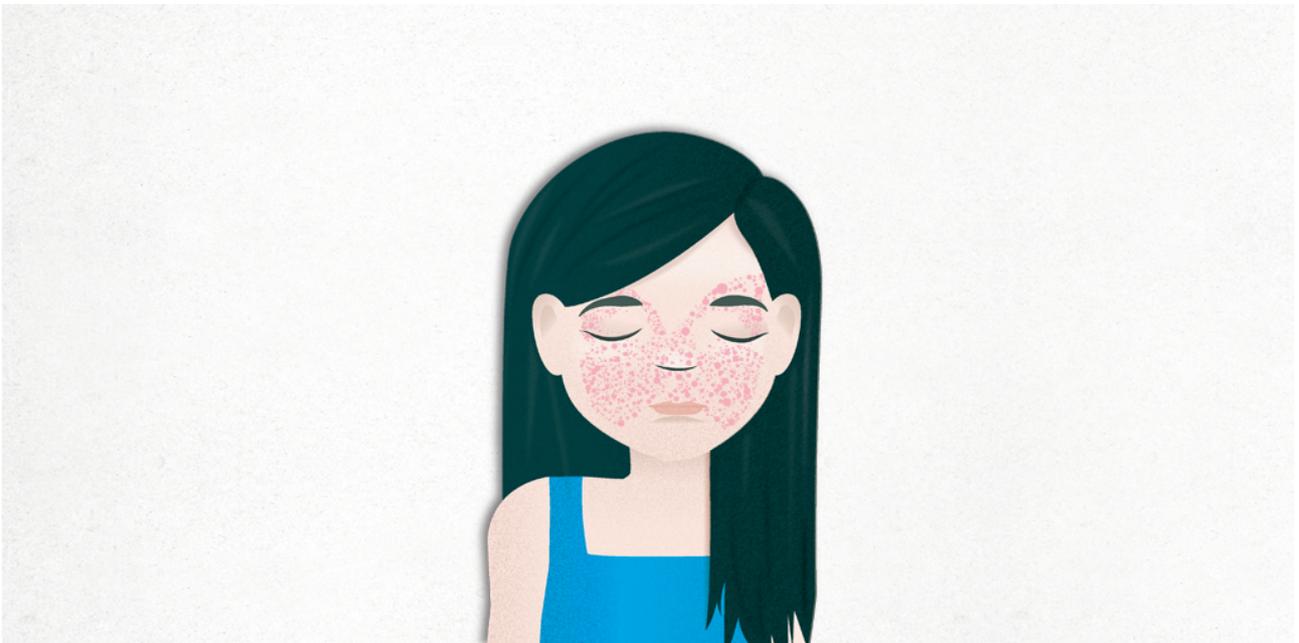


A RESEARCH ON THE IMPLICATIONS OF
LIVING IN THE UK OR SPAIN AND SUFFERING
FROM LUPUS DISEASE



ANNEXES

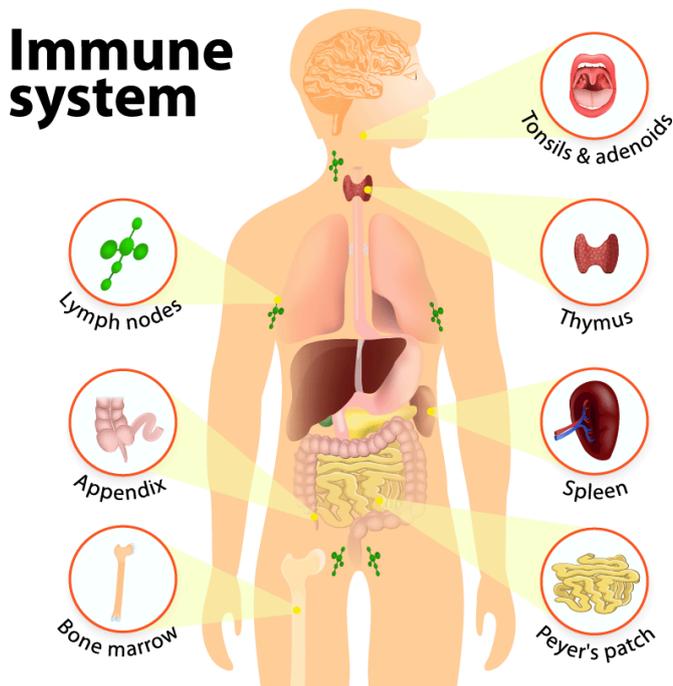
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ANNEX I. IMMUNE SYSTEM: PICTURES AND DRAWINGS

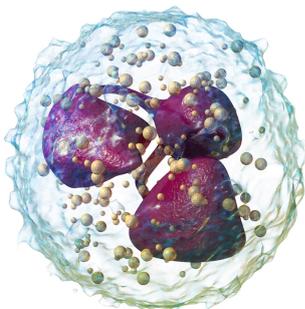
1. 2. IMMUNE SYSTEM'S ORGANS



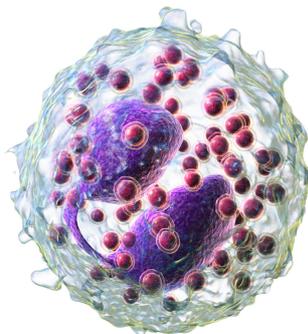
Drawing of the immune system's organs

- Thymus: gland situated between the lungs and the neck
- Spleen: organ that filters the blood. It sits in the upper left of the abdomen
- Bone marrow: found within the bones, it also produces red blood cells
- Lymph nodes: small glands positioned throughout the body, linked by lymphatic vessels
- Adenoids: two glands located at the back of the nasal passage
- Tonsils: two oval masses in the back of the throat
- Peyer's patch: lymphoid tissue in the small intestine

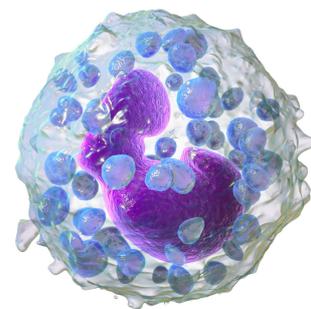
1. 2. MYELOID PROGENITOR CELLS REPRESENTATION



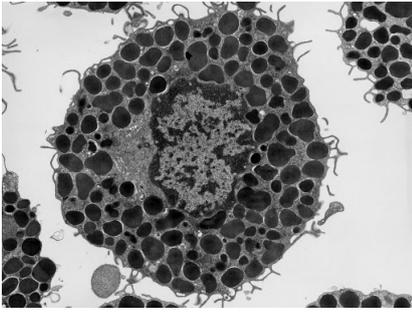
Neutrophil



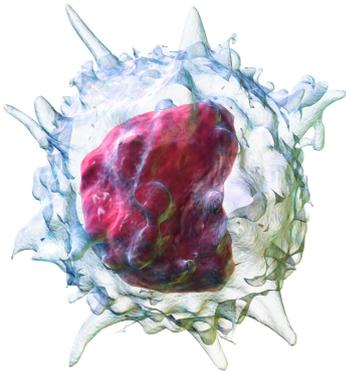
Eosinophil



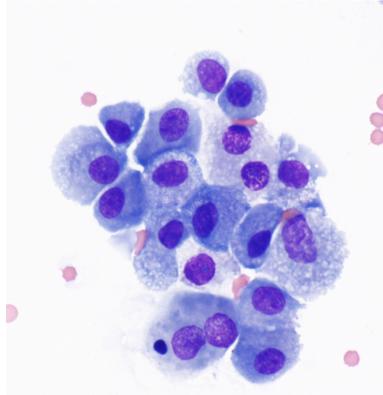
Basophil



Mast cell



Monocyte

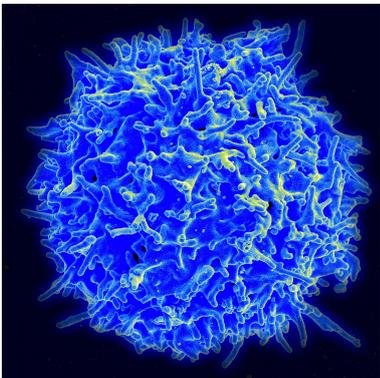


Macrophages

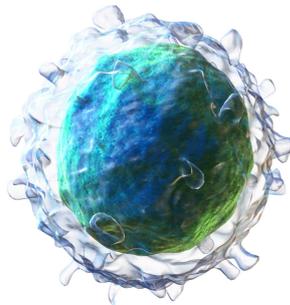


Dendritic cell

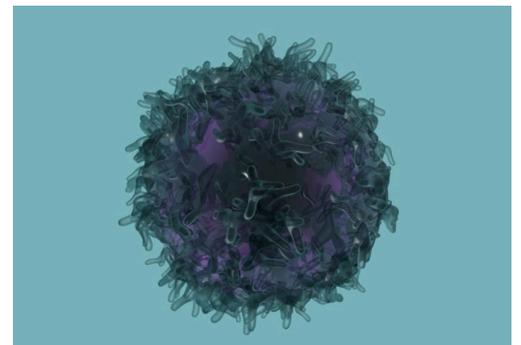
1. 3. LYMPHOID PROGENITOR CELLS REPRESENTATION



T lymphocyte



B lymphocyte



Natural killer cell

ANNEX II. LUPUS SYMPTOMS: PICTURES



Swelling in the joints



Lupus rash in the face



Swollen foot and ankle



Pale fingers

ANNEX III. REQUIRED DOCUMENTS TO POLL IN THE UK

3. 1. PARTICIPANTS' RIGHT TO WITHDRAW



RIGHT TO WITHDRAW

If you want to withdraw this interview research, please fill out this form and send it back.

DATA OF THE INSTITUTION IN CHARGE

Name: FUNDACIÓ PRIVADA ESCOLAR MARE DE DÉU DEL CLAUSTRE (ESCOLA ARRELS)

Address: Av. Cardenal Tarancón 49, 25280 Solsona, Lleida. (Spain)

DATA OF THE INTERVIEWEE

Mr./ Ms with legal age and address in
Street/ Avenue / Road.....
City / Town County Zip code.
Email:..... by means of this
form I express my desire to exercise my right to **WITHDRAW**, in accordance with
article 17 of Regulation (UE) 2016/679 on 27 April.

REQUEST -

1. In ten days of receiving this request, please proceed to the effective cancellation of any data relating to me in your research, in the terms provided in the article 6 and please communicate it to me in writing to the address or email indicated above.
2. In the event that the person in charge of the research considers that the aforementioned cancellation does not apply, she must also communicate this within the indicated ten-day period.

Date _____

Signature of interviewee

FUNDACIÓ PRIVADA ESCOLAR MARE DE DEU DEL CLAUSTRE (ESCOLA ARRELS), in compliance with the General Data Protection Regulation -EU-2016/679, of the Parliament and the Council of Europe, informs you that your personal data will be processed for the administrative, accounting and provision of the service offered by the school, it will not be assigned to third parties, unless it is a legal obligation, or for accounting and tax treatment, through a contract for the Provision of Services through the Data Controller.

You can exercise your rights of access, rectification, cancellation, opposition, portability and limitation by contacting the headquarters, located at :

AVDA. CARDENAL TARANCON, 49 - 25280 SOLSONA (LLEIDA), direccio@escolaarrels.com

3. 2. PROOF OF ETHICAL APPROVAL



CERTIFICATE OF ETHICAL APPROVAL

This certificate confirms that the application made by **ADAIA FLOTATS BOIX** to Secondary Arrels School in Solsona to research about lupus in Catalonia and in the UK during the year 2020 was approved.

Project title

Lupus: a clinical comparison between Catalonia and the United Kingdom

Project tutor

Esther Ginestà Ros (ester.ginesta@escolaarrels.com)

Description of the project

Clinical comparison of lupus between the United Kingdom and Catalonia. First, Adaia will find out how a lupus association works in Catalonia and how it does in the UK. Next, she will compare patients: diagnosis (tests that are carried out for the diagnosis, age when the disease appears, time since the first symptoms until the diagnosis, laboratory tests for the definitive diagnosis...), the most used treatments, survival, other autoimmune diseases in the family, prevalence, epigenetic factors... She will also compare the role of the family members in the life of a lupus patient.

Finally, she will make some interviews to:

- a Catalan lupus specialist and a British one
- Lupus Catalan Association President and Lupus UK President
- lupus patients from Catalonia and from UK
- lupus patients' family in Catalonia and in UK

Date approved: 16th July 2020

Solsona, 20th July 2020

Signed:

MIREIA MASSANA SERRA (Headteacher of Arrels School)

FUNDACIÓ PRIVADA ESCOLAR MARE DE DEU DEL CLAUSTRE (ESCOLA ARRELS): AVDA. CARDENAL TARANCON, 49 - 25280 SOLSONA (LLEIDA), direccio@escolaarrels.com

ANNEX IV. EXCEL BOOKS

4. 1. LUPUS PATIENTS' POLL EXCEL BOOK

Pen drive

4. 2. FAMILY MEMBERS TO LUPUS PATIENTS' POLL EXCEL BOOK

Pen drive

ANNEX V. POLL TO LUPUS PATIENTS

5. 1. POLL TO LUPUS PATIENTS IN SPANISH

Encuesta a pacientes con lupus

Hola a todas y a todos,

soy Adaia Flotats, estudiante de bachillerato y miembro del programa “Bojos per la Medicina” de la “Fundació Catalunya-La Pedrera”. Gracias a este programa conocí al Dr. Ricard Cervera, quien me transmitió su gran interés por estudiar y conocer mejor el lupus y las enfermedades autoinmunes.

Por esta razón decidí realizar mi “T treball de Recerca” sobre las diferencias en el diagnóstico, tratamientos, estilo de vida y otros factores del lupus entre España y el Reino Unido.

Hoy me atrevo a pedir os cinco minutos de vuestro tiempo, que es lo que os llevará contestar esta encuesta anónima. Gracias por adelantado.

No puedo terminar sin agradecer infinitamente la paciencia y ayuda de Pilar Lucas, presidenta de la Asociación Catalana de Lupus E. G.

Un abrazo.

*Required

1. Año de nacimiento *

2. Sexo *

Mark only one oval.

Mujer

Hombre

Prefiero no decirlo

3. País de residencia *

Mark only one oval.

España

Reino Unido

Other: _____

4. País de procedencia (si no es el mismo que el de residencia)

5. Número de hijos

Mark only one oval.

0

1

2

3

4+

6. ¿En qué entorno vive? *

Mark only one oval.

Urbano (1.000 a 15.000 hab.)

Urbano (15.000 a 100.000 hab.)

Urbano (más de 100.000 hab.)

Rural

7. ¿Qué tipo de lupus padece? *

Mark only one oval.

Lupus eritematoso sistémico (LES)

Lupus eritematoso cutáneo

Lupus inducido por fármacos

Síntomas

8. ¿Qué edad tenía cuando empezó a padecer los primeros síntomas? *

Mark only one oval.

- 0-9 años
- 10-14 años
- 15-19 años
- 20-24 años
- 25-29 años
- 30-34 años
- 35-39 años
- 40-44 años
- 45-60 años
- +60 años

9. ¿Cuáles fueron sus primeros síntomas? *

Tick all that apply.

- Dolor muscular
- Dolor articular
- Fiebre
- Erupciones cutáneas
- Dolor de pecho
- Pérdida de cabello
- Sensibilidad al sol o la luz
- Problemas renales
- Llagas en la boca
- Fatiga extrema o prolongada
- Anomalías hematológicas (por ej. anemia)
- Sequedad o inflamación ocular
- Coágulos
- Hinchazón en las piernas
- Dedos de las manos o de los pies pálidos o morados

Other: _____

10. ¿Cuáles son sus síntomas más frecuentes? *

Tick all that apply.

- Dolor muscular
- Dolor articular
- Fiebre
- Erupciones cutáneas
- Dolor de pecho
- Pérdida de cabello
- Sensibilidad al sol o la luz
- Problemas renales
- Llagas en la boca
- Fatiga extrema o prolongada
- Anomalías hematológicas (por ej. anemia)
- Sequedad o inflamación ocular
- Coágulos
- Hinchazón de piernas
- Dedos de las manos o de los pies pálidos o morados

Other: _____

11. ¿Puede definir la frecuencia de aparición de los brotes? *

Mark only one oval.

- Sí
- No

12. Si la respuesta anterior es afirmativa, ¿cada cuándo le aparecen aproximadamente?

Mark only one oval.

- Menos de 1 vez al año
- 1-2 veces al año
- 3-5 veces al año
- +5 veces al año

13. ¿Sabría decir cuántos brotes ha padecido en los últimos cinco años? *

Mark only one oval.

- 1 o 2
- De 3 a 5
- De 6 a 10
- Más de 10
- Ninguno
- No lo sé

Proceso diagnóstico

14. ¿Qué pruebas diagnósticas le realizaron para confirmar el diagnóstico de lupus? *

Tick all that apply.

- Analítica general no específica de sangre
- Analítica de autoinmunidad (AAN, anticuerpos anti-DNA, anticuerpos anti-Sm, anticuerpos anti-Ro...)
- Análisis de orina
- Biopsia de piel
- Biopsia de riñón
- Radiografía de tórax
- Electrocardiograma

Other: _____

15. ¿Cuánto tiempo pasó desde la aparición de los primeros síntomas hasta el diagnóstico final? *

Mark only one oval.

