistook lupus for another illness, while in the UK this happened in 70.25% of the cases.

#### 6. 1. 4. SECTION 4: TREATMENT

Section 4 is about everything related to lupus' treatment, and this includes: medical specialists visited regularly, drugs used nowadays and in the past, symptoms that have improved or have been eradicated with treatment, side effects from any drug, alternative therapies and adherence to treatment.

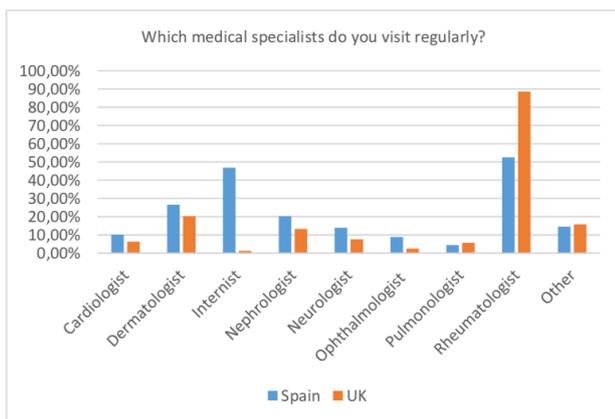


Fig. 4. 1. Graphic representing which medical specialist is most regularly visited by the poll responders

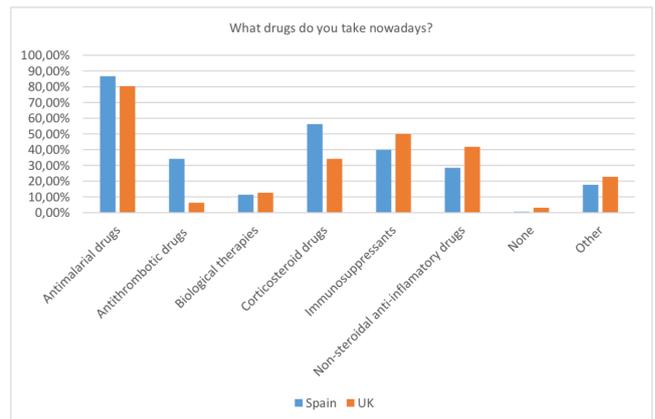


Fig. 4. 2. Graphic representing what drugs responders are currently taking

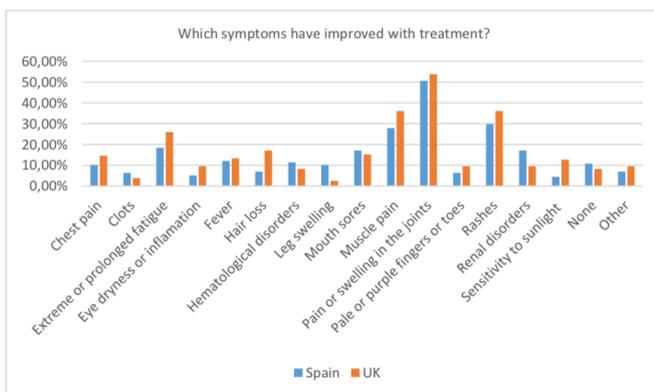


Fig. 4. 3. Graphic representing which of the responders' symptoms have improved with treatment

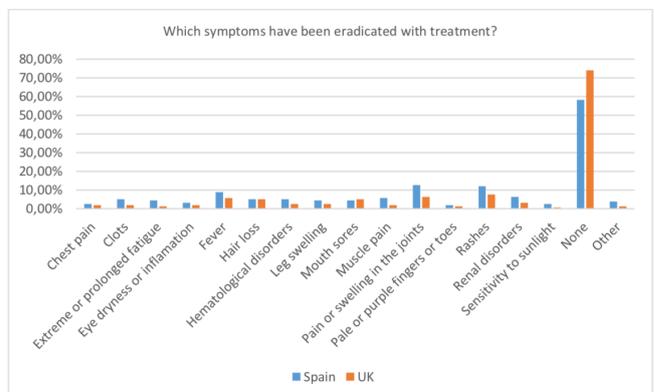


Fig. 4. 4. Graphic representing which of the responders' symptoms have been eradicated with treatment

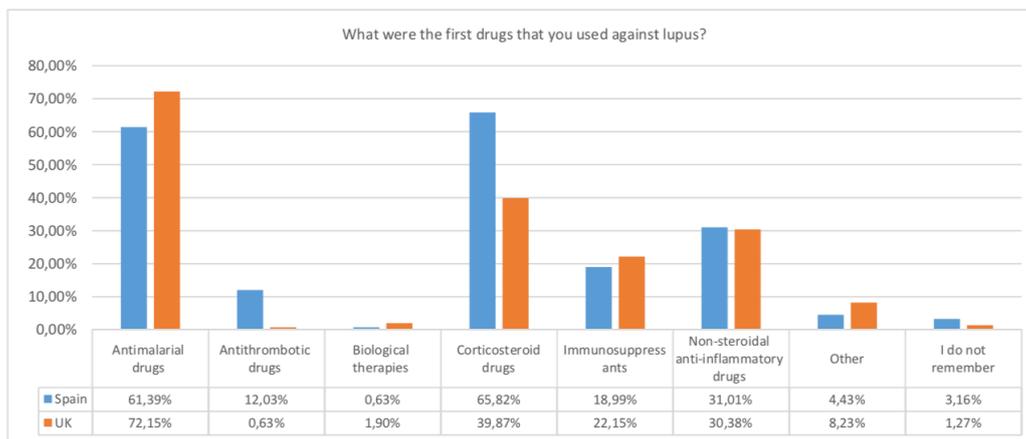


Fig. 4. 5. Graphic representing what were the first drugs responders used against lupus

Looking at Fig. 4. 1. we can see how results are very similar to the ones commented in the past section about the medical specialist who confirmed the diagnosis. This sign shows most patients keep visiting the doctor who diagnosed them. Still, we can see how other doctors who do not usually diagnose lupus are visited regularly by lupus patients. Cardiologists, dermatologists, nephrologists, neurologists, ophthalmologists and pulmonologists rarely diagnose lupus, although we can observe they are visited by lupus patients on the course of their disease.

When we look at Fig. 4. 2. we can detect how antimalarial drugs are the most used drugs in both countries. The biggest difference in this graphic is in antithrombotic drugs and corticosteroid drugs, which are more commonly used by Spanish patients. Also, we can see how immunosuppressants and non-steroidal anti-inflammatory drugs are slightly more used in the UK than in Spain.

Regarding the symptoms that have improved with treatment (Fig. 4. 3.), we rapidly discover the symptoms that improve the most are muscle and joint pain in both countries. If we look at it closer we can also observe how clots, leg swelling and renal disorders are the symptoms that improve more in Spain compared to the UK. And finally, the improvement of hair loss and sun sensitivity is notably more common in British patients than in patients from Spain.

Fig. 4. 4. is about the symptoms that treatment managed to eradicate. For most patients, none of their symptoms have been eradicated.