- 0-3 meses
- 4-6 meses
- 7-12 meses
- 1-2 años
- +2 años

16. ¿Qué médico especialista le confirmó el diagnóstico? *

Mark only one oval.

- Médico internista
- Nefrólogo
- Reumatólogo
- Dermatólogo
- Neumólogo
- Neurólogo
- Cardiólogo
- Other: _____

17. ¿Pensaron que podía tratarse de otra enfermedad antes de confirmar el diagnóstico de lupus? *

Mark only one oval.

- Sí
- No

18. Si ha contestado sí a la pregunta anterior, ¿de qué enfermedad sospechaban?

Tratamiento

19. ¿Qué especialista/s le trata/n actualmente? *

Tick all that apply.

- Médico internista
- Nefrólogo
- Reumatólogo
- Dermatólogo
- Neumólogo
- Neurólogo
- Cardiólogo

Other: _____

20. ¿Qué tratamiento/s sigue actualmente? *

Tick all that apply.

- Fármacos antiinflamatorios no esteroides (Ibuprofeno, naproxeno...)
- Fármacos antitrombóticos (ácido acetilsalicílico, sintrom...)
- Fármacos antipalúdicos o antimaláricos (hidroxicloroquina, cloroquina...)
- Fármacos corticoides (prednisona)
- Inmunodepresores (metotrexato, azatioprina...)
- Terapias biológicas (belimumab, rituximab)

Other: _____

21. ¿Podría indicar la pauta? *

22. ¿Qué síntoma/s han mejorado con el tratamiento? *

Tick all that apply.

- Dolor muscular
- Dolor articular
- Fiebre
- Erupciones cutáneas
- Dolor de pecho
- Pérdida de cabello
- Sensibilidad al sol o la luz
- Problemas renales
- Llagas en la boca
- Fatiga extrema o prolongada
- Anomalías hematológicas (por ej. anemia)
- Sequedad o inflamación ocular
- Coágulos
- Hinchazón de piernas
- Dedos de las manos o de los pies blancos o morados
- Ninguno

Other: _____

23. ¿Qué síntoma/s ha conseguido erradicar con el tratamiento? *

Tick all that apply.

- Dolor muscular
- Dolor articular
- Fiebre
- Erupciones cutáneas
- Dolor de pecho
- Pérdida de cabello
- Sensibilidad al sol o la luz
- Problemas renales
- Llagas en la boca
- Fatiga extrema o prolongada
- Anomalías hematológicas (por ej. anemia)
- Sequedad o inflamación ocular
- Coágulos
- Hinchazón de piernas
- Dedos de las manos o de los pies blancos o morados
- Ninguno

Other: _____

24. ¿Cuál o cuáles fueron los primeros fármacos que utilizó para tratar la enfermedad?

*

Tick all that apply.

- Fármacos antiinflamatorios no esteroides (ibuprofeno, naproxeno...)
- Fármacos antitrombóticos (ácido acetilsalicílico, sintrom...)
- Fármacos antipalúdicos o antimaláricos (hidroxicloroquina, cloroquina...)
- Fármacos corticoides (prednisona...)
- Inmunodepresores (metotrexato, azapaina...)
- Terapias biológicas
- No lo recuerdo

Other: _____

25. ¿Ha tenido que dejar algún fármaco debido a sus efectos secundarios? *

Mark only one oval.

- Sí
- No
- No lo recuerdo

26. Si su respuesta anterior es afirmativa, ¿cuál o cuáles?

27. ¿Recuerda algún fármaco que utilizó en un pasado y ya no utiliza? En caso afirmativo, ¿cuál o cuáles?

Tick all that apply.

- Fármacos antiinflamatorios no esteroides (Ibuprofeno, naproxeno...)
- Fármacos antitrombóticos (ácido acetilsalicílico, sintrom...)
- Fármacos antipalúdicos o antimaláricos (hidroxicloroquina, cloroquina...)
- Fármacos corticoides (prednisona...)
- Inmunodepresores (metotrexato, azapaina...)
- Terapias biológicas

Other: _____

28. ¿Ha probado alguna terapia alternativa para tratar el lupus? *

Mark only one oval.

- Sí
- No

29. Si la respuesta anterior es afirmativa, ¿cuál o cuáles?

30. Si ha contestado la pregunta anterior, ¿ha notado alguna mejora después de utilizar esta o estas terapias?

Mark only one oval.

- Sí
- No
- No lo sé

31. ¿Cómo considera su adherencia al tratamiento? (siendo 1 muy baja y 10 muy alta) *

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

Factores que pueden influir

32. ¿Tiene algún familiar con lupus? *

Mark only one oval.

- Sí
- No
- No lo sé

33. Si ha respondido sí a la pregunta anterior, este familiar es:

Tick all that apply.

- mi hermano/a
- mi padre / madre
- mi hijo/a
- mi abuelo/a
- mi nieto/a
- mi tío/a
- mi primo/a

Other: _____

34. ¿Tiene algún familiar que padezca una enfermedad autoinmune que no sea lupus? *

Mark only one oval.

- Sí
- No

35. Si ha respondido sí a la pregunta anterior, ¿es alguna/s de las siguientes? Si no, por favor, especifíquela.

Tick all that apply.

- Esclerosis múltiple
- Diabetes tipo I
- Miastenia gravis
- Artritis reumatoide
- Tiroiditis de Hashimoto

Other: _____

Del lupus

36. ¿Padece alguna enfermedad secundaria como consecuencia del lupus? *

Mark only one oval.

Sí

No

37. Si ha contestado sí a la pregunta anterior, ¿cuál o cuáles?

Tick all that apply.

Osteoporosi

Hipertensión

Cardiopatía

Diabetes tipo 2

Nefritis lúpica

Other: _____

38. En caso de ser mujer y tener hijos, ¿alguno sufre o sufrió lupus neonatal?

Mark only one oval.

Sí

No

Estilo de vida

39. ¿Cómo valoraría su calidad de vida? (siendo 1 muy mala y 10 muy buena) *

Mark only one oval.

1 2 3 4 5 6 7 8 9 10

40. ¿Qué aspectos de su vida ha tenido que cambiar debido a su enfermedad? *

Tick all that apply.

Horario laboral

Ocio

Vida social

Vida familiar

Other: _____

41. ¿Qué coste económico mensual le supone la enfermedad? *

Mark only one oval.

Menos de 10€

10-25€

25-50€

50-100€

+100€

Prefiero no contestar

Other: _____

42. ¿Tiene reconocida la discapacidad orgánica? *

Mark only one oval.

Sí

No

43. Si ha respondido que sí a la pregunta anterior, ¿qué grado?

Mark only one oval.

- Clase 1
- Clase 2
- Clase 3
- Clase 4
- Clase 5
- No lo sé

44. ¿Fuma o ha fumado nunca? *

Mark only one oval.

- Fumo actualmente
- Fumé en un pasado
- No he fumado nunca

45. ¿Hace ejercicio regularmente? *

Mark only one oval.

- Sí
- No

46. ¿Cuánto ha afectado el lupus a su vida social? (siendo 1 nada y 10 mucho) *

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

47. ¿Es miembro de alguna asociación? *

Mark only one oval.

Sí

No

48. Si ha respondido sí a la pregunta anterior, ¿de qué asociación o asociaciones es miembro?

Tick all that apply.

Asociación Catalana de Lupus E. G.

Federación Española de Lupus

Asociaciones locales

Other: _____

49. En caso de que sea miembro de una asociación, ¿cómo de importante cree que es serlo? (siendo 1 nada importante y 10 muy importante)

Mark only one oval.

1 2 3 4 5 6 7 8 9 10

<input type="radio"/>										
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Google Forms

5. 2. POLL TO LUPUS PATIENTS IN ENGLISH

Survey to lupus patients

Hello everyone,

I am Adaia Flotats, a Year 13 student from Catalonia, Spain. This year I received a scholarship to go to Hospital Clínic de Barcelona to learn about medicine. Thanks to this scholarship I met Dr. Ricard Cervera, a lupus specialist who conveyed to me his great interest in studying and learning more about lupus and autoimmune diseases. This is why I decided to do my end of school Research Project about lupus. I will be comparing the treatments, diagnostic process, lifestyle, family's role and other factors of lupus between the UK and Spain.

This is why I would really appreciate if you could answer this five minute long anonymous survey. Thank you in advance.

I could not finish without saying thank you to Lupus UK for all the help, specially Paul Howard.

Best wishes.

***Required**

1. Year of birth *

2. Sex *

Mark only one oval.

Female

Male

Prefer not to say

3. Country of residence *

Mark only one oval.

United Kingdom

Spain

Other: _____

4. Country of origin (if it is not the same as the country of residence)

5. Number of children

Mark only one oval.

0

1

2

3

4+

6. In what kind of environment do you live? *

Mark only one oval.

Town (1.000 - 15.000 inhabitants)

Small city (15.000 - 100.000 inhabitants)

Big city (more than 100.000 inhabitants)

Rural

7. What type of lupus do you have? *

Mark only one oval.

Systemic lupus erythematosus (SLE)

Cutaneous lupus (Lupus limited to the skin)

Drug-induced lupus

Symptoms

8. How old were you when you had your first symptoms? *

Mark only one oval.

- 0-9 years old
- 10-14 years old
- 15-19 years old
- 20-24 years old
- 25-29 years old
- 30-34 years old
- 35-39 years old
- 40-44 years old
- 45-60 years old
- +60 years old

9. What were your first symptoms? *

Tick all that apply.

- Muscle pain
- Pain or swelling in the joints
- Fever
- Rashes
- Chest pain
- Hair loss
- Sensitivity to sunlight or fluorescent light
- Renal problems
- Mouth sores
- Extreme or prolonged fatigue
- Hematologic abnormalities (e.g. anemia)
- Eye dryness or inflammation
- Clots
- Leg swelling
- Pale or purple fingers or toes

Other: _____

10. What are your most frequent symptoms? *

Tick all that apply.

- Muscle pain
- Pain or swelling in the joints
- Fever
- Rashes
- Chest pain
- Hair loss
- Sensitivity to sunlight or fluorescent light
- Renal disorders
- Mouth sores
- Extreme or prolonged fatigue
- Haematological disorders (e.g. anemia)
- Eye dryness or inflammation
- Clots
- Leg swelling
- Pale or purple fingers or toes

Other: _____

11. Could you tell how often your lupus flares-up? *

Mark only one oval.

- Yes
- No

12. If your previous answer is yes, how often?

Mark only one oval.

- Less than once a year
- 1 or 2 times a year
- 3-5 times a year
- +5 times a year

13. Could you tell how many flares you have had in the last five years? *

Mark only one oval.

- 1 or 2
- 3 to 5
- 6 to 10
- More than 10
- None
- I do not know

Diagnostic process

14. Which tests were carried out in order to confirm the diagnosis of lupus? *

Tick all that apply.

- General blood test
- Tests for autoimmune diseases (ANA, dsDNA, ENA...)
- Urine testing
- Skin biopsy
- Kidney biopsy
- Chest X-ray
- Electrocardiogram

Other: _____

15. How long did it take from the appearance of the first symptoms to the final diagnosis? *

Mark only one oval.

- 0-3 months
- 4-6 months
- 7-12 months
- 1-2 years
- +2 years

16. Which medical specialist confirmed the diagnosis? *

Mark only one oval.

- Internist
- Nephrologist
- Rheumatologist
- Dermatologist
- Pulmonologist
- Neurologist
- Cardiologist
- Other: _____

17. Before confirming the diagnosis of lupus, did any doctor think it could be another illness? *

Mark only one oval.

- Yes
- No

18. If your previous answer is yes, what illness did the doctor think it could be?

Treatment

19. Which medical specialists do you visit regularly? *

Tick all that apply.

- Internist
- Nephrologist
- Rheumatologist
- Dermatologist
- Pulmonologist
- Neurologist
- Cardiologist

Other: _____

20. What drugs do you take nowadays? *

Tick all that apply.

- Non-steroidal anti-inflammatory drugs (ibuprofen, naproxen...)
- Antithrombotic drugs (acetylsalicylic acid, sinthrome...)
- Antimalarial drugs (hidroxicloroquine, cloroquine...)
- Corticosteroid drugs (prednisolone...)
- Immunosuppressants (methotrexate, azathioprine...)
- Biological therapies (belimumab, rituximab...)

Other: _____

21. Could you share the regimen of your treatment? *

22. Which symptoms have improved with treatment? *

Tick all that apply.

- Muscle pain
- Pain or swelling in the joints
- Fever
- Rashes
- Chest pain
- Hair loss
- Sensitivity to sunlight or fluorescent light
- Renal disorders
- Mouth sores
- Extreme or prolonged fatigue
- Hematological disorders (e.g. anemia)
- Eye dryness or inflammation
- Clots
- Leg swelling
- Pale or purple fingers or toes
- None

Other: _____

23. Which symptoms have been eradicated with treatment? *

Tick all that apply.

- Muscle pain
- Pain or swelling in the joints
- Fever
- Rashes
- Chest pain
- Hair loss
- Sensitivity to sunlight or fluorescent light
- Renal disorders
- Mouth sores
- Extreme or prolonged fatigue
- Hematological disorders (e.g. anemia)
- Eye dryness or inflammation
- Clots
- Leg swelling
- Pale or purple fingers or toes
- None

Other: _____

24. What were the first drugs that you used against lupus? *

Tick all that apply.

- Non-steroidal anti-inflammatory drugs (ibuprofen, naproxen...)
- Antithrombotic drugs (acetylsalicylic acid, sinthrome...)
- Antimalarial drugs (hidroxicloroquine, cloroquine...)
- Corticosteroid drugs (prednisolone...)
- Immunosuppressants (methotrexate, azathioprine...)
- Biological therapies (belimumab, rituximab...)
- I do not remember

Other: _____

25. Have you had to stop taking a drug due to side effects? *

Mark only one oval.

- Yes
 No
 I do not remember

26. If your previous answer is yes, which one/s?

27. Do you remember any drug you used in the past that you don't use anymore? In case you do remember, which one/s?

Tick all that apply.

- Non-steroidal anti-inflammatory drugs (ibuprofen, naproxen...)
 Antithrombotic drugs (acetylsalicylic acid, sinthrome...)
 Antimalarial drugs (hidroxicloroquine, cloroquine...)
 Corticosteroid drugs (prednisolone...)
 Immunosuppressants (methotrexate, azathioprine...)
 Biological therapies (belimumab, rituximab...)

Other: _____

28. Have you tried alternative therapies to treat lupus? *

Mark only one oval.

- Yes
 No

29. If your previous answer is yes, which one/s?

30. If you have answered the previous question, have you noticed an improvement?

Mark only one oval.

- Yes
- No
- Maybe

31. How is your adherence to treatment? (being 1 very low and 10 very high) *

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

Factors that can influence having lupus

32. Do you have any family member/s with lupus? *

Mark only one oval.

- Yes
- No
- I do not know

33. If your previous answer is yes, who is it?

Tick all that apply.

- My brother/sister
- My mother/father
- My son/daughter
- My grandmother/grandfather
- My grandson/granddaughter
- My uncle/aunt
- My cousin

Other: _____

34. Do you have any family member/s with an autoimmune disease that is not lupus? *

Mark only one oval.

Yes

No

35. If your previous answer is yes, which disease is it?

Tick all that apply.

- Multiple sclerosis
- Diabetes type 1
- Myasthenia gravis
- Rheumatoid arthritis
- Hashimoto's thyroiditis

Other: _____

About lupus

36. Do you have any secondary illness related to lupus? *

Mark only one oval.

Yes

No

37. If your previous answer is yes, which one/s?

Tick all that apply.

Osteoporosis

Hypertension

Heart disease

Diabetes type 2

Lupus nephritis

Other: _____

38. If you are a female and you have children, has any of them had neonatal lupus?

Mark only one oval.

Yes

No

Lifestyle

39. How would you evaluate your quality of life? (being 1 very poor and 10 very good) *

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

40. What aspects of your life have you had to change due to lupus? *

Tick all that apply.

Working hours

Leisure

Social life

Family life

Other: _____

41. How much do you have to spend each month because of lupus? *

Mark only one oval.

Less than 10£

10-25£

25-50£

50-100£

+100£

I prefer not to answer

Other: _____

42. Are you in receipt of Personal Independence Payments (PIP) and/or Employment & Support Allowance (ESA)? *

Mark only one oval.

Yes, I am in receipt of PIP

Yes, I am in receipt of ESA

Yes, I am in receipt of both

No

43. Do you smoke or have you ever smoked? *

Mark only one oval.

- I smoke nowadays
- I used to smoke
- I have never smoked

44. Do you exercise often? *

Mark only one oval.

- Yes
- No

45. How much has lupus affected your social life? (being 1 nothing and 10 a lot) *

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

46. Are you a member of any lupus association or charity? *

Mark only one oval.

- Yes
- No

47. If your previous answer is yes, which lupus association/s or charity/s are you a member of?

Tick all that apply.

Lupus UK

Local charity/association

Other: _____

48. If you are a member of a lupus association or charity, how important do you think it is to be part of one? (being 1 not important and 10 very important)

Mark only one oval.

1	2	3	4	5	6	7	8	9	10
<input type="radio"/>									

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ANNEX VI. POLL TO FAMILY MEMBERS TO LUPUS PATIENTS

6. 1. POLL TO FAMILY MEMBERS TO LUPUS PATIENTS IN SPANISH

Encuesta a familiares de pacientes con lupus

Hola a todos y a todas,

soy Adaia Flotats, estudiante de bachillerato y miembro del programa “Bojos per la Medicina” de la “Fundació Catalunya-La Pedrera”. Gracias a este programa conocí al Dr. Ricard Cervera, quien me transmitió su gran interés por estudiar y conocer mejor el lupus y las enfermedades autoinmunes.

Por esta razón decidí realizar mi “T treball de Recerca” sobre las diferencias en el diagnóstico, tratamientos, estilo de vida, rol de los familiares y otros factores del lupus entre España y el Reino Unido.

Hoy me atrevo a pedir dos minutos de vuestro tiempo, que es lo que os llevará contestar esta encuesta anónima. Gracias por adelantado.

No puedo terminar sin agradecer infinitamente la paciencia y ayuda de Pilar Lucas, presidenta de la Asociación Catalana de Lupus E. G.

*Required

1. Año de nacimiento *

2. Sexo *

Mark only one oval.

- Mujer
- Hombre
- Prefiero no decirlo

3. País de residencia *

Mark only one oval.

- España
- Reino Unido
- Other: _____

4. Parentesco con el paciente. El paciente es: *

Mark only one oval.

- mi hermano/a
- mi padre/madre
- mi hijo/a
- mi pareja
- Other: _____

Preguntas generales

5. ¿Cuánto hace que convive con un paciente con lupus? *

Mark only one oval.

- Menos de un año
- 1-2 años
- 3-5 años
- 6-10 años
- +10 años
- Other: _____

6. ¿Conocía la enfermedad previamente? *

Mark only one oval.

- Sí
- No

7. Cuando se le diagnosticó lupus, ¿ya convivía con él/ella? *

Mark only one oval.

Sí *Skip to question 8*

No *Skip to question 13*

Preguntas para familiares que ya convivían con el paciente antes del diagnóstico

8. ¿Cuánto tiempo ha pasado desde el diagnóstico hasta la actualidad? *

Mark only one oval.

0-6 meses

6-12 meses

1-2 años

3-5 años

6-10 años

+10 años

9. ¿Cuál era el estado de ánimo del paciente antes del diagnóstico? (siendo 1 muy bajo y 5 muy bueno) *

Mark only one oval.

1 2 3 4 5

10. ¿Cuál era el estado de ánimo del paciente durante el diagnóstico? (siendo 1 muy bajo y 5 muy bueno) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

11. ¿Cuál es el estado de ánimo del paciente en la actualidad? (siendo 1 muy bajo y 5 muy bueno) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

12. ¿Cuánto ha cambiado el estilo de vida del paciente? (siendo 1 nada y 5 mucho) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

Preguntas a los familiares

13. ¿Qué síntoma/s del paciente le afectan más a usted como familiar? *

Tick all that apply.

- Dolor muscular
- Dolor articular
- Fiebre
- Erupciones cutáneas
- Dolor de pecho
- Pérdida de cabello
- Sensibilidad al sol o la luz
- Problemas renales
- Llagas en la boca
- Fatiga extrema
- Anomalías hematológicas (por ej. anemia)
- Sequedad o inflamación ocular
- Coágulos
- Hinchazón de piernas
- Dedos de los pies o las manos pálidos o morados

Other: _____

14. ¿Ha tenido que cambiar algún aspecto de su vida debido al lupus? *

Mark only one oval.

Sí

No

15. Si ha respondido que sí, ¿cuál/es?

Tick all that apply.

- Horario laboral
- Ocio
- Vida social
- Vida familiar

Other: _____

16. ¿Considera importante su papel en la adherencia al tratamiento por parte del paciente? *

Mark only one oval.

Sí

No

17. ¿Percibe cuándo su familiar va a sufrir un brote? *

Mark only one oval.

Sí

No

Algunas veces

18. ¿Cree que la sociedad tiene suficiente conocimiento del lupus? *

Mark only one oval.

Sí

No

19. ¿Cree que se invisibiliza el papel de los familiares? *

Mark only one oval.

Sí

No

20. ¿Su familiar está involucrado en alguna asociación? *

Mark only one oval.

- Sí
- No
- No lo sé

21. Si es así, ¿en cuál/es?

Tick all that apply.

- Asociación Catalana del Lupus E. G.
- Federación Español de Lupus
- Asociaciones locales

Other: _____

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6. 2. POLL TO FAMILY MEMBERS TO LUPUS PATIENTS IN ENGLISH

Survey to family members to lupus patients

Hello everyone,

I am Adaia Flotats, a Year 13 student from Catalonia, Spain. This year I received a scholarship to go to Hospital Clínic de Barcelona to learn about medicine. Thanks to this scholarship I met Dr. Ricard Cervera, a lupus specialist who conveyed to me his great interest in studying and learning more about lupus and autoimmune diseases. This is why I decided to do my end of school Research Project about lupus. I will be comparing the treatments, diagnosis process, lifestyle, family's role and other factors of lupus between the UK and Spain.

This is why I would really appreciate if you could answer this two minute long anonymous survey. Thank you in advance.

I could not finish without saying thank you to Lupus UK for all the help, specially Paul Howard.

***Required**

1. Year of birth *

2. Sex *

Mark only one oval.

Female

Male

Prefer not to say

3. Country of residence *

Mark only one oval.

United Kingdom

Spain

Other: _____

4. Relationship with the person with lupus. She/he is: *

Mark only one oval.

- My brother/sister
- My mother/father
- My son/daughter
- My partner
- Other: _____

General questions

5. How long have you been cohabiting with the patient? *

Mark only one oval.

- Less than 1 year
- 1-3 years
- 3-5 years
- 5-10 years
- +10 years
- Other: _____

6. Did you know about lupus before? *

Mark only one oval.

- Yes
- No

7. Did you already live with the patient when he/she was diagnosed? *

Mark only one oval.

Yes

No *Skip to question 13*

Questions for family members who already lived with the patient when he/she was diagnosed

8. How long has it been since the diagnosis? *

Mark only one oval.

0-6 months

6-12 months

1-3 years

3-5 years

5-10 years

+10 years

9. In what mood was the patient in before the diagnosis? (being 1 very bad and 5 very good) *

Mark only one oval.

1 2 3 4 5

10. In what mood was the patient in during the diagnosis? (being 1 very bad and 5 very good) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

11. In what mood is the patient in nowadays? (being 1 very bad and 5 very good) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

12. How much has the lifestyle of the patient changed since before the diagnosis? (being 1 nothing and 5 a lot) *

Mark only one oval.

1	2	3	4	5
<input type="radio"/>				

Questions for all family members

13. What symptom/s affect you the most as a family member? *

Tick all that apply.

- Muscle pain
- Pain or swelling in the joints
- Fever
- Rashes
- Chest pain
- Hair loss
- Sensitivity to sunlight or fluorescent light
- Renal disorders
- Mouth sores
- Extreme or prolonged fatigue
- Hematological disorders (e.g. anemia)
- Eye dryness or inflammation
- Clots
- Leg swelling
- Pale or purple fingers or toes

Other: _____

14. Have you had to change your lifestyle due to lupus? *

Mark only one oval.

Yes

No

15. If the previous answer is yes, what has changed?

Tick all that apply.

- Working hours
- Leisure
- Social life
- Family life

Other: _____

16. Do you consider you have an important role in the the patient's adherence to treatment? *

Mark only one oval.

Yes

No

17. Do you perceive when your family member is going to have a flare? *

Mark only one oval.

Yes

No

Sometimes

18. Do you think society has enough knowledge about lupus? *

Mark only one oval.

Yes

No

19. Do you think the relatives' role in these situations is ignored? *

Mark only one oval.

Yes

No

20. Is your family member involved in an association or charity? *

Mark only one oval.

Yes

No

I do not know

21. If your previous answer is yes, in which one/s?

Tick all that apply.

Lupus UK

Local charity/association

Other: _____

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ANNEX VII. INTERVIEWS TO LUPUS PATIENTS AND FAMILY MEMBERS

7. 1. INTERVIEW TO A SPANISH FEMALE LUPUS PATIENT

Good morning,

First of all I wanted to thank you for answering this interview. I will be asking you some questions related to your experience with lupus.

According to what is said, there are no two patients of lupus who experience it the same way, so, today I will be able to know a little bit about how lupus affects you.

First of all I would like to ask you some questions about your diagnostic process. So let's start:

How was your diagnostic process, since the appearance of your first symptoms until the final diagnosis?

Everything went very quick. I clearly remember how everything took place when I was 13 years old during summer time. It all started because I had a lot of leg and knee swelling and pain, so I visited de General Practitioner, who ordered a general blood test for me. When I had the results I went back to see the General Practitioner, and when she saw them she immediately sent me to a bigger hospital in Manresa, where I was hospitalised for a week. After staying in Manresa for a week I was sent to Hospital de Bellvitge in Barcelona. Once there, I had a skin biopsy and a kidney biopsy, and after analysing everything, they could diagnose me with lupus.

What were your first symptoms? And what are your most frequent symptoms?

As I said in the previous question, the first symptoms I had were knee and leg swelling and pain. My most frequent symptoms nowadays are: pain or swelling in the joints, extreme or prolonged fatigue and lack of sleep.

Now I will be asking some questions about lupus flares:

What factors increase the risk of having a lupus flare?

It is said that stress, although stress doesn't make my lupus flare up. There have been times in my life when I have been extremely stressed and my lupus did not flare up, so I suppose it is different for everyone.

I must also say I have only had three lupus flares, and I have no idea what caused them.

How does your life change every time your lupus flares up?

It changes completely. The three times my lupus has flared up, I have been hospitalised for a long time. Also, I have had to take much higher doses of all my medication.

What is/are the most important thing/s to do in order to prevent a lupus flare?

The most important thing to do is to remain calm and to not think about your lupus all the time. When you are diagnosed with a chronic illness like lupus, the first thing you need to do is to assimilate that you will have it forever. If this first step is done successfully, then everything is much better. It might not help you avoid having a lupus flare, but it will definitely help you to cope with it much better.

Can you foresee when you are going to have a lupus flare?

Not at all, because when you have any new symptoms or a symptom gets a little worse, you never expect it to end up being a lupus flare. This is because the appearance of new symptoms or the getting worse of some is something that happens very often.

Now that I know a little bit more about your personal experience with lupus, I would like to ask you some questions related to your lifestyle and quality of life.

Is there anything that lupus prevents you from doing? If so, what does lupus prevent you from doing?

Right now, lupus prevents me from going on walks for example, which is something that I used to be able to do in the past. Due to the lupus, I get tired very quickly nowadays.

What do you think is essential to keep a good mood despite lupus?

I have never thought of lupus as an impediment, so I have done anything I wanted without thinking about lupus. If I have wanted to travel I have done so, if I have wanted to study I have also done so, if I have felt like going out I have done so... I have never said: I have lupus so I cannot do some things others can, and I think this is essential to keep a good mood.

Furthermore, for everyone with lupus I think it is very important that people around you support you, despite anything, since the first day. I have been lucky in this aspect, as my family and friends have always given me support, and my husband is always watching out for me and making sure that I am feeling fine.

And I almost forgot to say that I am never worried about how my lupus will evolve or about small things, and this attitude is fundamental to carry on and keep up a good mood.

Do you think that your life would have been different without lupus?

I do not know, as I have had lupus for nearly my whole life. However, I imagine so, but I can't tell in what aspects it would have been different. Nevertheless, I would not change my life for anyone's life, as I have had the opportunity to meet great people and have learned a lot thanks to lupus.

What measures in the following fields do you think could be taken to improve your quality of life? (Social field, economic field, health field)

The social field is the one that needs to improve the most I think. Not many people know about lupus, and when you tell them that you suffer from it, they look at you in a weird way. Something should be done to make lupus better-known around the world... And for example, when celebrities, such as Selena Gomez, talk about it they do not say all the truth and it makes it seem much less important and severe. They should show the reality of lupus, so people really know how much some lupus patients suffer. Some people, specially from America, have a lot of economic problems which makes it hard for them to pay for all the medication.

What role do your family and loved ones in your life have when it comes to your lupus?

Since the first day, my family has supported me a lot. Unluckily, my older brother passed away thirteen years ago, and he was the one who used to take me to the doctor when I was younger. Now it is very different. I have my husband who is the greatest support I have and I also have my sister, who also has an autoimmune disease and who I talk to at least twice a day.

How did the people around you react when you told them you had lupus? And how did you react when you found out you had lupus?

My parents took it very naturally and accepted it very well. At first they were a little bit scared, but little by little they got to know the disease and were a lot more calm about it. My sister has also accepted it very well

since the beginning, and nowadays I still have a very close relationship with her, we talk nearly every day, as I have already said. At the beginning it was something very new for her, but she has never tried to hide it from anyone, and this helped me a lot.

In a personal level, I must say I was very young when all of this happened, so I wasn't too conscious about everything that was going on.

What do you think is the toughest thing about having lupus?

For me, the worst thing about having lupus is everything that comes as a consequence of lupus. For example: memory leaks, fatigue... Due to all of this I need to write down everything in order to not forget it. Also, I used to go on walks very often, but, suddenly, I can't do this any more.

What symptom affects you the most psychologically? And physically?

I feel like all the pain and the fatigue affect me a lot more psychologically than physically. I can't think of anything that really affects me physically, I mean, I have always had rashes all over my body, but those have never affected me at all. It is the feeling of knowing you can't do what you used to do, the always being tired, being unable to think clearly sometimes... what "annoys" me the most.

Do you think that having lupus has changed the way you are and the way you see things?

I have lived with lupus almost all my whole life, so I do not know what life would be like without lupus. I like to say there are three individuals at home: David, my husband, me, and lupus. This is how I think of lupus. It is always there but I can't let it control my life. Lupus has also led me to meet amazing people, so, as it is said, everything bad brings something good.

And finally, I wanted to end the interview with the following question:

What would you say to someone who has just been diagnosed with lupus?

I would tell this person to accept it naturally. I would also tell this person to get surrounded by people who support him or her. It is also very important, on the other hand, to tell them to never hide other people they suffer from lupus, and anything negative others might say should never be relevant to them.

Thank you very much for answering the interview and for letting me know your experience with lupus.

7. 2. INTERVIEW TO A BRITISH FEMALE LUPUS PATIENT

Good morning,

First of all I wanted to thank you for answering this interview. I will be asking you some questions related to your experience with lupus.

According to what is said, there are no two patients of lupus who experience it the same way, so today I will be able to know a little bit about how lupus affects you.

First of all I would like to ask you some questions about your diagnostic process. So let's start:

How was your diagnostic process, since the appearance of your first symptoms until the final diagnosis?

When I was a little baby, I seemed to be all right, although the summer after I was born, when I was about eight months old, I was at the seaside visiting my grandmother who lived near NYC, and I got a terrible rash all over my torso and my arms. My mother got so upset that she made my grandmother take me to a friend of her who was a doctor, and this doctor diagnosed me with lupus, without doing any tests, as tests were not as effective as they are nowadays. This was on 1954. The only problem is that my mother never told me that I had lupus, so I thought that all of my medical problems were just worse than other children's. That's what's so deceptive about lupus if you have a relatively mild form, it doesn't seem that different from what happens to everybody else. It wasn't until I was in my twenties that it became more severe.

What were your first symptoms? And what are your most frequent symptoms?

When I was a child, I hyper reacted to all environmental toxins, everything from insect bites, to sunlight, or plant toxins... And when I got a cold or an infection it was always worse than my friends' or my siblings'. I also had vertigo, which prevented me from doing things other kids could do. So, all of those kind of symptoms as well as persistent infections or sinusitis that never went away were signs of my now diagnosed lupus. I also had difficulty with my joints, but everyone told me they were growing pains.

It was when I was in my twenties that my symptoms got a lot more debilitating. However, I wasn't diagnosed until 2010, when I was generally very debilitated and stuck at home.

Nowadays, symptoms only appear if I feel nervous. Thanks to medication I can control my symptoms very well.

Now I will be asking some questions about lupus flares:

What factors increase the risk of having a lupus flare?

As I previously said, my lupus flares up whenever I don't pace myself. Whenever I go on a plane, or have a friend come over, or I expose myself in very hot or cold temperatures, or recovering from a surgery... Anything that disturbs my routine usually makes my symptoms a lot worse.

How does your life change when your lupus flares up?

When my lupus flares up my comprehension becomes very poor, I find it more difficult to find words and think straight, my stamina reduces a lot... so I need to sit quietly and sleep all day.

What is/are the most important thing/s to do in order to prevent a lupus flare?

The most important things that I can do to prevent a lupus flare are: pacing myself and avoiding the triggers. It is also very important for me to take my medicines and to be a very compliant patient.

Can you foresee when you are going to have a lupus flare?

Yes, if I for example go in the sun I know I'll have one!

Now that I know a little bit more about your personal experience with lupus, I would like to ask you some questions related with your lifestyle and quality of life. Also, some questions about your other conditions and how they complement with lupus.