Finally, we have a graphic that shows the first drugs that patients used against lupus (Fig. 4. 5.). In the UK, antimalarial drugs are the most frequent ones to be used at the beginning of the treatment. Corticosteroid drugs are the most common in Spanish patients, followed by antimalarial drugs. This graphic is very similar to the one that shows what drugs patients are taking nowadays (Fig. 4. 2.), except for the fact that antimalarial drugs are not as used at the beginning of the treatment in Spanish patients as much as they are

used nowadays. Moreover, we see how antithrombotic drugs, biological therapies and immunosuppressants are more likely to be used once the patient has been receiving treatment for a while in both countries.

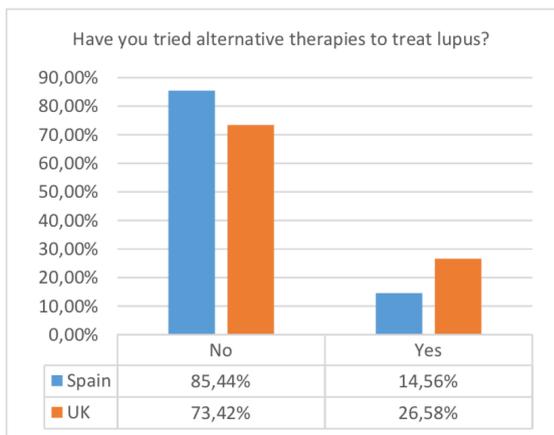


Fig. 4. 6. Graphic representing how many responders have tried alternative therapies

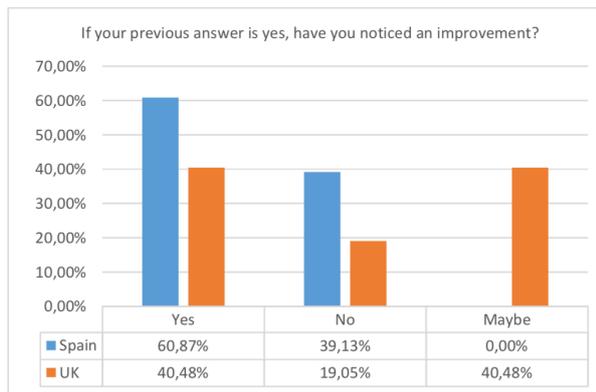


Fig. 4. 7. Graphic representing how many of the responders who have tried alternative therapies think those have worked

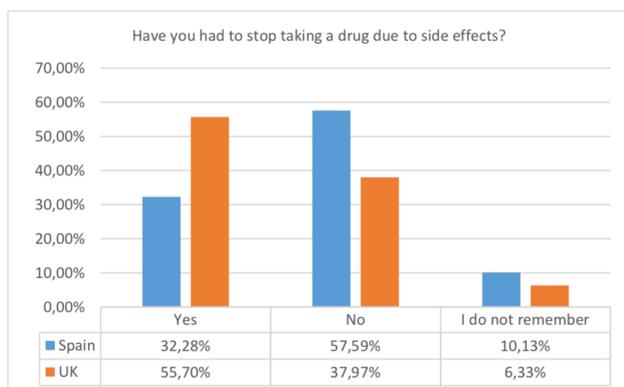


Fig. 4. 8. Graphic representing the amount of responders who had to stop taking a drug due to side effects

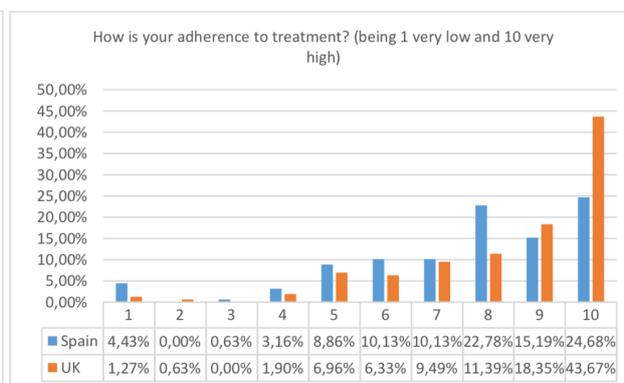


Fig. 4. 9. Graphic representing how high or low responders consider their adherence to the treatment is

These graphics show us a little more about other aspects related to the treatment. The first one we see is about what percentage of patients have tried alternative therapies (Fig. 4. 6.). In both, Spain and the UK, over 70% of patients have never tried alternative therapies, although there are more than 14% who have. To be specific, 26.58% of lupus patients from the UK and 14.56% of patients from Spain have tried alternative therapies. If we look at the next graphic, Fig. 4. 7., we observe how over 60% of Spanish patients have noticed an improvement and about 40% have not. When it comes to the English patients, about 40% considered the alternative therapy had improved their symptoms, nearly 20% thought their symptoms had not improved and the other 40% were not sure whether the alternative therapy had worked or not. Then, we have a graphic showing how many of the patients who answered the poll had to stop taking a drug due to side effects (Fig. 4. 8.). Over 55% of British lupus patients had to stop taking a drug due to side effects, although only 32.28% of Spanish lupus patients have had to do so.

The final graphic in this section is about the adherence to the treatment (Fig. 4. 9.). We notice that, in general, British patients have a higher adherence to the treatment. Over 40% consider their adherence to the treatment a 10, which is the highest it can be in the scale, whereas only 24,68% of Spanish patients consider it a 10.

### 6. 1. 5. SECTION 5: FACTORS THAT MAY LEAD TO SUFFER FROM LUPUS

This section was created with the aim to know how many lupus patients have family members with lupus or any other autoimmune disease. Also, if this is the case, how close they are to that relative.

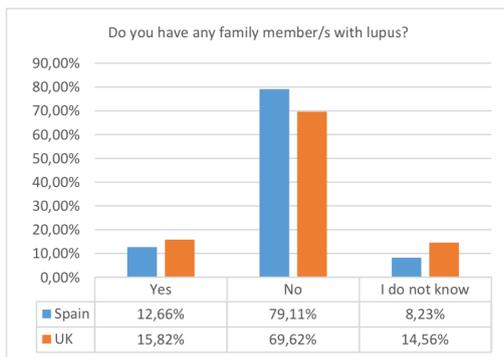


Fig. 5. 1. Graphic representing how many of the responders have family members with lupus

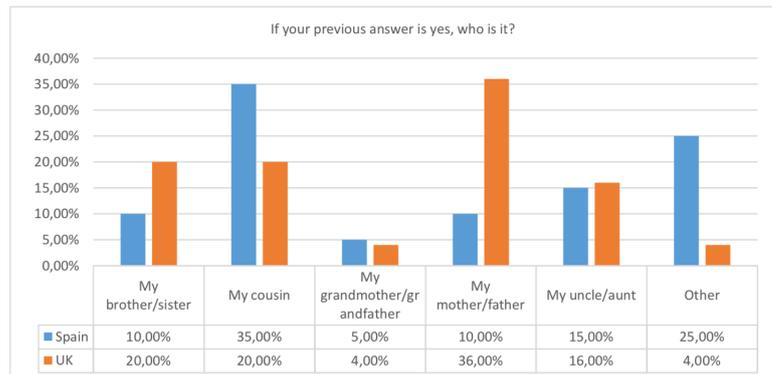


Fig. 5. 2. Graphic representing what relative is the one suffering from lupus to those who have a family member with lupus

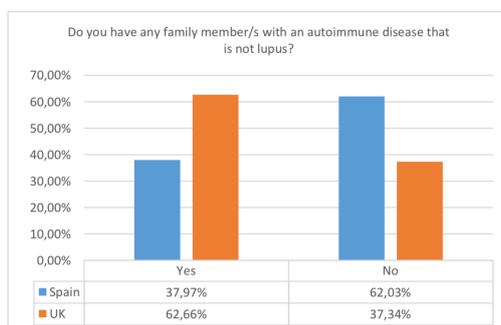


Fig. 5. 3. Graphic representing the amount of responders who have relatives with an autoimmune disease

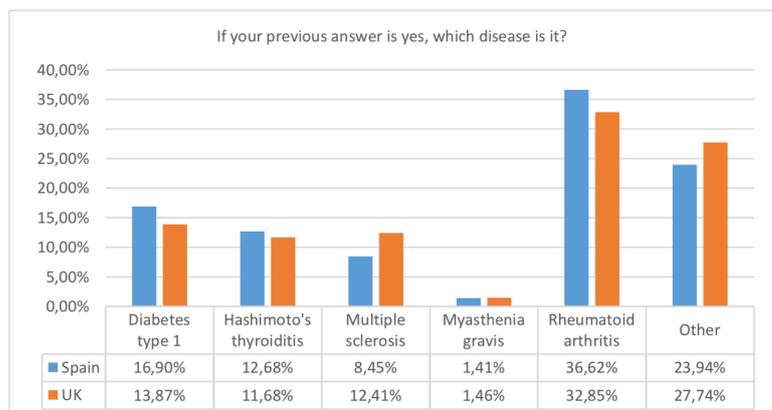


Fig. 5. 4. Graphic representing what disease the relative to those who have a family member with an autoimmune disease has

In Fig. 5. 1. we observe that 12.66% of Spanish patients and 15.82% of British patients have a relative with lupus. For 35% of these Spanish patients, this relative is a cousin, which is the fourth level of kinship, and for 36% of these patients from the UK this relative is their mother or father, which is the first level of kinship. It is also important to mention how for only 10% of Spanish patients who have a relative with lupus this relative is a first level of kinship family member. These relatives can also be a brother/sister, grandmother/grandfather, uncle/aunt or any other.

Then, we have two graphics which are also related to each other. With Fig. 5. 3. we know the number of lupus patients who have a family member with an autoimmune disease that is not lupus, and with Fig. 5. 4.

we know what autoimmune disease these relatives suffer from. We observe how over 37% of lupus patients from Spain and 62.66% of British lupus patients have a relative with an autoimmune disease that is not lupus. With Fig. 5. 4. we learn that, in both countries, this autoimmune disease the family member suffers from is, in more than 30% of the cases, rheumatoid arthritis. Other diseases they might suffer from include: diabetes type 1, Hashimoto's thyroiditis, multiple sclerosis, myasthenia gravis and others.

### 6. 1. 6. SECTION 6: ABOUT LUPUS

This is a very short section which only included three questions about any secondary illness related to lupus the patient might have; and about neonatal lupus.

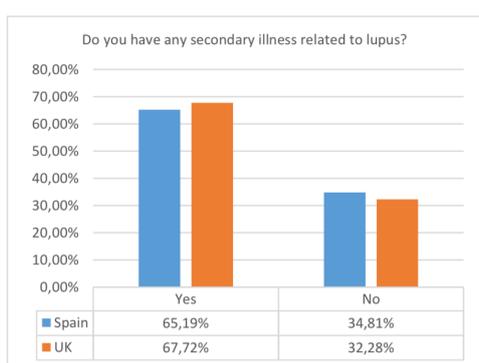


Fig. 6. 1. Graphic representing how many responders have a secondary illness related to lupus

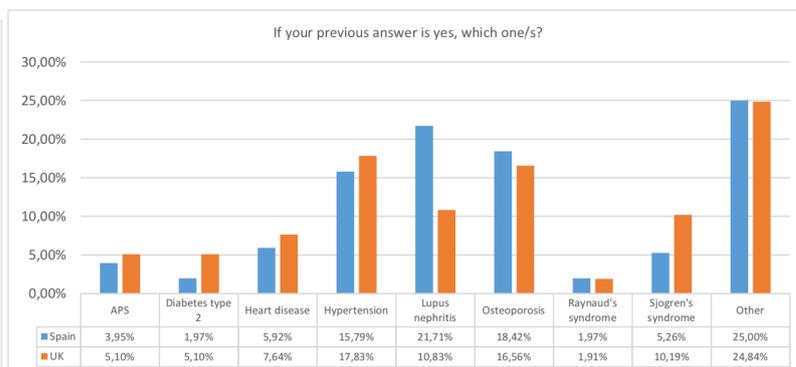


Fig. 6. 2. Graphic representing what secondary illness/es responders who have answered yes in the previous question have

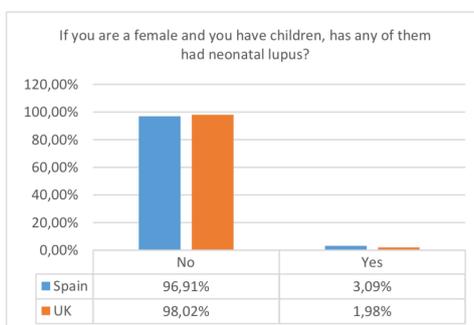


Fig. 6. 3. Graphic representing how many of the female responders who have children have had a child who suffered from neonatal lupus

With Fig. 6. 1. we learn about how many lupus patients have a secondary illness related to lupus and which illness it is. We see almost the same amount of patients from Spain and from the UK have a secondary illness, and this is over 65% of them. Thanks to the second graphic (Fig. 6. 2.) we can observe that in the case of Spanish patients, the most common secondary illness they suffer from is lupus nephritis, whereas for British patients it is hypertension, followed by osteoporosis. Nevertheless, hypertension and osteoporosis are also common in Spanish patients. Other less common secondary illnesses for both countries include: APS, diabetes type 2, heart diseases, Raynaud's syndrome, Sjögren's syndrome and others.

From Fig. 6. 3. we learn about the number of women with lupus who had a child with neonatal lupus. Over 96% of women with lupus from both countries had children who did not suffer from neonatal lupus, although there is a small percentage, which is less than 4% in each country, who did give birth to children with neonatal lupus.

### 6. 1. 7. SECTION 7: LIFESTYLE

This last section involves questions related to the way lupus has affected patients' life, their day-to-day life and lupus charities.