Is there anything that lupus prevents you from doing? If so, what does lupus prevent you from doing?

Lupus prevents me from doing almost everything. It begun to stop me doing things in my twenties, and I had to give up my work in my fifties. Nowadays I would say that the effect of having had lupus for many years inadequately medicated means that the progression adds up to the way I am now. I haven't had a social life in my life, and I am unable to travel...

How do you manage to keep a good mood despite the situation?

I've had a lot of therapy, and I also live in a very beautiful place. I also have a very supportive husband and sister, and I have the Lupus UK Forum! And when I was so unwell that the NHS began to realise that I needed to see a rheumatologist who knew about autoimmune conditions, I was psychologically and emotionally in a very bad place. I was totally beaten up by the whole experience, and if it hadn't been for Lupus UK and meeting other people who could help me put my condition in perspective, things would have been a lot more difficult. They also helped me navigate the health system, which is very important.

What role do your family and loved ones in your life have when it comes to your lupus?

Well, my dear mother, who I adore, made the strange decision to never tell me that I had lupus, and when I told her in 2010 that I had been diagnosed with it (when I was rediagnosed), she said: But you've always had lupus! However, she always made sure (since I was a toddler) that I ate healthy and took care of myself, and my doctors now tell me that if it hadn't been for that, my lupus would be in a much worse state now.

My husband also helps me a lot, and he specially helped me through the diagnostic process. Before the doctors could diagnose me with lupus, they would say that all the pains that I had were due to a spine problem. However, every time I told my husband that my pains were due to a spine problem he would somehow know that there was something else to it. This made me become a lot more open minded.

How did the people around you react when you told them you had lupus? And how did you react when you found out you had lupus?

It was fantastic! I took my best friend out for lunch and we had a lot of fun! At this day she still laughs at how funny it is that I was so happy. When I told my mum, as I said earlier, she replied with a: but you've always had lupus! And I said, what's lupus? My husband said: what's lupus? You know, neither me nor my friends and family knew anything about lupus. When I was diagnosed for the first time as an infant, there was such a minimal knowledge of lupus that my mother didn't even realise it was anything! And as you look all right after a flare-up disappears, my mother thought I was fine.

What do you think is the toughest thing about having lupus?

It's relentless... You will never be able to forget about it, and that really wears you down. And perhaps alongside that it's relentless is that it's reasonably invisible, and due to this some people don't understand what lupus is.

What symptom affects you the most psychologically? And physically?

Psychologically it would be the lack of comprehension, when my brain can't understand. I can't cope with anything, and as a very cerebral person it gets very hard. The lack of stamina also affects me a lot psychologically, as it feels like you just got hit by a car, and you don't know what's going to happen next.

And physically I think it is about the neurological effects as well, because they affect whether or not I can walk or stand, or how well I can move.

Do you think that having lupus has changed the way you are and the way you see things?

For sure! Certainly, knowing that I have lupus has changed the way I am. It has made me much more confident, but, before I knew what it was, it made me very insecure.

What order were you diagnosed in with each condition?

The first one was the lupus, the second one was Diethylstilbestrol Syndrome (DESS), and next one was the Hypermobile Ehlers Danlos Syndrome (hEDS). After that, I was rediagnosed with lupus in 2010.

Does any of your primary conditions affect negatively another one?

They all affect each other. It's like a Venn diagram for me, it all overlaps. Having to deal with so many conditions meant that my lupus was always flaring, but since immunology specialist diagnosed me in 2010, I have managed to keep my lupus a lot better thanks to specialised treatments.

Do treatments for each condition have anything in common?

Yes, because they all affect my connective tissues. First of all, they are all immune dysfunction conditions and, you know, they all interrelate, they all affect each other. And due to this interrelation, I think that there should be a correction on how all these things are classified, as they are all treated separately nowadays and

they should be treated as related illnesses. Also, an illness should be treated differently depending on how severe it is.

Back to the question, I am lucky that all my illnesses are responding very well to treatment, every single one. I react very badly when a medicine doesn't suit me, but when one does suit me then I take off, it is very noticeable.

And finally, I wanted to end the interview with the following question:

What would you say to someone who has just been diagnosed with lupus?

I would say: join Lupus UK! I would also say that this is a trial and error process of collaboration with your doctors. One doctor alone can't solve it, you will be the one who works with all the doctors that help the different systems in your body. You need to become a coordinator of your own care, and if you don't feel that you can bear to understand what the doctors are doing, just make sure that you get to know your body so that you can explain them how your body feels, because nobody knows your body as well as you do.

Thank you very much for answering the interview and for letting me know about your experience with lupus.

7. 3. INTERVIEW TO A SPANISH MALE LUPUS PATIENT

Good morning,

First of all I wanted to say thank you for answering this interview. I will be asking you some questions about your experience with lupus.

According to what is said, there are no two patients of lupus who experience it the same way, so, today, I will be able to know a little bit about how lupus affects you.

To start off with the interview I would like to ask you some questions about your diagnostic process. So let's start:

How was your diagnostic process, since the appearance of your first symptoms until the final diagnosis?

In my case, the diagnosis didn't have to do with me not feeling well and going to the doctor. It had to do with the yearly tests they did to all the workers in the place where I worked. What happened was that, in my urine test, there were three values which were not right. I didn't give it too much importance at first, as I thought that those wrong values were due to the fact that I ate a lot of meat. But after a while, I went to the doctor to check different things, so I showed him my results from the urine tests I had had done. When he saw them, he made me do those tests again. The results turned out not to be good again so the doctor sent me to a nephrologist, who made me do some more urine tests and now some blood tests as well. The nephrologist also asked me some questions such as: do your joints hurt? Do you feel tired often? And this type of questions. As he wasn't too sure of what I had either, he sent me to see a rheumatologist. And now, thanks to this doctor, they confirmed the diagnosis. Later on the nephrologist also diagnosed me with lupus nephritis.

The first urine test that I did was on 2014, and the final diagnosis was about one year and a half later.

What were your first symptoms? And what are your most frequent symptoms?

Consciously, I did not have any symptoms at first, because for me it was something normal to feel tired and to have pain in my wrists and ankles. And nowadays my most frequent symptom is fatigue, and thanks to medication I have been able to eradicate the joint pains that I used to have.

Now I will be asking some questions about lupus flares:

What factors increase the risk of having a lupus flare?

For me it is probably stress, whenever things aren't going as well as I expected or I am feeling overwhelmed. Another thing that, in my case, increases the risk of having a lupus flare, are the routine changes. For example, before the diagnosis, I would go out and come back home at 6 am in the morning and I would be unable to get back to work and to my normal life until three or four days later.

How does your life change when your lupus flares up?

Well, apart from going to work I do not do any of the housework, as I feel too tired to do so.

What is/are the most important thing/s to do in order to prevent a lupus flare?

The most important things would be to avoid stress and changes in my daily routine. Also to avoid the exposure to sun. Due to this last thing I had to quit my past job, as I worked as a gardener and this meant that I would work under the sun all day.

Can you foresee when you are going to have a lupus flare?

I don't really foresee it, although I can see how my personality changes just before one. I get more sensitive, I get mad easily, I might be quieter...

Now that I know a little bit more about your personal experience with lupus, I would like to ask you some questions related with your lifestyle and quality of life.

Is there anything that lupus prevents you from doing? If so, what does lupus prevent you from doing?

The main thing that lupus prevents me from doing is working as a gardener, which is the job I studied for. It also prevents me from playing sports, as they cause me a lot of joint pains. I told the doctor about this so he prescribed corticosteroid drugs. Thanks to this treatment my joint pain is much better, and I can barely feel it.

You also have to think about the fact that fatigue is always present in my life, so I can't do things like playing with my son very often or being very active.

What do you think is essential to keep a good mood despite lupus?

I would say that you need a lot of mental capacity. I think that the psychological part is very important.

What measures do you think could be taken to improve your quality of life in the following fields? (Social field, economic field, sanitary field)

When it comes to society, I think it would be crucial that there was more knowledge of lupus, this would definitely make many aspects of lupus patients' life improve.

When it comes to the economic field I believe it would be necessary that lupus patients had a recognised "organic disability" by the government. This would suppose a financial help that, for example, in my case, would let me look for a job that I like and enjoy, instead of having to work as anything possible in order to maintain my family. If I had a recognised "organic disability" I would have probably studied something that would let me work as something that I enjoy and, at the same time, maintain my family well.

And finally, in the sanitary field I have noticed that rheumatologist and other doctors who treat autoimmune diseases usually focus more on more well-known diseases. This means that sometimes a rheumatologist doesn't know how to treat a patient with lupus. So, in my opinion, there should be multidisciplinary units in every hospital. This would mean that many different doctors with different experience could work together, which would prevent patients from having to go from a doctor to another, and having to explain how the disease affects them so many times to so many different doctors. It would also be really helpful to have a General Practitioner for lupus patients, so, in case anything happens to a lupus patient he or she can visit this doctor.

What role do your family and loved ones in your life have when it comes to your lupus?

My wife is always making sure that I do not spend too much time in the sun nor get too tired. And same with my parents, although as I do not live with them it is only when I spend time with them.

How did the people around you react when you told them you had lupus? And how did you react when you found out you had lupus?

At first they were very confused because they did not know what lupus was, so I had to explain it to them. But they were never scared nor worried, as in my family we try not to give too much importance to diseases and illnesses.

Well, at first I did not know what lupus was either, and I was very confused. I remember visiting the rheumatologist once and telling her that I smoked, and then she asked: are you sure you know what lupus is? She asked this because the way that lupus affects me makes smoking very bad for my health. But of course I had not idea what lupus actually was! Doctors had been telling me not to look it up on the internet, but they never explained it to me either. So I didn't really know what I had and what I was going to experience.

What symptom affects you the most psychologically? And physically?

Definitely, fatigue. I managed to get rid of my joint pains thanks to treatment, as I said earlier, and I have lupus nephritis, which is something I don't even notice. So fatigue is definitely what affects me the most psychologically.

And the symptom that affects me the most physically is also fatigue, as it is the one that I feel and notice more often.

Do you think that having lupus has changed the way you are and the way you see things?

I reckon so. I had to stop playing sport and I had to quit my job, which were things that definitely changed me. What I have noticed the most is that I have stoped judging people by their appearance, which is something that many people do unconsciously.

The following questions will be about how it is for you to have a disease which mostly affects women:

Have you ever not felt identified with the other lupus patients?

I wouldn't say so. However, I do realise how most information about lupus is aimed at women. And in the times we are living in, in which feminism is something very present, there are many women who disrespect you whenever you refer to men.

What does it mean to you to be a man with a disease that mostly affects women?

It isn't any problem for me. I have never cared about stereotypes, so this does not affect me at all. The only thing that I can say about this is that, socially, there is a misconception about men being stronger and more able than women, so maybe some men with lupus feel like they can't do what society expects from them. But as I said, this doesn't affect me in any way.

And finally, I wanted to end the interview with the following question:

What would you say to someone who has just been diagnosed with lupus?

I would tell him or her that having lupus sucks, but luckily, nowadays, he or she will be able to have a lifestyle very similar to that of healthy people. Well, as you said at the beginning of the interview, every patient experiences lupus in a different way, but in general, I believe most lupus patients are able to have a pretty common life.

I mean, I would make clear that since the beginning of the diagnostic process until when the doctor manages to find what medications make you feel at your best, it really sucks. But once this time is over they don't need to worry too much, because, as I said, they will probably be able to have a pretty normal lifestyle.

Thank you very much for answering the interview and for letting me know your experience with lupus.

7. 4. INTERVIEW TO A BRITISH MALE LUPUS PATIENT

Good morning,

First of all I wanted to thank you for answering this interview. I will be asking you some questions about your experience with lupus.

According to what is said, there are no two patients of lupus who experience it the same way, so, today, I will be able to know a little bit about how lupus affects you.

To start off with the interview, I would like to ask you some questions about your diagnostic process. So let's start:

How was your diagnostic process, since the appearance of your first symptoms until the final diagnosis?

Basically, I had various symptoms over a five-year period, and what happened was that my symptoms were being treated individually. I had eye problems, joint pains, and other symptoms, and I went to different specialists for several years. Then I was unable to work for some months due to all of my pains, so I decided to visit a rheumatologist, who diagnosed me with lupus in only five minutes.

What are your most frequent symptoms?

My symptoms are very much controlled now, I don't have any, really. I am on hydroxychloroquine and everything is controlled, apart from four years ago when I had to have a heart surgery.

Now I will be asking some questions about lupus flares:

What factors increase the risk of having a lupus flare?

I haven't really had any since it is controlled, and in the past I had them because I wasn't diagnosed and I wasn't taking medication.

How did your life change when your lupus flared up?

If I had a very bad flare it would even be difficult for me to walk across the room. I would have heavy fatigue, sweats, fevers, etc. I would also get very bad wet eyes which made it very difficult to focus. So lupus flares had a big impact in my life.

Could you foresee when you were going to have a lupus flare-up?

No, it just happened, it's not like I start getting more symptoms, it just appeared all of a sudden.

Now that I know a little bit more about your personal experience with lupus, I would like to ask you some questions about your lifestyle and quality of life.

Is there anything that lupus prevents you from doing? If so, what does lupus prevent you from doing?

Nowadays, thanks to the medication, there is nothing that lupus prevents me from doing. I have a pretty good diet, which I think also helps. I am able to go on walks several days a week, and I can do many other things. So my lifestyle would be pretty much the same as if I didn't have lupus. I understand that for some people lupus has a bigger impact in their life, although my lupus is largely controlled.

What do you think is essential to keep a good mood despite lupus?

I think that you need a good diet. You should also do things that you like, as if lupus wasn't there, as long as this can be that way, because, if you don't do so, it is very difficult to have a happy life. Exercise is also extremely important, and it has personally helped me a lot.

What measures do you think could be taken to improve your quality of life in the following fields? (social field, economic field, sanitary field)

As lupus is not affecting me largely I can't think of anything that could be improved. However, I understand there are other lupus patients whose lupus is worse and affects them more, so they might need extra help.

What role do your family and loved ones in your life have when it comes to your lupus?

Before I was diagnosed my family helped me out a lot, but not so much anymore, as my lupus is now controlled.

How did the people around you react when you told them you had lupus?

I think that when I was diagnosed my family and friends were relieved, because I had had several symptoms for five years, and knowing what it was was more of a relief than anything else.

What do you think is the toughest thing about having lupus?

For me there isn't too much, but ordinarily I think it is probably that you never know when your lupus is going to flare up. Also fatigue and tiredness. For me the toughest thing throughout the whole time I have had lupus was when it affected my heart, as I had to undergo surgery. Luckily, I am feeling fine nowadays.

What symptom affects you the most psychologically? And physically?

At the moment none affect me really. In the past it probably would have been fatigue, as it can impact you a lot.

Do you think that having lupus has changed the way you are and the way you see things?

I don't know, I think that since I have it I tend to help charities more. Actually, nowadays I raise money for lupus by preparing events. I am also part of the Lupus UK staff.

The following questions will be about how it is for you to have a disease which mostly affects women:

Have you ever felt not identified with the other lupus patients?

I don't really think about it, to be fair.

What does it mean to you to be man with a disease that mostly affects women?

It doesn't mean anything! It has no impact.

And finally, I wanted to end the interview with the following question:

What would you say to someone who has just been diagnosed with lupus?

I would say that the treatments are quite good these days, and that you can have a normal life with lupus. They just need to live life, do exercise and take all their medication. With treatment they will be able to go back to a normal life without nearly any pains.

Thank you very much for answering the interview and for letting me know your experience with lupus.

7. 5. INTERVIEW TO A SPANISH FAMILY MEMBER TO A LUPUS PATIENT

Good morning,

First of all I would like to thank you for answering this short interview for my Research Project. In this interview I will be asking you about your experience with lupus. So let's start:

How long have you lived with a person with lupus for?

I have lived with Manoli for 11 years now.

How does lupus affect your life?

I can easily adapt to everything, really. However, I had always wanted to have children, and Manoli had always been sure that she would never have a child, because she feels like it would not be compatible with lupus. But when I met her I had to give up the idea of having children, which I think was worth it.

What challenges does your family member with lupus face often? How can you help?

There are many challenges she faces daily, so the only thing I can do to help is to keep her in a good mood. I also need to remind her that whatever people think is irrelevant to us as long as she feels well with herself.

Can you foresee when your family member is going to have a lupus flare? If so, how do you foresee it?

Luckily, since I have met her, she hasn't experienced any lupus flare.

What aspects of your life have changed due to lupus?

I don't think anything too relevant has changed. The thing I enjoy the most doing is travelling, and we have been able to travel a lot. So, as I said, I don't think anything has changed too much.

Do you think that lupus affects the mood your family member is in? How?

Well, her mood doesn't change that much, although she does get worried a lot more. For example, if she has any pain, she gets very nervous and worried about it. However, that's the only thing I can see. She takes it very well and accepts it, which is very important, and she manages to put a smile on her face pretty much all the time.

Do you think that the family member's role is ignored? If so, what could be done about it?

If you are a relative to a lupus patient you need to stop thinking about yourself in these situations, like wherever people know what you do and how you help the family member with lupus. The most important thing is that you support the person with lupus and that he or she does not feel alone.

Thank you very much.