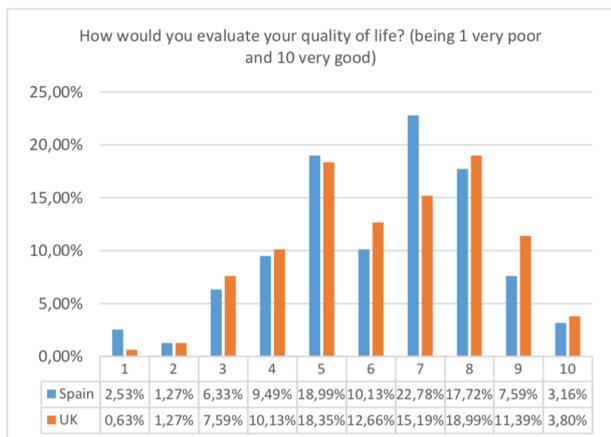


Fig. 7. 1. Graphic representing how responders evaluate their quality of life

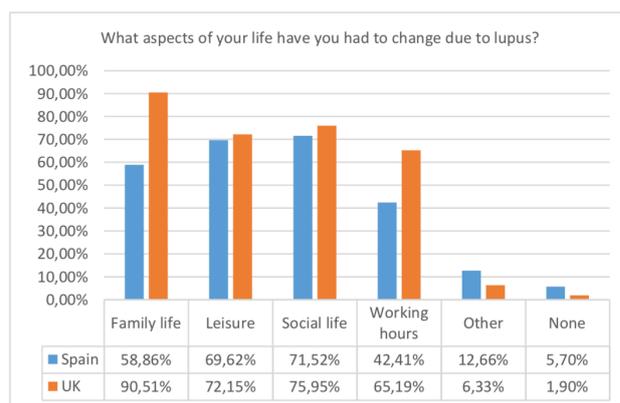


Fig. 7. 2. Graphic representing what aspects of their life responders have had to change due to lupus

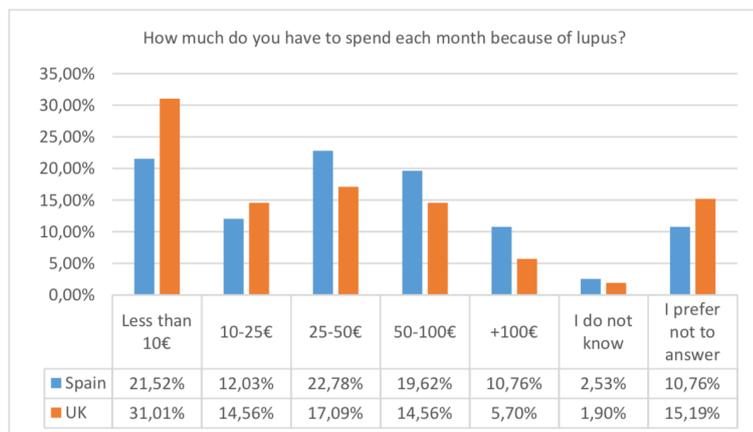


Fig. 7. 3. Graphic representing how much money responders need to spend each month because of lupus

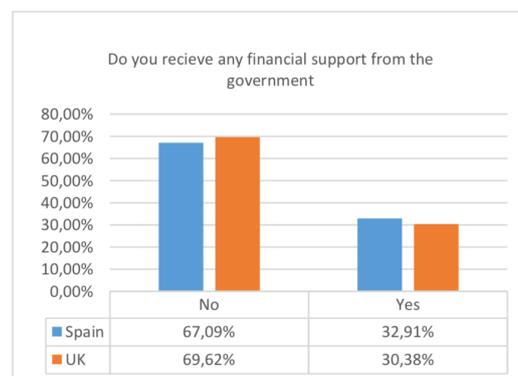


Fig. 7. 4. Graphic representing the amount of responders receiving financial support from the government.

This first part of section 7 contains four graphics.

The first one (Fig. 7. 1.) gives us an idea of how patients evaluate their quality of life. We see there are not many differences between each country, although there is a big variety of answers. The most common ones are: 5, 6, 7 and 8. Together, they represent 69.62% of patients from Spain and 65.1% of British patients. The following graphic (Fig. 7. 2.) is about the aspects of life that have changed the most for lupus patients due to the illness itself. Again, we cannot spot big differences between the two countries except for family life.

90.51% of British patients consider their family life has changed due to lupus, whereas in Spain, only 58.86% of patients do. Nevertheless, most aspects of life have changed for lupus patients, and less than 6% in each country think there is not any aspect that has changed.

Moving on to Fig. 7. 3., we learn about the amount of money patients need to spend every month because of lupus. British patients generally need to spend a lower amount of money each month, and 31.01% of those spend less than 10€ each month. When it comes to Spanish patients, the amount of money they spend every month due to lupus varies a lot.

From Fig. 7. 4. we know that less than 33% of patients in each country receive financial support from the government.

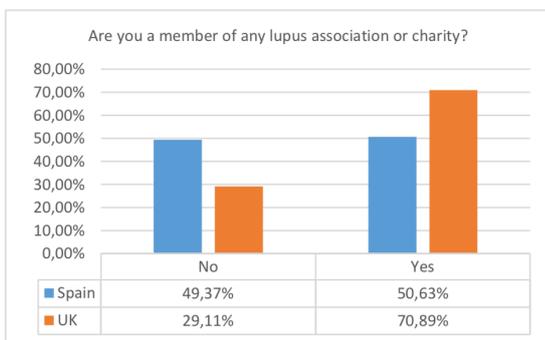


Fig. 7. 5. Graphic representing how many responders are part of a lupus charity

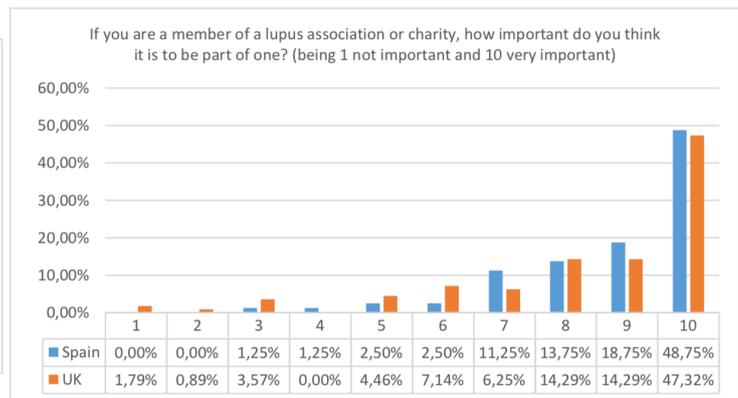


Fig. 7. 6. Graphic representing how important responders who are part of charity think it is to be part of one

With these two last graphics from the patients’ poll, we learn about the number of patients who are part of a charity/association and how important they think it is to be part of one. In Spain, 50.63% of the patients who responded to this poll are part of one, while in the UK, it represents 70.89% of them. More than 75% of patients who are part of a charity/association from both countries rated it 8, 9 or 10 in the poll, meaning they think it is very important to be part of one.

*(see ANNEX VIII where dynamic graphics and tables which were used to analyse the data from the patients’ poll appear)*

## 6. 2. FAMILY MEMBERS TO LUPUS PATIENTS’ POLL

Below, the data obtained from the poll answered by family members to lupus patients will appear in graphics.

### 6. 2. 1. SECTION 1: GENERAL QUESTIONS

In this short section we get to know about the relationship between the patient and the relative answering the poll, how long they have been cohabiting and their previous knowledge of lupus.