7. 6. INTERVIEW TO A BRITISH FAMILY MEMBER TO A LUPUS PATIENT

Good morning,

First of all I would like to thank you for answering the following questions for my Research Project. In this interview I will be asking you about your experience with lupus. So let's start:

How long have you lived with a person with lupus for?

It will be 19 years this year, as my daughter was diagnosed with lupus in 2001, aged 15.

How does lupus affect your life?

We provided extra support so that she is able to have a balanced life and plenty of rest at the weekend. She works full time as a solicitor and she recently got married.

What challenges does your family member with lupus often face? How can you help?

Making sure that she can get her medication, especially during Covid-19. Her husband and I help her with driving to work if she has a flare up.

Can you foresee when your family member is going to have a lupus flare-up? If so, how do you foresee it?

My daughter knows it first and adjusts her medications.

What aspects of your life have changed due to lupus?

Mainly allowing a few extra hours of time per week to provide support.

Do you think that lupus affects the mood your family member is in? How?

Not very often. Occasionally my daughter will not attend an event if she is very tired.

Do you think that the family member's role is ignored? If so, what could be done about it?

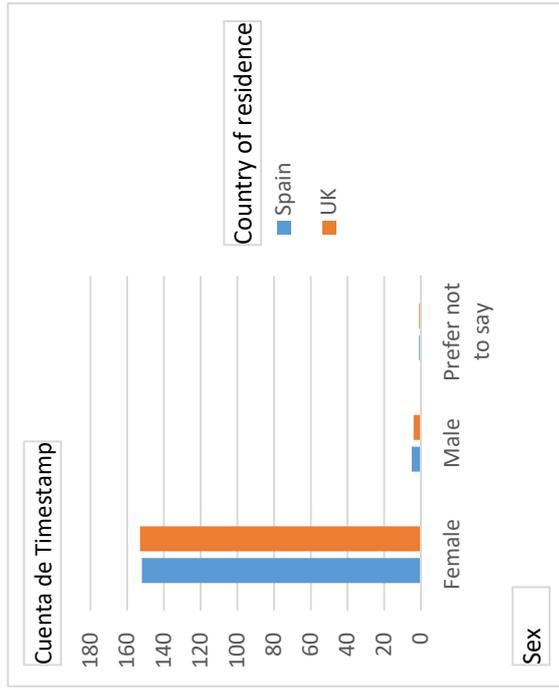
No, it's not ignored. Occasionally some medical professional appears to be unsympathetic to the needs of lupus patients.

Thank you very much.

ANNEX VIII. DYNAMIC GRAPHICS AND DYNAMIC TABLES USED TO ANALYSE THE DATA FROM THE PATIENTS' POLL

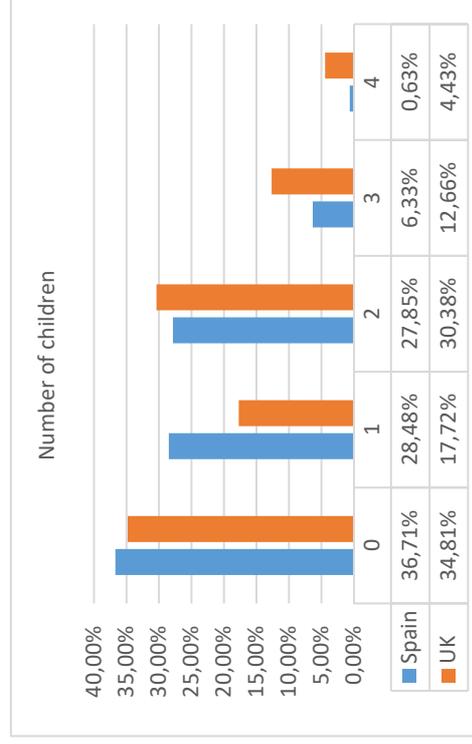
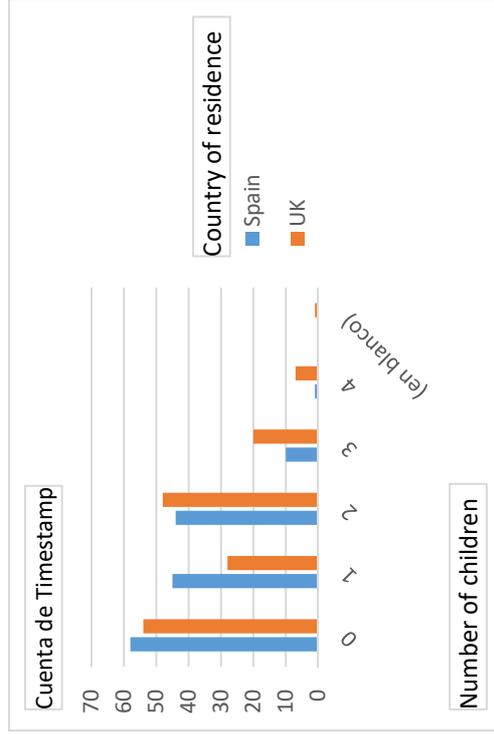
Cuenta de Timestamp	Etiquetas de columna			Total
Etiquetas de fila	Spain	UK		
Female	152	153		305
Male	5	4		9
Prefer not to say	1	1		2
Total	158	158		316

	Spain	UK
Female	96,20%	96,84%
Male	3,16%	2,53%
Prefer not to say	0,63%	0,63%



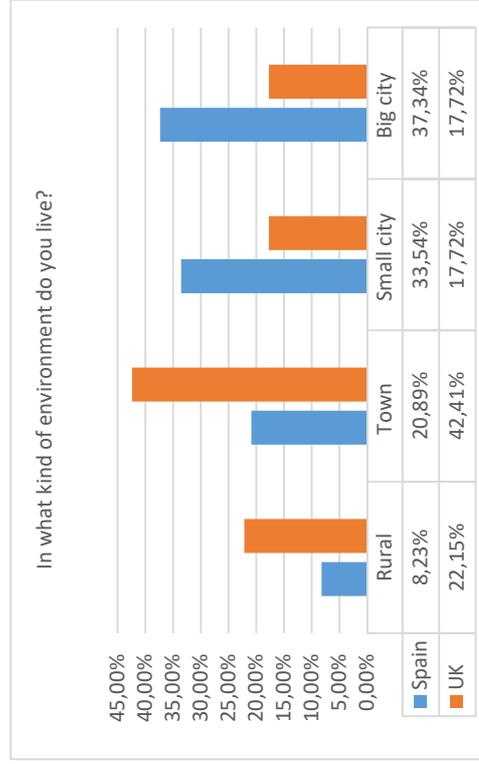
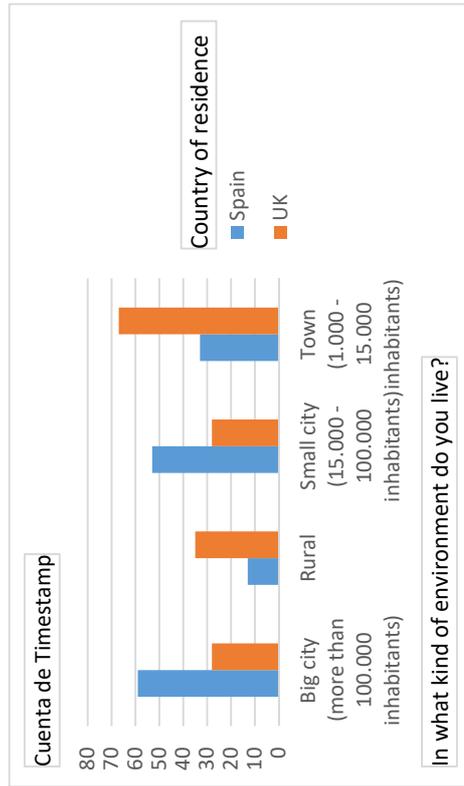
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
0	58	54	112
1	45	28	73
2	44	48	92
3	10	20	30
4	1	7	8
(en blanco)		1	1
Total	158	158	316

	Spain	UK
0	36,71%	34,81%
1	28,48%	17,72%
2	27,85%	30,38%
3	6,33%	12,66%
4	0,63%	4,43%



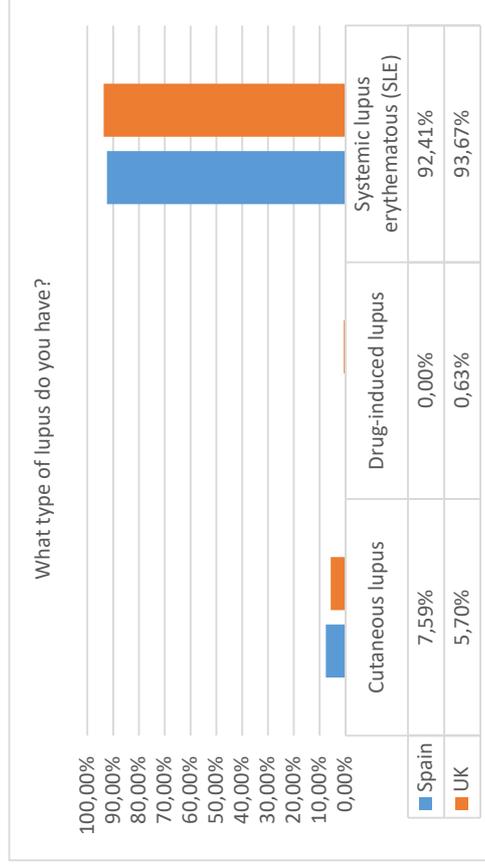
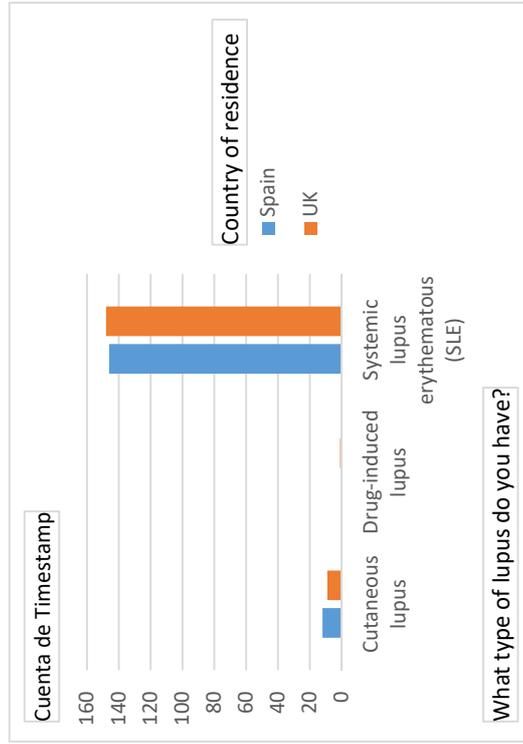
Cuenta de Timestamp	Etiquetas de columna			
	Etiquetas de fila	Spain	UK	Total
Big city (more than 100.000 inhabitants)		59	28	87
Rural		13	35	48
Small city (15.000 - 100.000 inhabitants)		53	28	81
Town (1.000 - 15.000 inhabitants)		33	67	100
Total		158	158	316

	Spain	UK
Rural	8,23%	22,15%
Town	20,89%	42,41%
Small city	33,54%	17,72%
Big city	37,34%	17,72%



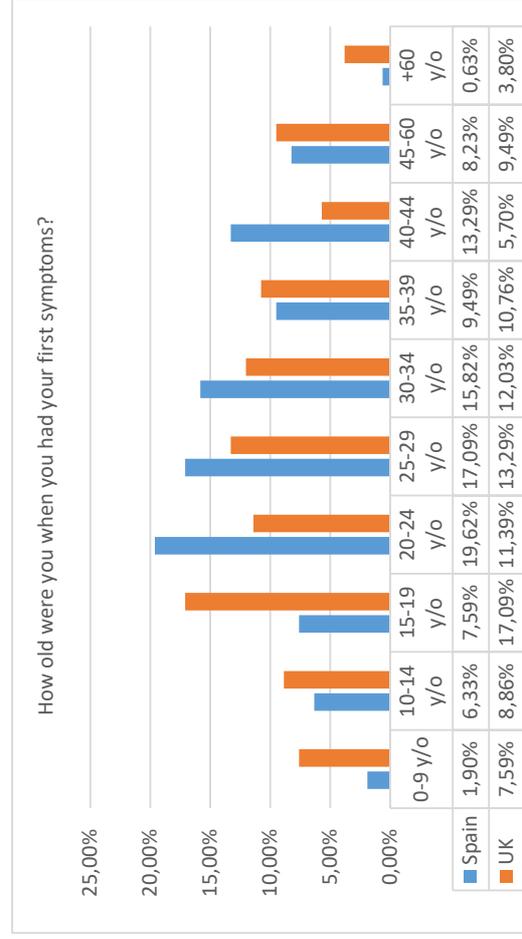
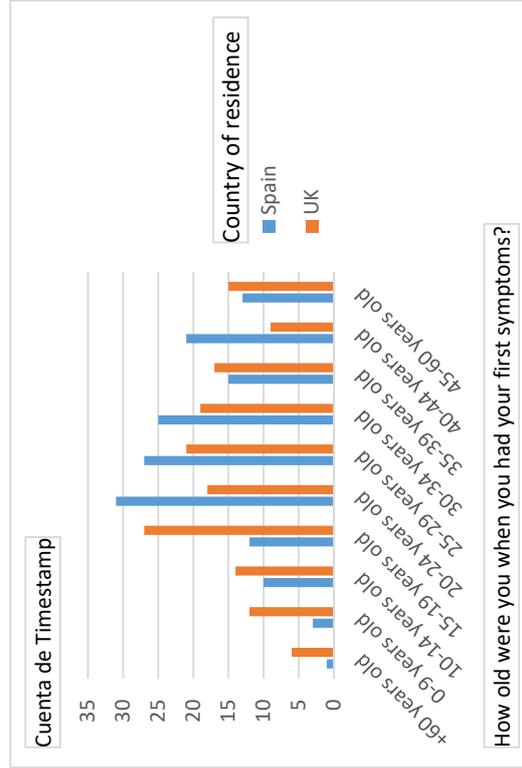
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
Cutaneous lupus	12	9	21
Drug-induced lupus		1	1
Systemic lupus erythematosus (SLE)	146	148	294
Total	158	158	316

	Spain	UK
Cutaneous lupus	7,59%	5,70%
Drug-induced lupus	0,00%	0,63%
Systemic lupus erythematosus (SLE)	92,41%	93,67%



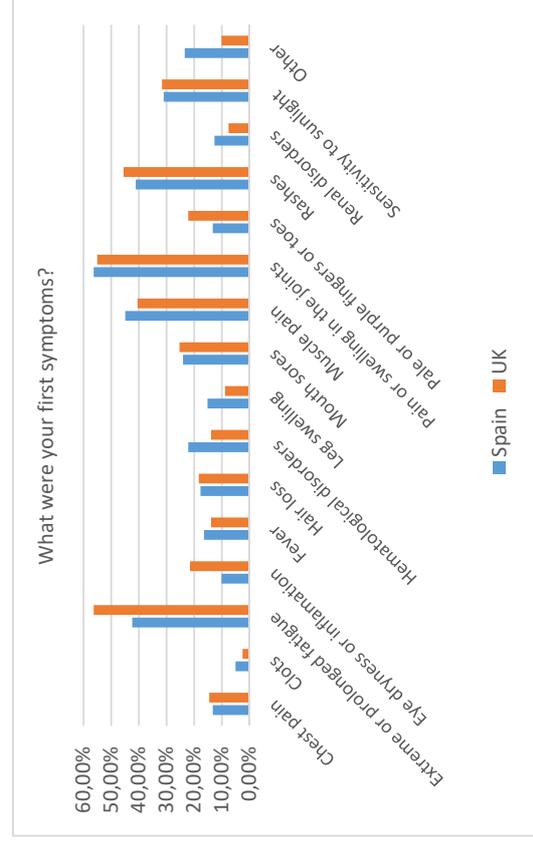
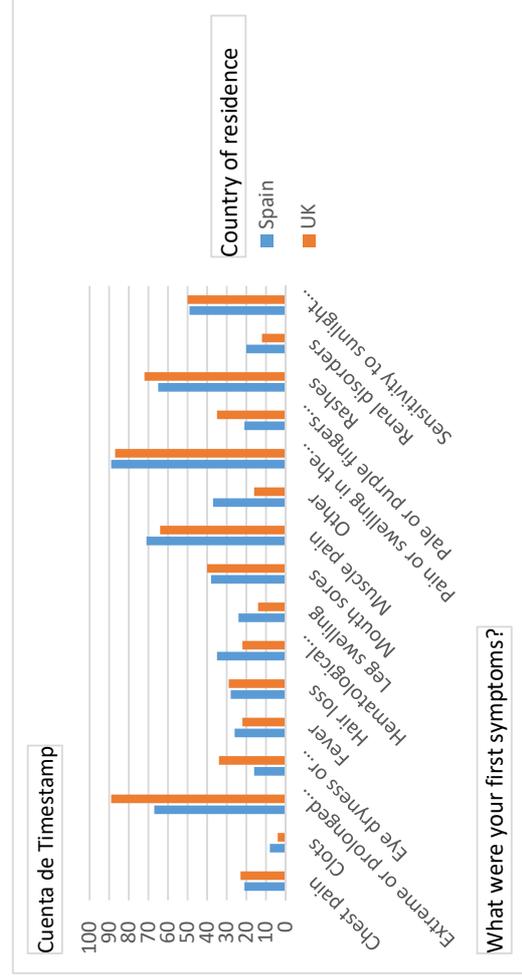
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Etiquetas de fila	Spain	UK	
+60 years old	1	6	7
0-9 years old	3	12	15
10-14 years old	10	14	24
15-19 years old	12	27	39
20-24 years old	31	18	49
25-29 years old	27	21	48
30-34 years old	25	19	44
35-39 years old	15	17	32
40-44 years old	21	9	30
45-60 years old	13	15	28
Total	158	158	316