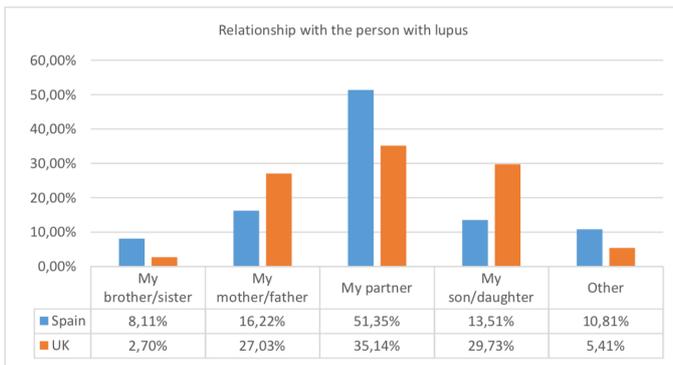


Fig. 8. 1. Graphic representing what relationship the responder has with the lupus patient

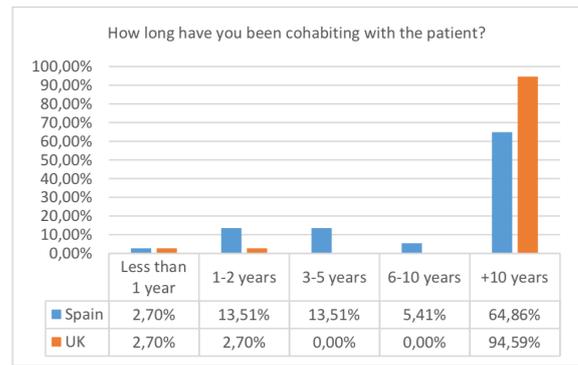


Fig. 8. 2. Graphic representing for how long the responder has been cohabiting with a lupus patient

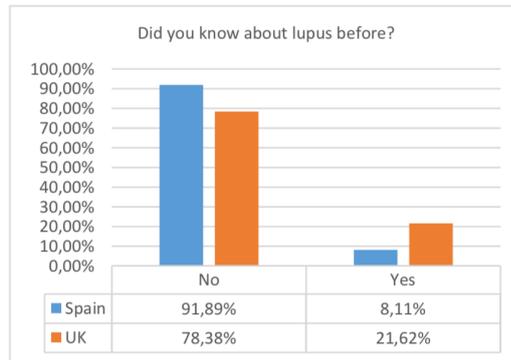


Fig. 8. 3. Graphic representing how many responders knew about lupus before their family member was diagnosed with it

Fig. 8. 1. lets us know that more than 50% of the responders of this poll from both countries are the lupus patients' partner. Then, when we look at Fig. 8. 2. we learn about how long this relative has been cohabiting with the patient for, and we see that 94.59% of family members to lupus patients from the UK who have answered this poll have been cohabiting with the patient for over 10 years. In the case of Spain, most relatives have also been cohabiting with the patient for over ten years (64. 86% of the responders).

From Fig. 8. 3. we learn that most of the responders did not know about lupus before being in contact with someone who suffered from it. Nevertheless, over 20% of family members from the UK did know about lupus previously, whereas less than 10% of family members from Spain did so.

## 6. 2. 2. SECTION 2: QUESTIONS FOR FAMILY MEMBERS WHO ALREADY LIVED WITH THE PATIENT BEFORE HE/SHE WAS DIAGNOSED

As the title of this section informs, the following questions were only answered by those who were already living with the lupus patient when he/she was diagnosed. The main aim of this section is to discover to what extent the patients' mood and lifestyle have changed before and after the diagnosis.

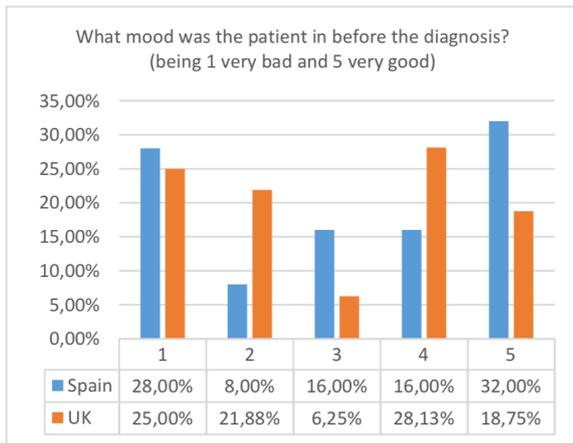


Fig. 9. 1. Graphic representing what mood the lupus patient was in before the diagnosis

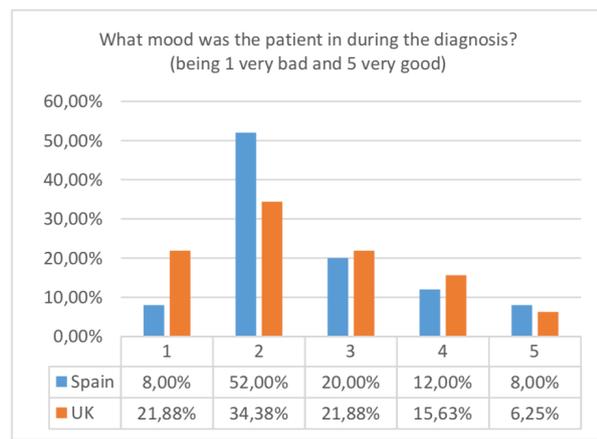


Fig. 9. 2. Graphic representing what mood the lupus patient was in during the diagnostic process

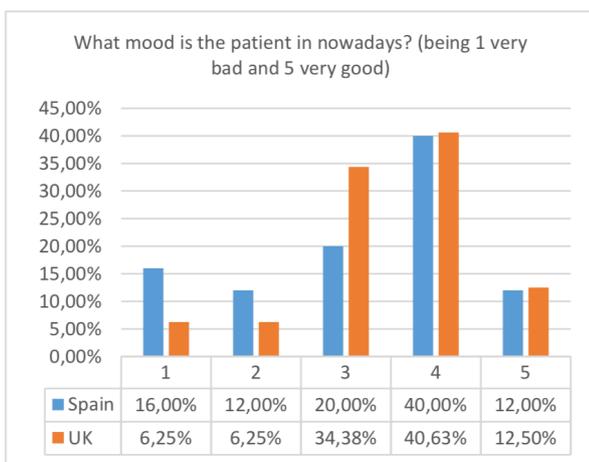


Fig. 9. 3. Graphic representing what mood the lupus patient is in nowadays

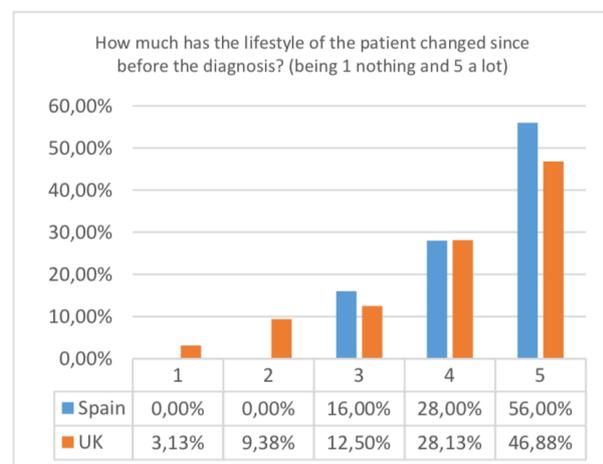


Fig. 9. 4. Graphic representing how much the lupus patient's lifestyle has changed due to lupus

The first 3 graphics from this section show us how much the patients' mood has changed throughout the diagnostic process from the family members' perspective. The Spanish patients' mood before the diagnosis was mainly either very good (5) or very bad (1). For British patients the mood before the diagnosis was very varied and none of the numbers stands out. When it comes to the mood during the diagnosis, for over 50% of Spanish patients' family members it was considered quite bad (2). British relatives to lupus patients have also considered it quite bad or medium, as number 2 and 3 make up 56.26% of the responses. Nevertheless, for over 40% of family members from both countries, the patients' mood nowadays is considered to be quite good (4). With Fig. 9. 4. we see how 56% of Spanish relatives and 46.88% of British family members consider the patients' lifestyle has changed a lot (5).