	Spain	UK
0-9 y/o	1,90%	7,59%
10-14 y/o	6,33%	8,86%
15-19 y/o	7,59%	17,09%
20-24 y/o	19,62%	11,39%
25-29 y/o	17,09%	13,29%
30-34 y/o	15,82%	12,03%
35-39 y/o	9,49%	10,76%
40-44 y/o	13,29%	5,70%
45-60 y/o	8,23%	9,49%
+60 y/o	0,63%	3,80%



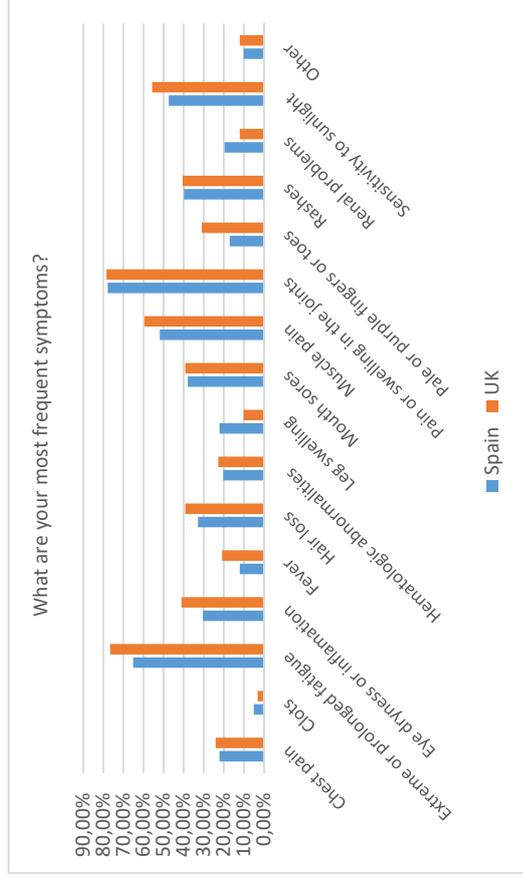
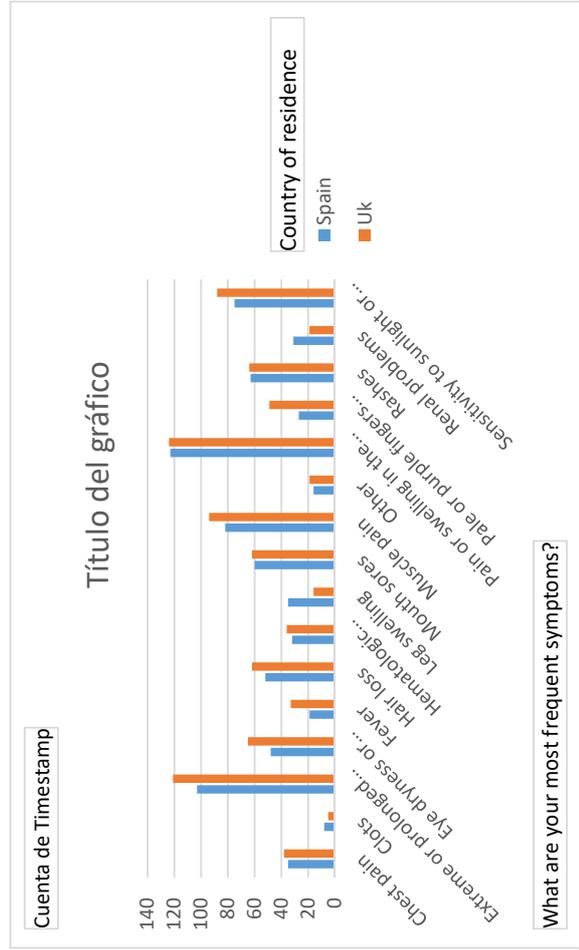
Cuenta de Timestamp		Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total	
Chest pain	21	23	44	
Clots	8	4	12	
Extreme or prolonged fatigue	67	89	156	
Eye dryness or inflammation	16	34	50	
Fever	26	22	48	
Hair loss	28	29	57	
Hematological disorders (e.g. anemia)	35	22	57	
Leg swelling	24	14	38	
Mouth sores	38	40	78	
Muscle pain	71	64	135	
Other	37	16	53	
Pain or swelling in the joints	89	87	176	
Pale or purple fingers or toes	21	35	56	
Rashes	65	72	137	
Renal disorders	20	12	32	
Sensitivity to sunlight or fluorescent light	49	50	99	
Total	615	613	1228	

	Spain	UK
Chest pain	13,29%	14,56%
Clots	5,06%	2,53%
Extreme or prolonged fatigue	42,41%	56,33%
Eye dryness or inflammation	10,13%	21,52%
Fever	16,46%	13,92%
Hair loss	17,72%	18,35%
Hematological disorders	22,15%	13,92%
Leg swelling	15,19%	8,86%
Mouth sores	24,05%	25,32%
Muscle pain	44,94%	40,51%
Pain or swelling in the joints	56,33%	55,06%
Pale or purple fingers or toes	13,29%	22,15%
Rashes	41,14%	45,57%
Renal disorders	12,66%	7,59%
Sensitivity to sunlight	31,01%	31,65%
Other	23,42%	10,13%



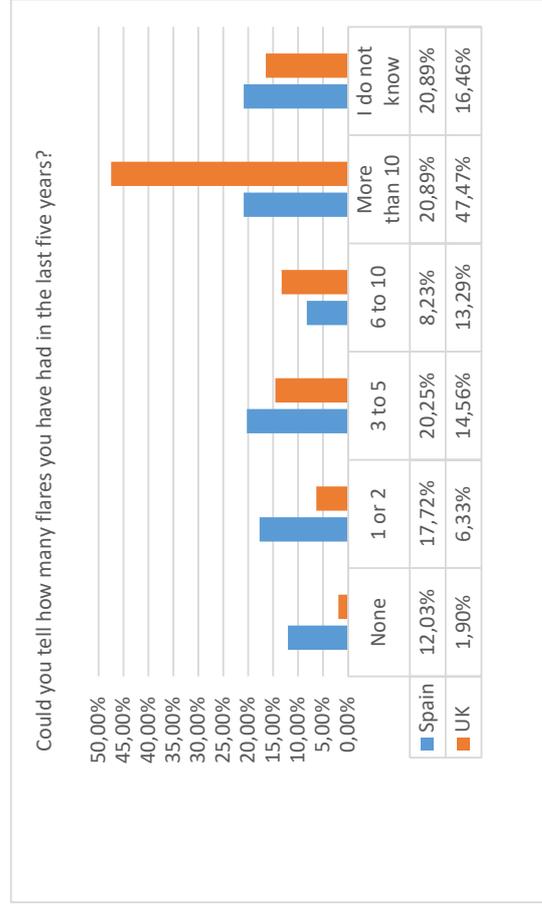
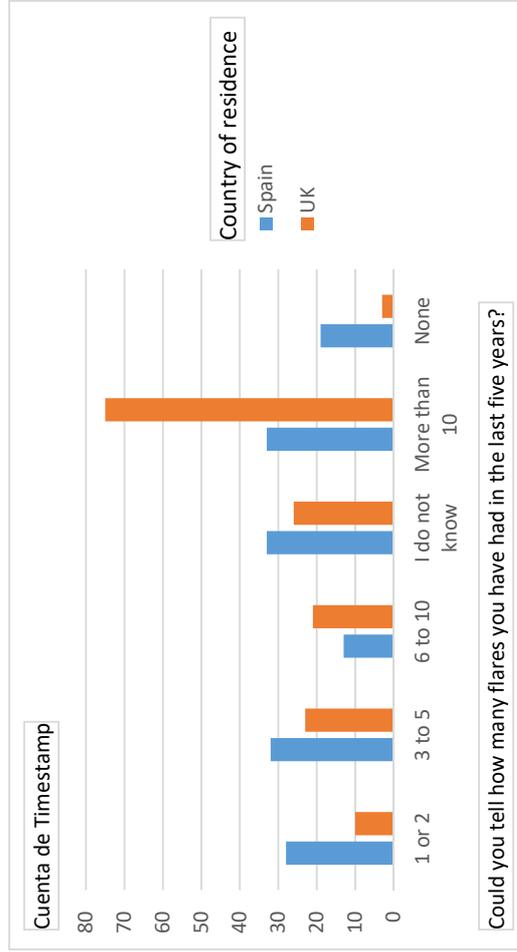
Cuenta de Timestamp	Etiquetas de columna		Total	
	Etiquetas de fila	Spain		Uk
Chest pain		35	38	73
Clots		8	5	13
Extreme or prolonged fatigue		103	121	224
Eye dryness or inflammation		48	65	113
Fever		19	33	52
Hair loss		52	62	114
Hematologic abnormalities (e.g. anemia)		32	36	68
Leg swelling		35	16	51
Mouth sores		60	62	122
Muscle pain		82	94	176
Other		16	19	35
Pain or swelling in the joints		123	124	247
Pale or purple fingers or toes		27	49	76
Rashes		63	64	127
Renal problems		31	19	50
Sensitivity to sunlight or fluorescent light		75	88	163
Total		809	895	1704

	Spain	UK
Chest pain	22,15%	24,05%
Clots	5,06%	3,16%
Extreme or prolonged fatigue	65,19%	76,58%
Eye dryness or inflammation	30,38%	41,14%
Fever	12,03%	20,89%
Hair loss	32,91%	39,24%
Hematologic abnormalities	20,25%	22,78%
Leg swelling	22,15%	10,13%
Mouth sores	37,97%	39,24%
Muscle pain	51,90%	59,49%
Pain or swelling in the joints	77,85%	78,48%
Pale or purple fingers or toes	17,09%	31,01%
Rashes	39,87%	40,51%
Renal problems	19,62%	12,03%
Sensitivity to sunlight	47,47%	55,70%
Other	10,13%	12,03%



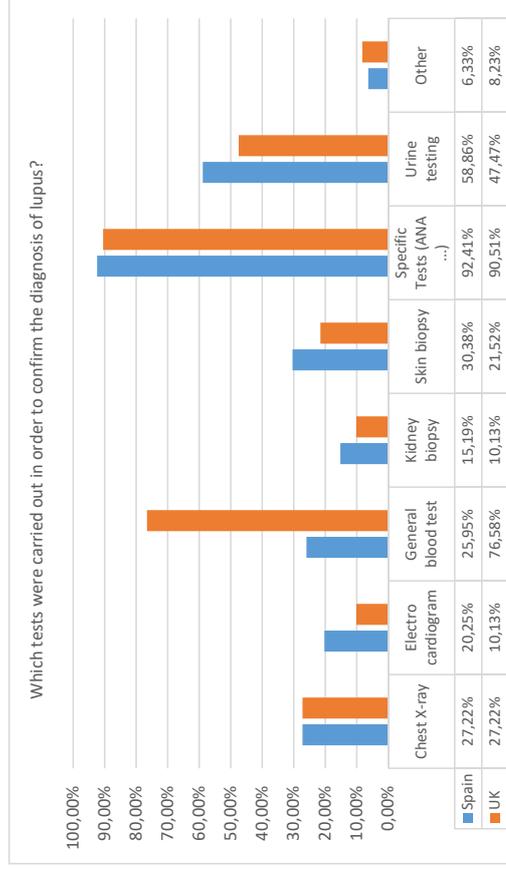
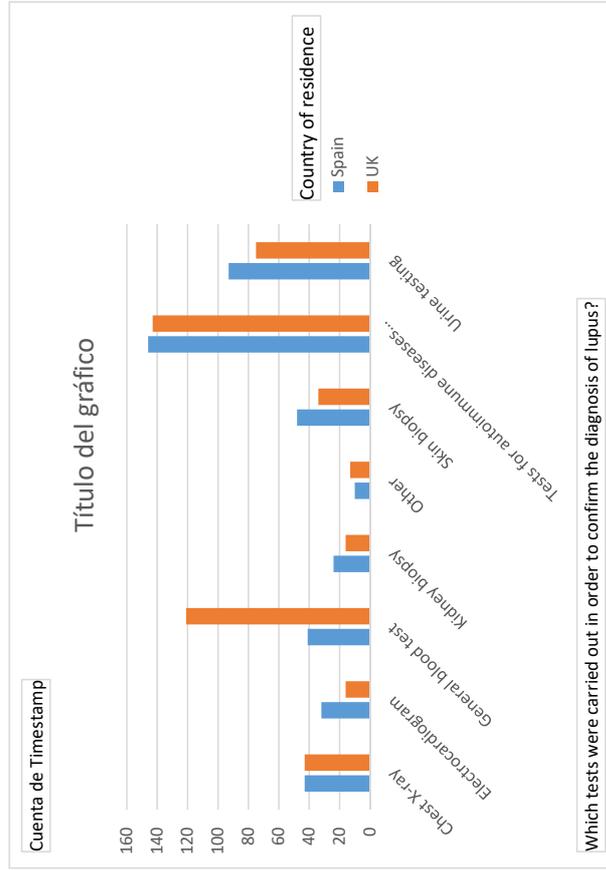
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
1 or 2	28	10	38
3 to 5	32	23	55
6 to 10	13	21	34
I do not know	33	26	59
More than 10	33	75	108
None	19	3	22
Total	158	158	316

	Spain	UK
None	12,03%	1,90%
1 or 2	17,72%	6,33%
3 to 5	20,25%	14,56%
6 to 10	8,23%	13,29%
More than 10	20,89%	47,47%
I do not know	20,89%	16,46%



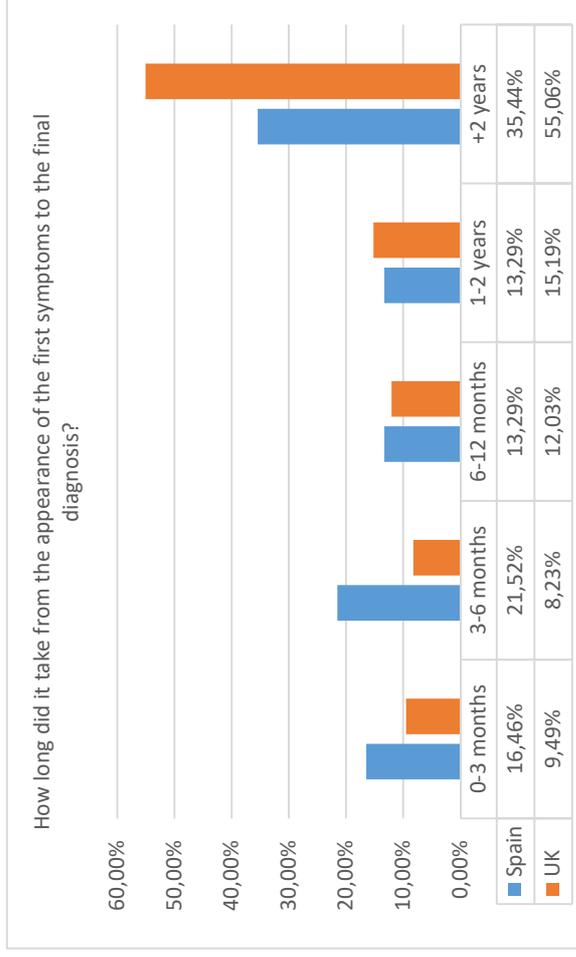
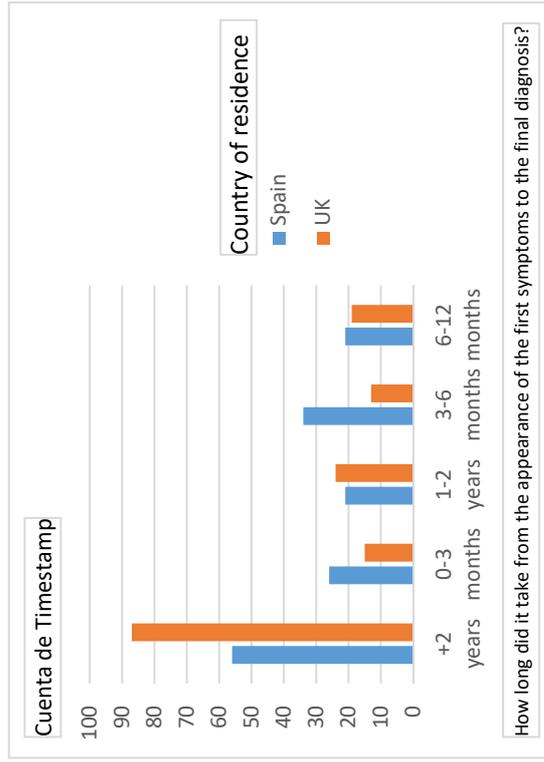
Cuenta de Timestamp	Etiquetas de columna		Total
	Spain	UK	
Chest X-ray	43	43	86
Electrocardiogram	32	16	48
General blood test	41	121	162
Kidney biopsy	24	16	40
Other	10	13	23
Skin biopsy	48	34	82
Tests for autoimmune diseases (ANA, dsDNA, ENA...)	146	143	289
Urine testing	93	75	168
Total	437	461	898

	Spain	UK
Chest X-ray	27,22%	27,22%
Electrocardiogram	20,25%	10,13%
General blood test	25,95%	76,58%
Kidney biopsy	15,19%	10,13%
Skin biopsy	30,38%	21,52%
Specific Tests (ANA ...)	92,41%	90,51%
Urine testing	58,86%	47,47%
Other	6,33%	8,23%



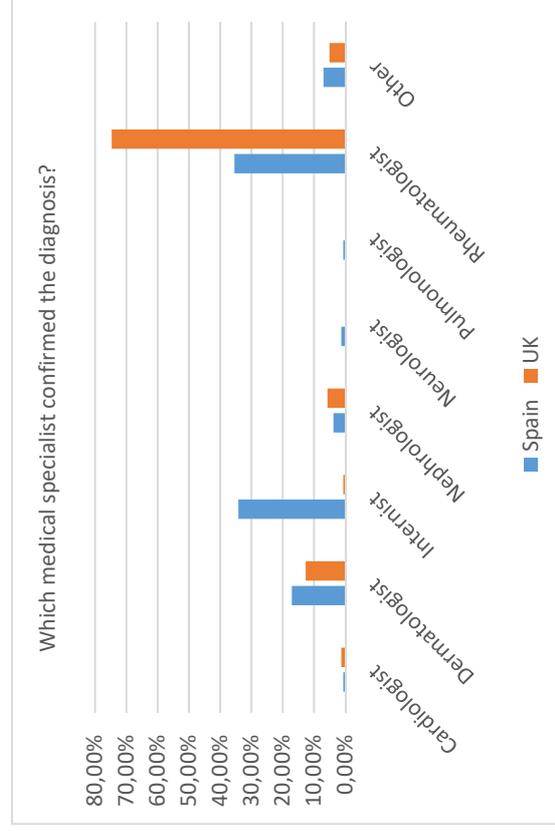
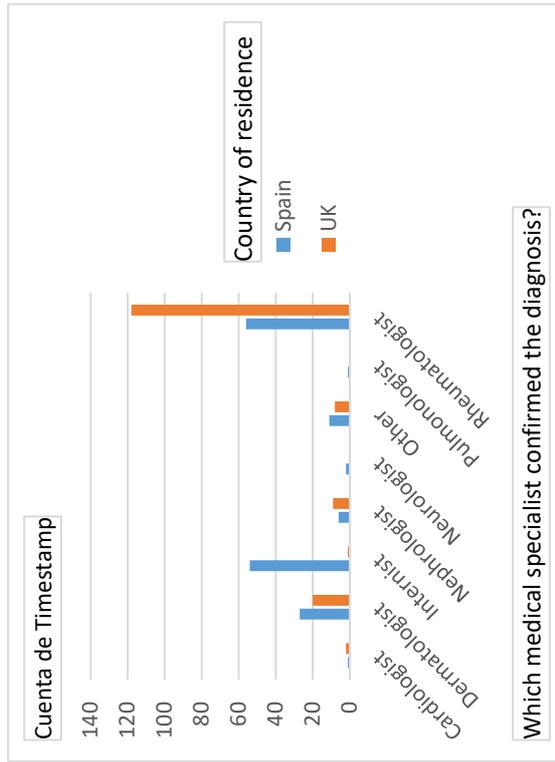
Cuenta de Timestamp		Etiquetas de columna		Total
Etiquetas de fila	Spain	UK		
+2 years	56	87	143	
0-3 months	26	15	41	
1-2 years	21	24	45	
3-6 months	34	13	47	
6-12 months	21	19	40	
Total	158	158	316	

	Spain	UK
0-3 months	16,46%	9,49%
3-6 months	21,52%	8,23%
6-12 months	13,29%	12,03%
1-2 years	13,29%	15,19%
+2 years	35,44%	55,06%



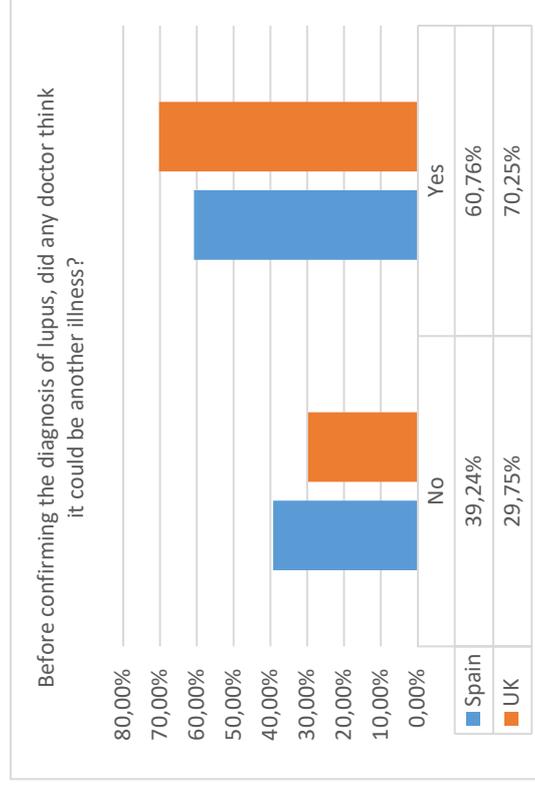
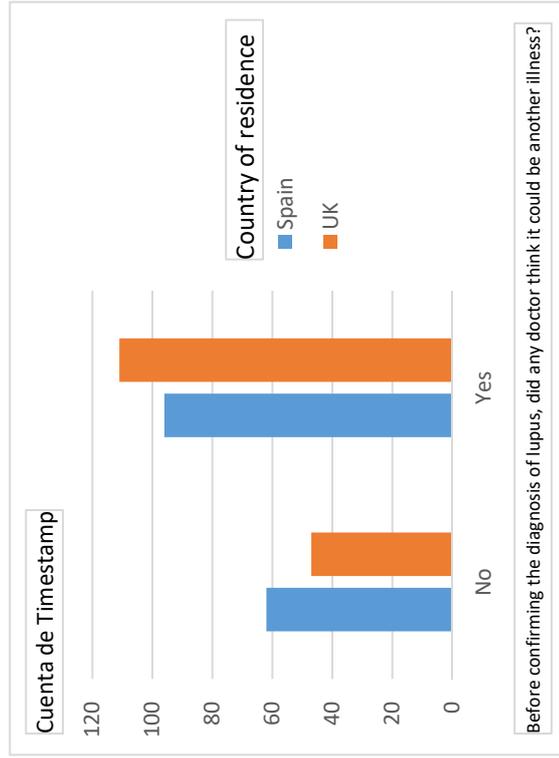
Cuenta de Timestamp				
Etiquetas de fila	Spain	UK	Total	
Cardiologist	1	2	3	
Dermatologist	27	20	47	
Internist	54	1	55	
Nephrologist	6	9	15	
Neurologist	2		2	
Other	11	8	19	
Pulmonologist	1		1	
Rheumatologist	56	118	174	
Total	158	158	316	

	Spain	UK
Cardiologist	0,63%	1,27%
Dermatologist	17,09%	12,66%
Internist	34,18%	0,63%
Nephrologist	3,80%	5,70%
Neurologist	1,27%	0,00%
Pulmonologist	0,63%	0,00%
Rheumatologist	35,44%	74,68%
Other	6,96%	5,06%



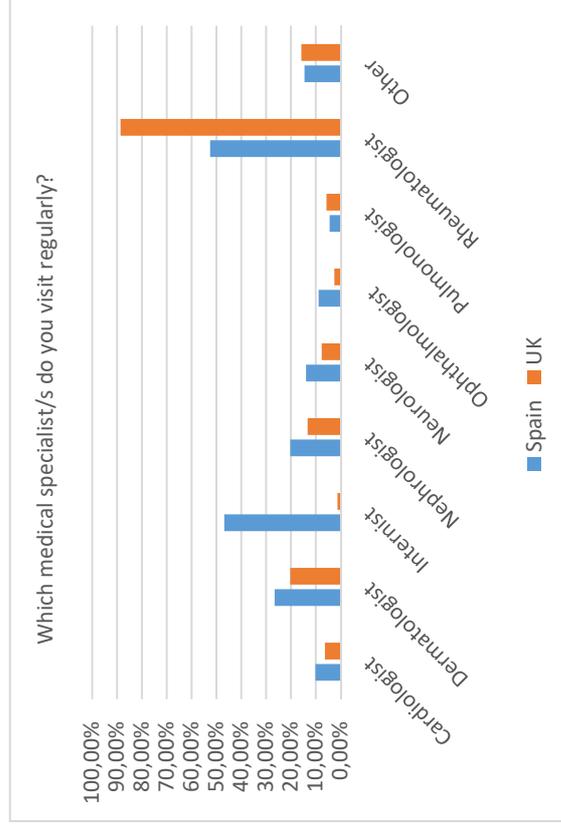
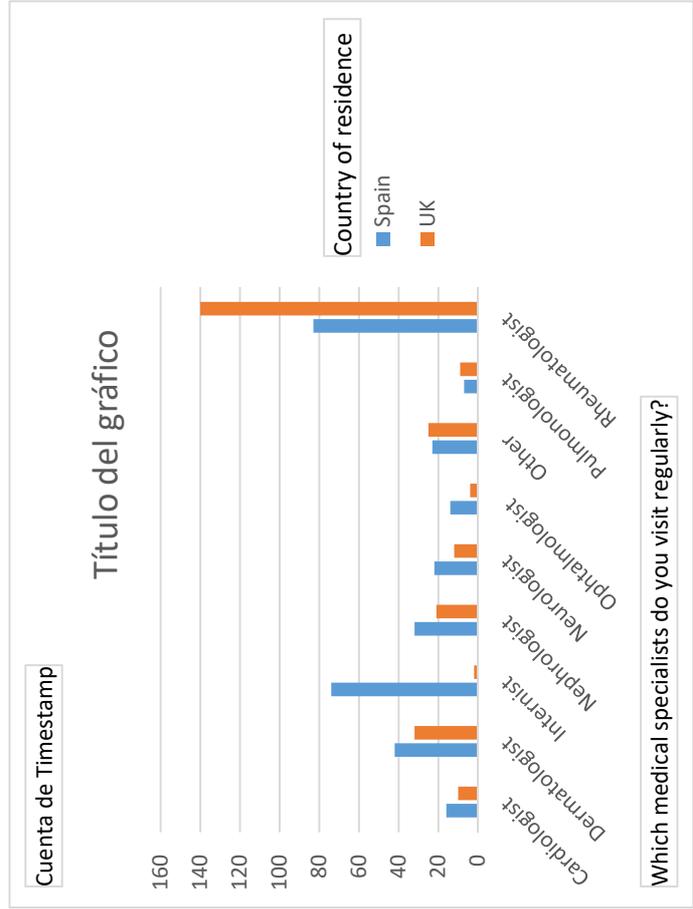
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	62	47	109
Yes	96	111	207
Total	158	158	316

	Spain	UK
No	39,24%	29,75%
Yes	60,76%	70,25%



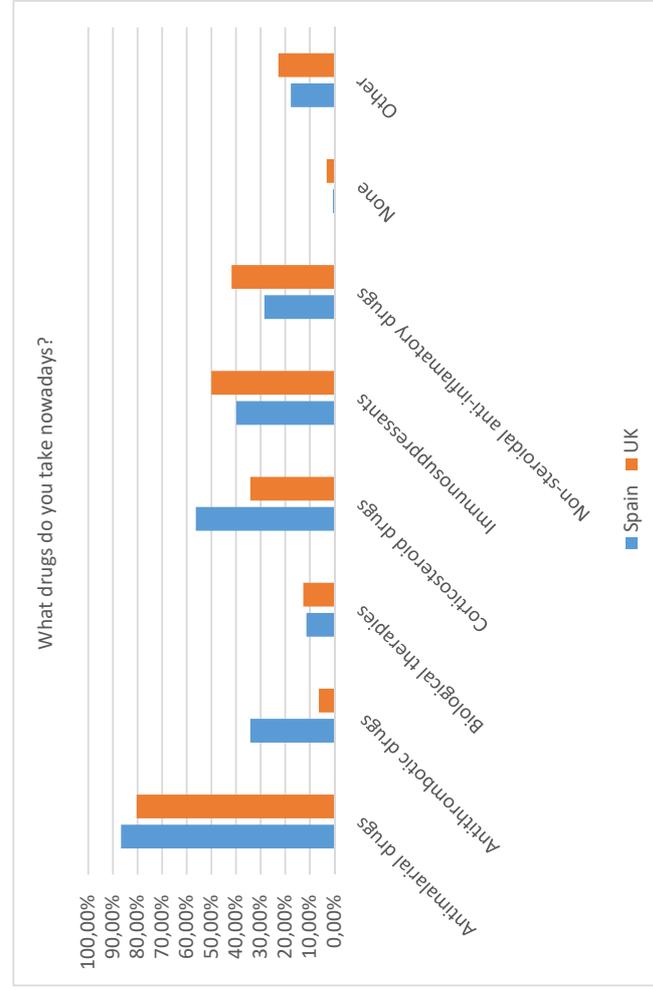
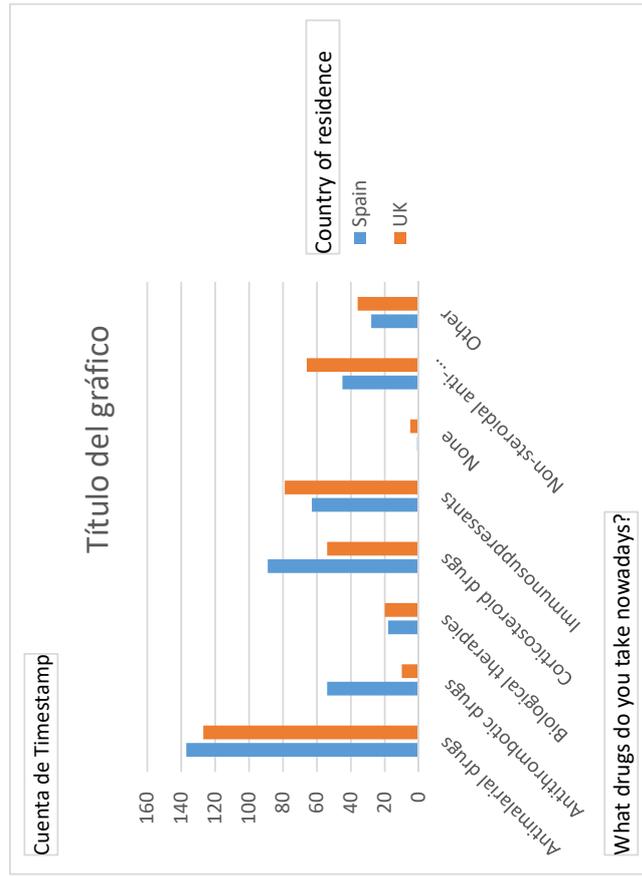
Cuenta de Timestamp Etiquetas de columna				
Etiquetas de fila	Spain	UK	Total	
Cardiologist	16	10	26	
Dermatologist	42	32	74	
Internist	74	2	76	
Nephrologist	32	21	53	
Neurologist	22	12	34	
Ophtalmologist	14	4	18	
Other	23	25	48	
Pulmonologist	7	9	16	
Rheumatologist	83	140	223	
Total	313	255	568	

	Spain	UK
Cardiologist	10,13%	6,33%
Dermatologist	26,58%	20,25%
Internist	46,84%	1,27%
Nephrologist	20,25%	13,29%
Neurologist	13,92%	7,59%
Ophthalmologist	8,86%	2,53%
Pulmonologist	4,43%	5,70%
Rheumatologist	52,53%	88,61%
Other	14,56%	15,82%