### 6. 2. 3. SECTION 3: QUESTIONS FOR ALL FAMILY MEMBERS

This last section includes a range of questions related to how lupus affect family members to lupus patients.

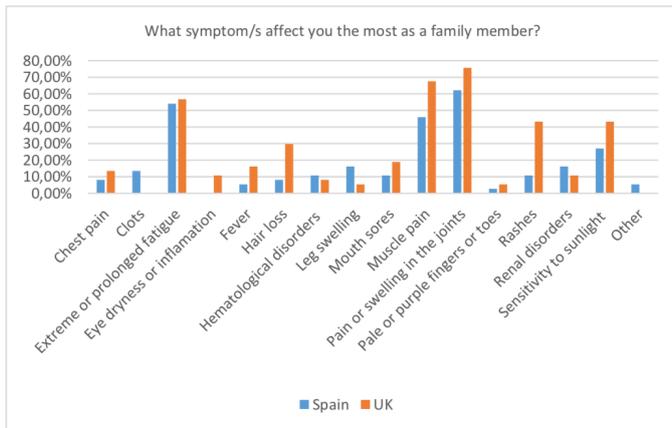


Fig. 10. 1. Graphic representing which of the lupus patient's symptoms affects the responders most as family members

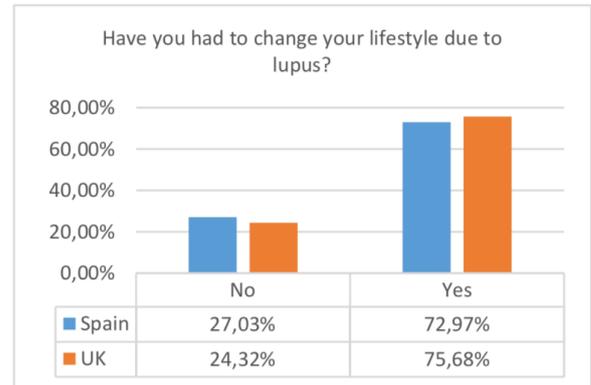


Fig. 10. 2. Graphic representing how many responders had to change their lifestyle due to lupus

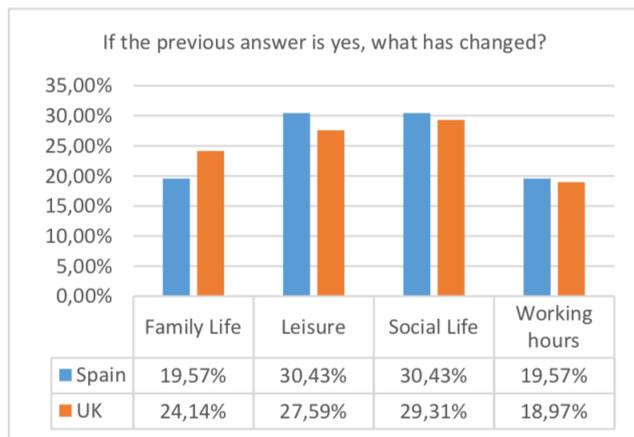


Fig. 10. 3. Graphic representing which aspects of their lifestyle have changed for responders

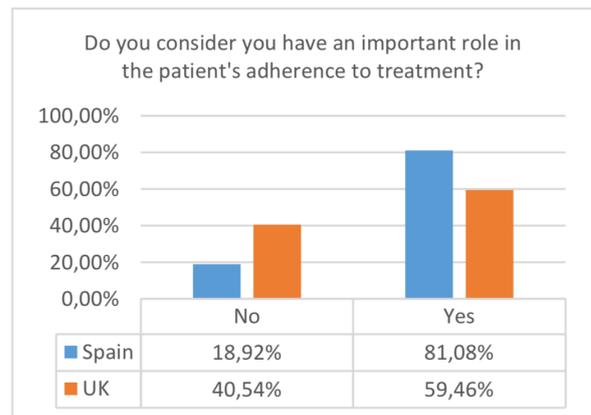


Fig. 10. 4. Graphic representing how many responders consider they have an important role in the patient's adherence to treatment

These four graphics show which of the patients' symptom/s effect relatives the most, how much their lifestyle has changed and how important their role is in the patients' adherence to the treatment.

With Fig. 10. 1. we learn how the symptoms that affect family members the most are: extreme or prolonged fatigue, muscle pain and pain or swelling in the joints.

If we move on to Fig. 10. 2. we observe that more than 72% of family members from both countries have had to change their lifestyle due to lupus. With Fig. 10. 3. we see how most aspects of their life have changed a lot, although leisure and social life are the ones that have changed the most.

Fig. 10. 4. shows how a total of 59.46% of relatives to patients from the UK consider they do have an important role in the patient's adherence to the treatment, whereas 81.08% of family members to Spanish lupus patients think so.

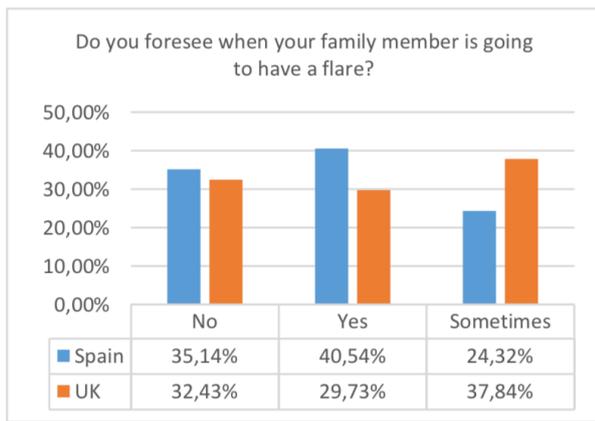


Fig. 10. 5. Graphic representing how many responders foresee when their relative with lupus is going to have a flare

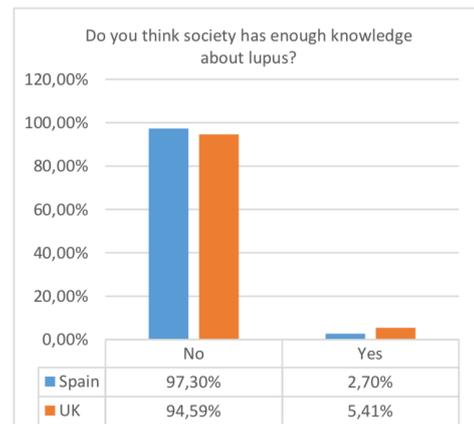


Fig. 10. 6. Graphic representing how many responders think society has enough knowledge about lupus

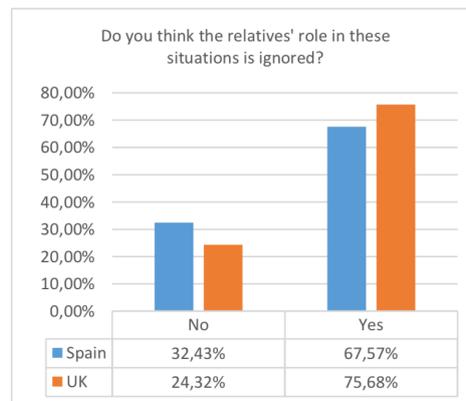


Fig. 10. 7. Graphic representing the amount of responders who think their role is ignored

These last three graphics are about flares, knowledge of lupus and relatives' role.

With Fig. 10. 5. we learn that about 40% of relatives from Spain and 30% of relatives from the UK can foresee when the lupus patient is going to have a flare. Some of the others can only foresee it some times and others cannot foresee at all.

Looking at Fig. 10. 6. we can observe how nearly all family members from both countries think that society does not have enough knowledge of lupus.

Finally, from Fig. 10. 7. can see how 75.68% of family members from the UK and 67.57% of relatives from Spain think their role is ignored.

(see ANNEX IX where dynamic graphics and tables which were used to analyse the data from the family members to lupus patients' poll appear)

## 7. INTERVIEWS

In this chapter I will be commenting the interviews done to both lupus charities staff members and to lupus specialists.

### 7. 1. INTERVIEW TO LUPUS CHARITIES STAFF MEMBERS

This interview was answered by Pilar Lucas, ACLEG's founder and CEO, and Chanpreet Walia, Social Media & Projects officer from Lupus UK. With these interviews I could learn what the aim of a lupus charity is, how they work, what problems they face, etc. Also, I could learn about how differently two charities who dedicated their work to the same disease function in two different countries.

With the first questions we learn that Lupus UK has a total of 5,000 members and ACLEG has a total of 180. We have to take into account that in the UK there are about 50,000 lupus patients, and in Catalonia, which is where ACLEG is from, has a total of 7,000 lupus patients.

Moving on we see how both charities consider their main aim to be: providing support to lupus patients, making sure all doctors have enough knowledge about lupus in order to treat patients adequately and raising awareness of lupus.

We also see that the charities have recently been working on ensuring that patients receive financial support. Chanpreet Walia said: *"Lupus UK created a Coronavirus Emergency Assistance Fund where lupus patients in crisis can apply for one-off cash grant to help with financial uncertainty and current hardships"*. And about this same topic, Pilar Lucas explained: *"another thing we are doing is helping our members get some financial support from the government"*.

From these interviews we also detect that government and other institutions do not offer these charities financial help. It is always the charities themselves who have to ask for it.

The final similarity we can spot in both charities is about the future of lupus, as they both say they are optimistic. Chanpreet comments: *"we should remain hopeful"*, and Pilar says: *"I have a lot of hope"*.

The differences between the two charities are not many but they are yet very important. The most noticeable one is that Lupus UK does everything for the patients, and Chanpreet mentions how *"Lupus UK is a patient-focused charity who places patients at the forefront of what we do"*.

Nevertheless, ACLEG's approach is linked to the conception of creating a second family where all members help each other. Pilar Lucas explains it very well: *"The idea of ACLEG is not that people become members thinking: what will the association be able to help me with? But thinking: how can I help and support the association and everyone else with lupus?"*

(see ANNEX X to read the full interviews)

## 7. 2. INTERVIEW TO LUPUS SPECIALISTS

The interview to a lupus specialist was answered by two very prestigious doctors. From Spain, we have Dr. Ricard Cervera, internist and Head of Autoimmune Diseases Department at Hospital Clínic de Barcelona. From the UK, Prof. David d’Cruz, rheumatologist and clinical team lead for the Louise Coote Lupus Unit.

Thanks to these two interviews I now know about what research related to lupus is being carried out both in Spain and in the UK. I also learned about past and future lupus investigations.

Prof. David d’Cruz is currently doing research about *“the adverse impact of Covid-19 on the care of lupus patients”*, whereas Dr. Ricard Cervera mentions he is *“currently working in more than fifty projects related to autoimmune diseases. They range from laboratory studies that help us understand better how these diseases occur, to epidemiological and clinical studies, to testing new drugs (clinical trials)”*

Through the interviews I could also learn Prof. D’Cruz regards the development of biological treatments as the most important discovery in lupus in the last few years. Dr. Cervera however, thinks that the most important discovery has been the discovery of the APS (antiphospholipid syndrome), as *“it is a disease that occurs in 30-40% of patients with lupus”*.

Then, they both talked about working in networks. Doctors usually work in the so-called networks, which means many doctors from the same speciality, in this case, lupus, send information to each other about their research. They also create scientific magazines related to lupus where all the new discoveries and advances are published. In relation to this, both specialists agree that networking and sharing information are very important. Dr. Cervera thinks: *“it is fundamental”* to work in networks.

Finally, both specialists, when being asked about how they see the near and not so near future of lupus, both talk about biological treatments. Prof. D’Cruz says: *“we are on the cusp of a revolution in the treatment of lupus with potentially many new biological treatments being approved”*, and Dr. Cervera comments: *“we will soon have some biological treatments that will allow us to treat lupus better”*.

*(see ANNEX XI to read these two interviews)*

## 8. CONCLUSIONS

After analysing all data obtained from the polls and interviews made for this research project, relevant conclusions have been reached. As mentioned in the introduction, initially, I did not expect to find many differences between the UK and Spain regarding the way lupus affects medically. To my surprise however, I have discovered numerous dissimilarities. Differences between both countries have also been found analysing the social and human sides of lupus.

Interpreting the first graphics some expected results were detected: most lupus patients are women (more than 96% of responders from both countries are women), and the most common type of lupus is SLE (more than 92% of the patients from both countries suffer from it).

The earliest difference found from the patients' poll results is that, in the UK, the age of appearance of the first symptoms is lower than in Spain. In fact, a total of 33.54% of British patients have their first symptoms before the age of 20, whereas only 15.82% of Spanish patients have symptoms before their twenties. Related to this, I have noticed how the most common first and usual symptoms in both countries are: extreme or prolonged fatigue, muscle pain, pain or swelling in the joints and rashes.

Moving on, I could see how nearly 50% of British patients have experienced more than 10 lupus flares in the last 5 years, although only 20.89% of Spanish patients have. This means that, in general terms, patients from the UK experience a lot more lupus flares than patients from Spain. It is for this reason that later on I discovered how immunosuppressant drugs are taken nowadays by more British lupus patients than Spanish ones, as they help to damp down the immune system's activity.

One of the most relevant conclusions reached in this project is that Spanish patients are more likely to suffer from renal disorders than patients from the UK. We learn that Spanish patients are twice as likely to experience renal disorders and leg swelling, which is caused by the renal problems. Then, we see how kidney biopsies and urine tests are carried out more often in Spain, and these two tests help define the affectation of the kidney. In fact, kidney biopsies are done to 15.19% of Spanish lupus patients but only to 10.13% of patients from the UK. Urine tests are carried out in nearly 60% of patients from Spain and in less than 50% of British patients. Moreover, we notice how nephrologists are visited by about 10% of Spanish patients and by a lower amount of British patients. Furthermore, we learn that non-steroidal anti-inflammatory drugs are taken nowadays by more British patients than Spanish patients, and this is because this type of drugs should be avoided by patients with renal disorders. Finally, the last evidence about this is that Spanish patients' most common secondary illness is lupus nephritis, whereas for British patients it is hypertension, followed by osteoporosis.

Thanks to this project I have also detected how clots are more often suffered by Spanish patients than by the British ones. We observe how clots appear as one of the first symptoms twice as often in Spanish patients than in patients from the UK. It remains this way when looking at the most frequent symptoms. In addition, antithrombotic drugs are taken by 12.41% of Spanish responders but only by 2.52% of British ones.

Related to the tests carried out to diagnose lupus, I have identified that in both, Spain and the UK, over 90% of the patients had a specific blood test done. It is also very interesting that 76.58% of British patients had a general blood test done, and this was only the case for 25.95% of Spanish patients.

It is also engrossing that, in the UK, the diagnostic process lasts more than 2 years for 55.06% of the patients, while it is only like this for 35.44% of Spanish patients. We can relate this to the fact that lupus is most commonly mistaken by another illness in the UK (it has happened to 70.25% of British responders), which could slow down the diagnostic process' pace.

Regarding the type of lupus specialists visited by patients, it is curious how more than 45% of Spanish patients visit internists, whereas less than 2% of the patients from the UK do so. Most patients from the UK (nearly 90%) visit a rheumatologist regularly. Rheumatologists are also commonly visited by Spanish patients (over 50% of the responders have visited one).

To boot, I identified how sensitivity to sunlight is one of the symptoms that improves the most in British patients, as it is also a more common frequent symptom in the UK than in Spain. Even so, the majority of symptoms are suffered equally by patients from Spain than by patients from the UK.

Furthermore, I have discovered a shocking result: most patients from the UK consider they have a good or very good adherence to treatment. Nevertheless, over 55.70% have had to stop taking drugs due to side effects. This means that, although having more side effects, they tried to change their medicine but still take their pills every day.

More than 12% of the patients from both countries have a family member with lupus, which is actually a very high percentage (lupus affects 1 in 1000). In the UK, for 36% of the patients who have a relative who suffers from lupus, this person is either their mother or father. In Spain, this is only this way for 10% of the responders, and the family member most commonly affected is the responder's cousin (35%). Also, over 37% of patients from Spain and over 62% of patients from the UK have a family member who suffers from an autoimmune disease that is not lupus. This disease the relative suffers from is most commonly rheumatoid arthritis in both countries.

Although in some cases lupus is not noticeable, it affects patients more than we can imagine. Due to this invisibility, it is very hard for patients to get financial support from the government. As shown, less than 33% of the responders from both countries receive financial support from the government.

Finally, from the patients' poll I could see that most responders from both countries are members of an association or charity related to lupus, and most of them consider it to be very important to be part of one.

From the relatives' poll, some conclusions have also been reached. The first I could see is that, although more relatives from the UK knew about lupus previously, a very small number of responders knew about it. This is a clear evidence that lupus is very unknown in our society. In fact, over 94% of relatives from both countries later expressed how they think society does not have enough knowledge about lupus.

Then, I could see how the patients' mood, from the family members' perspective, was at it worse during the diagnostic process (in general). This shows us how hard it can be to cope with lupus while not having any treatment for it.

Up to this point, not many differences have been spotted between both countries. However, following these conclusions I noticed how most Spanish family members (over 80%) consider themselves important when it comes to the patient's adherence to treatment. The amount of relatives from the UK who also considered themselves important in this aspect was a bit smaller (59.46%). Nevertheless, as previously commented, responders from the UK considered they had a higher adherence to treatment.

When it comes to the interviews done to lupus charities staff members, the first dissimilarity I saw was how a higher percentage of patients from the UK become members of a charity than in Spain (in this case, Catalonia). Another clear difference between those two charities is their ideology. ACLEG (Spanish charity) considers the charity to be like a second family for both, patients and staff members. This means that members also help the charity greatly, although Lupus UK's ideology is about doing everything for the patients, without them interfering in the charity's activity.

Last but not least, I will comment the conclusions reached from the specialists' interviews. They both agreed in most aspects discussed, although something curious is that Dr. Cervera, the Spanish lupus specialist, considers the discovery of APS to be the most important advance in lupus. Even so, Prof. d'Cruz, the British lupus specialist, considers the development of biological therapies to be the most important discovery so far. Dr. Cervera, however, considers biological therapies the future of lupus.

In the next paragraphs I would like to articulate an evaluation of this research project at a personal level.

I started this project looking forward to learning as much as possible about lupus, and I have finished it with even more willingness to keep learning about it. It has passionated me in every way. Having the opportunity

to meet lupus patients, to talk to specialists, to converse with lupus charities, amongst others, has truly made me realise I want to continue my studies in the health field. This project has also made me notice that the human and social sides of a disease are as important as the medical one and equally magnificent.

Choosing a topic I enjoyed working on since the first day has made me stay motivated throughout the whole making of this project. It has been many hours of dedication and effort, but today, I am grateful for what this project has brought me. At a personal level, the main goals of this project were to learn as much as possible about autoimmune diseases and lupus, to understand how research projects are done, and, most importantly, to enjoy the opportunity of profoundly learning about a disease, which passionates me. Now, I can say I have achieved all of those better than I could have ever expected.

The main aim of this project however, was to be able to compare how differently lupus affects in the UK than in Spain. Not just the medical side of lupus, but also the human and social sides. I feel like I have managed to reflect how this goal has also been achieved.

I started this project having very little knowledge of lupus and autoimmune disease, and, even so, I have managed to complete this project with deep knowledge about them. Without having ever studied a disease so profoundly, it was hard to know how to start off this project, but thanks to the help of many people, I could end up making it as it is now. Although some obstacles have appeared throughout the process, I feel like I have been able to overcome them successfully. The most important ones have been not being able to meet people face-to-face due to Covid-19 and having to learn not just about lupus and autoimmune diseases but also about Excel, the programme I have used to process all the data.

The methodology used for this research project has been complex but the appropriate one, as it has permitted me get the most out of my research. It included getting in touch with an endless amount of people, creating polls and interviews, analysing the data obtained using different programmes, translating half of the data, etc. Now this project has come to an end, but the investigation could go on. With all the data obtained I could have compared not just how differently lupus affects patients in the UK and in Spain. I could also compare, for example, the importance of the environment where lupus patients live in, or the importance of the age of appearance of the first symptoms, etc.

From this project, leaving the research aside, I have also learned so many things that will help me in my future, both academically and personally. I have learned personal skills such as becoming more independent, more organised, etc., but also very important lessons. I feel like the most important one I have learned is to never judge people by their appearances and to be more open-minded. I would like to end expressing how much I admire everyone I have met thanks to this research project, they will always be an inspiration.

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