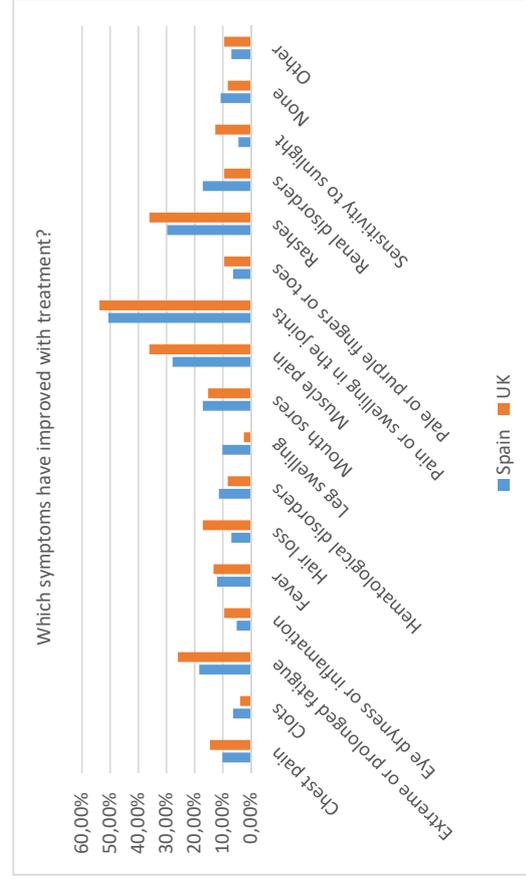
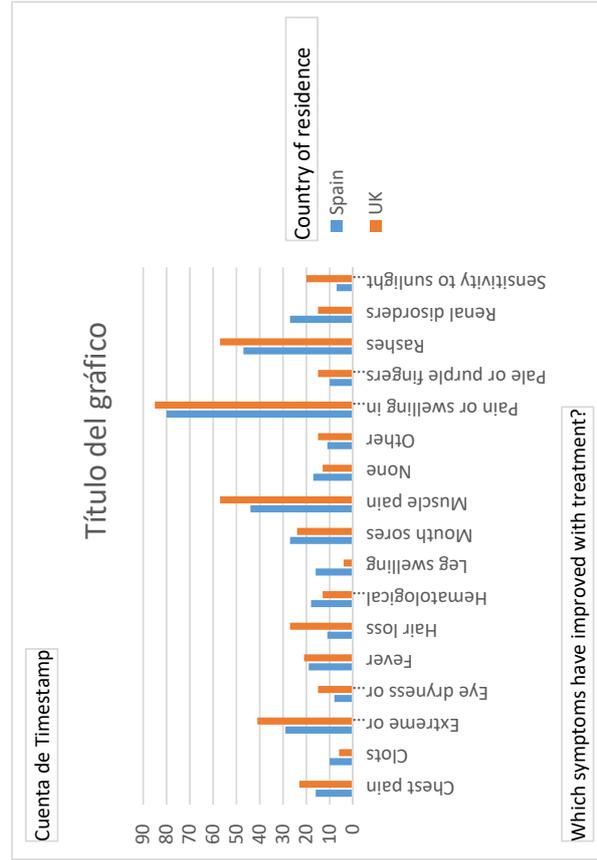
Cuenta de Timestamp	Etiquetas de columna		Total
	Etiquetas de fila	Spain	
Antimalarial drugs	137	127	264
Antithrombotic drugs	54	10	64
Biological therapies	18	20	38
Corticosteroid drugs	89	54	143
Immunosuppressants	63	79	142
None	1	5	6
Non-steroidal anti-inflammatory drugs	45	66	111
Other	28	36	64
Total	435	397	832

	Spain	UK
Antimalarial drugs	86,71%	80,38%
Antithrombotic drugs	34,18%	6,33%
Biological therapies	11,39%	12,66%
Corticosteroid drugs	56,33%	34,18%
Immunosuppressants	39,87%	50,00%
Non-steroidal anti-inflammatory drugs	28,48%	41,77%
None	0,63%	3,16%
Other	17,72%	22,78%



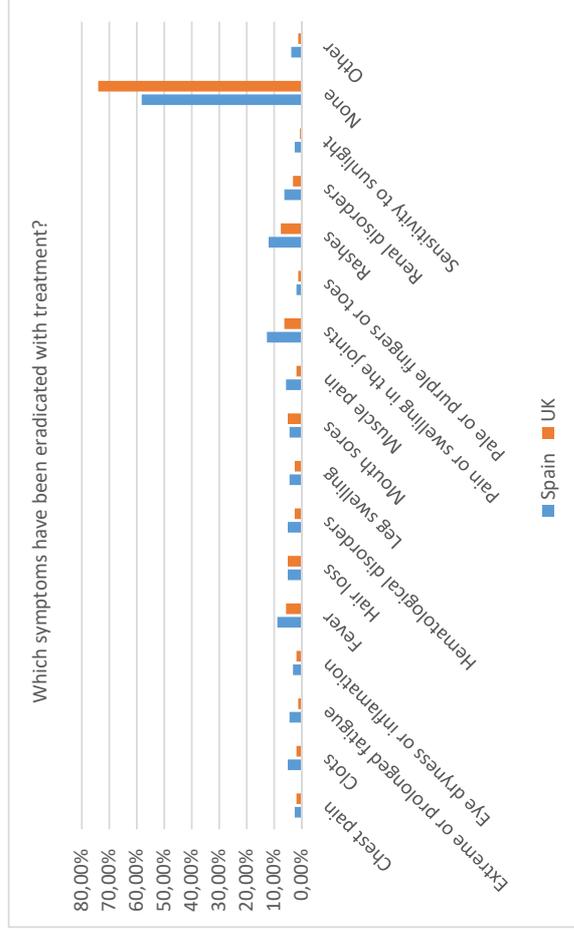
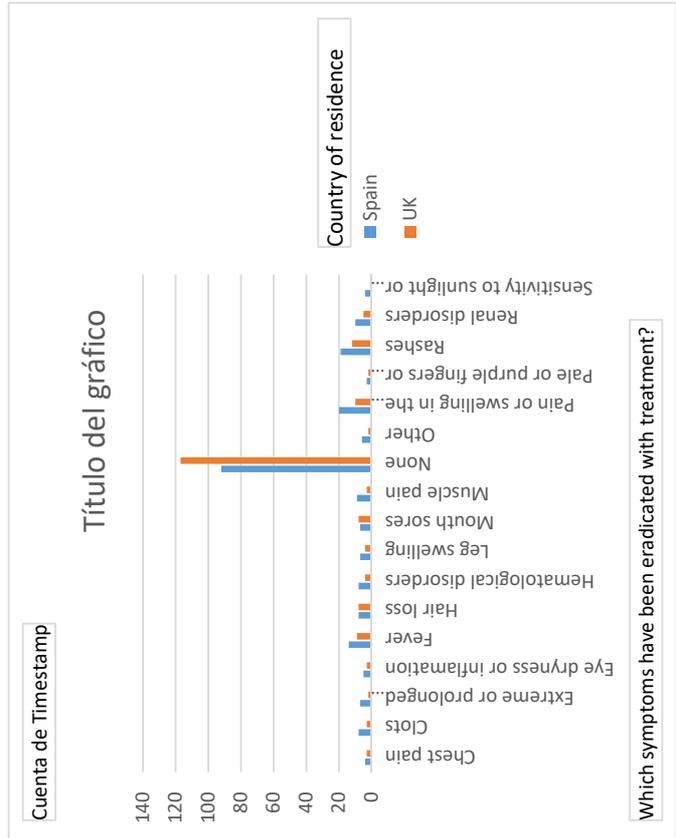
Cuenta de Timestamp	Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total
Chest pain	16	23	39
Clots	10	6	16
Extreme or prolonged fatigue	29	41	70
Eye dryness or inflammation	8	15	23
Fever	19	21	40
Hair loss	11	27	38
Hematological disorders	18	13	31
Leg swelling	16	4	20
Mouth sores	27	24	51
Muscle pain	44	57	101
None	17	13	30
Other	11	15	26
Pain or swelling in the joints	80	85	165
Pale or purple fingers or toes	10	15	25
Rashes	47	57	104
Renal disorders	27	15	42
Sensitivity to sunlight or fluorescent light	7	20	27
Total	397	451	848

	Spain	UK
Chest pain	10,13%	14,56%
Clots	6,33%	3,80%
Extreme or prolonged fatigue	18,35%	25,95%
Eye dryness or inflammation	5,06%	9,49%
Fever	12,03%	13,29%
Hair loss	6,96%	17,09%
Hematological disorders	11,39%	8,23%
Leg swelling	10,13%	2,53%
Mouth sores	17,09%	15,19%
Muscle pain	27,85%	36,08%
Pain or swelling in the joints	50,63%	53,80%
Pale or purple fingers or toes	6,33%	9,49%
Rashes	29,75%	36,08%
Renal disorders	17,09%	9,49%
Sensitivity to sunlight	4,43%	12,66%
None	10,76%	8,23%
Other	6,96%	9,49%



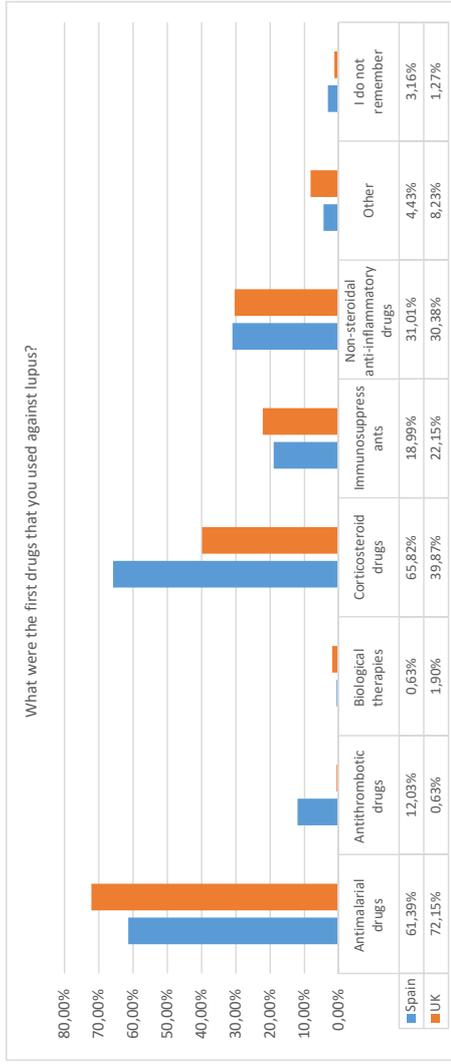
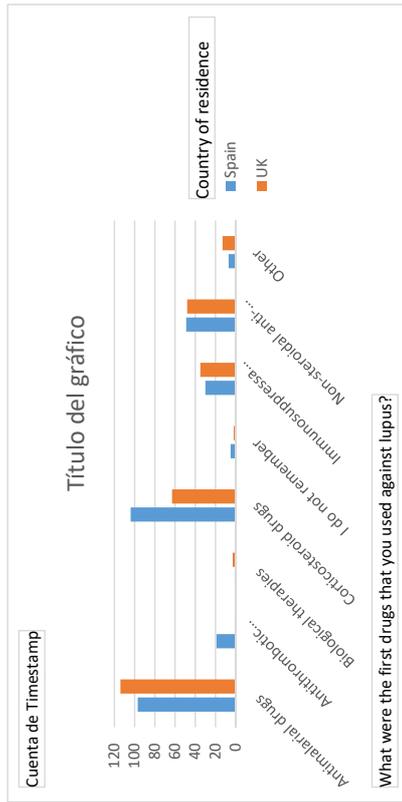
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
Chest pain	4	3	7
Clots	8	3	11
Extreme or prolonged fatigue	7	2	9
Eye dryness or inflammation	5	3	8
Fever	14	9	23
Hair loss	8	8	16
Hematological disorders	8	4	12
Leg swelling	7	4	11
Mouth sores	7	8	15
Muscle pain	9	3	12
None	92	117	209
Other	6	2	8
Pain or swelling in the joints	20	10	30
Pale or purple fingers or toes	3	2	5
Rashes	19	12	31
Renal disorders	10	5	15
Sensitivity to sunlight or fluorescent light	4	1	5
Total	231	196	427

	Spain	UK
Chest pain	2,53%	1,90%
Clots	5,06%	1,90%
Extreme or prolonged fatigue	4,43%	1,27%
Eye dryness or inflammation	3,16%	1,90%
Fever	8,86%	5,70%
Hair loss	5,06%	5,06%
Hematological disorders	5,06%	2,53%
Leg swelling	4,43%	2,53%
Mouth sores	4,43%	5,06%
Muscle pain	5,70%	1,90%
Pain or swelling in the joints	12,66%	6,33%
Pale or purple fingers or toes	1,90%	1,27%
Rashes	12,03%	7,59%
Renal disorders	6,33%	3,16%
Sensitivity to sunlight	2,53%	0,63%
None	58,23%	74,05%
Other	3,80%	1,27%



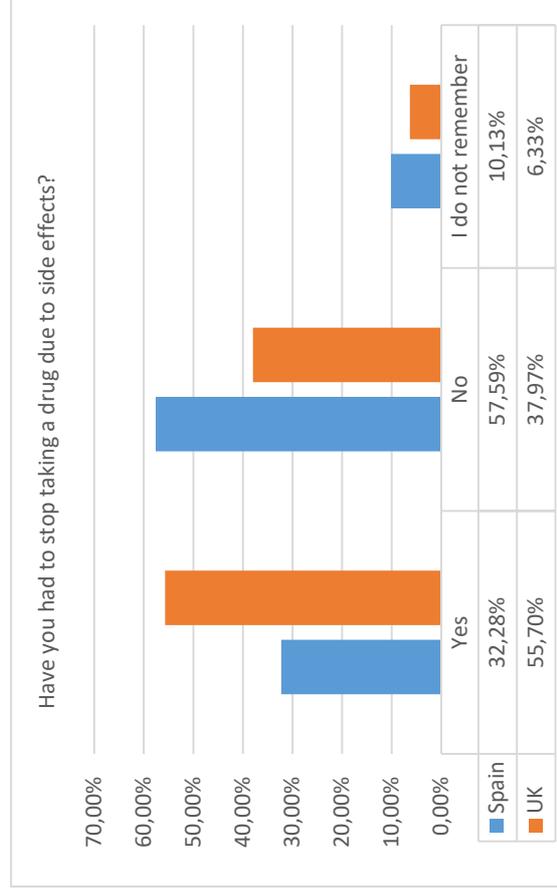
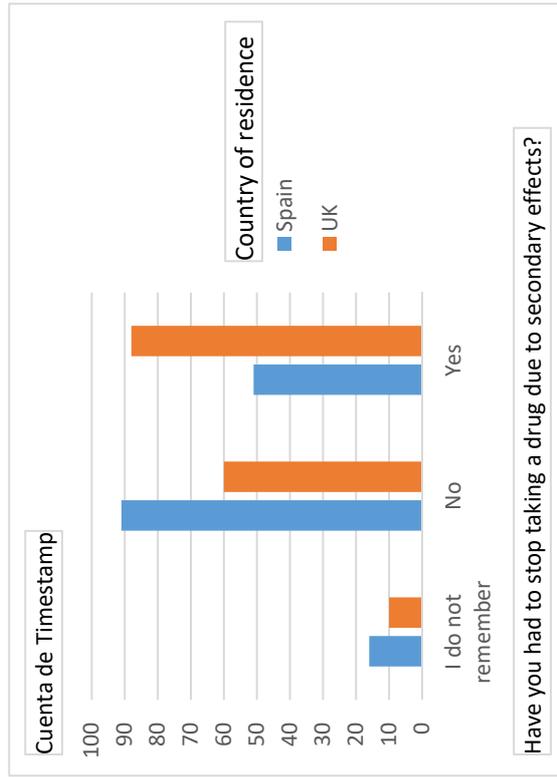
Etiquetas de columna				
Cuenta de Timestamp	Etiquetas de fila	Spain	UK	Total
	Antimalarial drugs	97	114	211
	Antithrombotic drugs	19	1	20
	Biological therapies	1	3	4
	Corticosteroid drugs	104	63	167
	I do not remember	5	2	7
	Immunosuppressants	30	35	65
	Non-steroidal anti-inflammatory drugs	49	48	97
	Other	7	13	20
Total		312	279	591

	Spain	UK
Antimalarial drugs	61,39%	72,15%
Antithrombotic drugs	12,03%	0,63%
Biological therapies	0,63%	1,90%
Corticosteroid drugs	65,82%	39,87%
Immunosuppressants	18,99%	22,15%
Non-steroidal anti-inflammatory drugs	31,01%	30,38%
Other	4,43%	8,23%
I do not remember	3,16%	1,27%



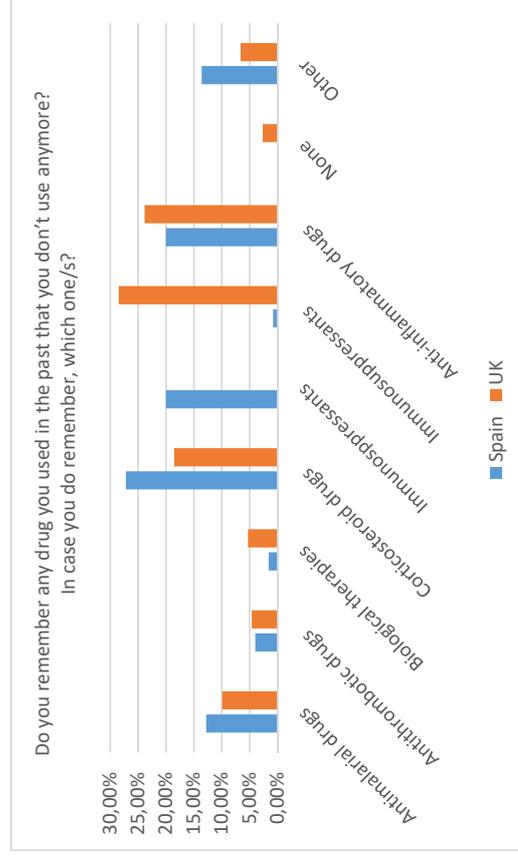
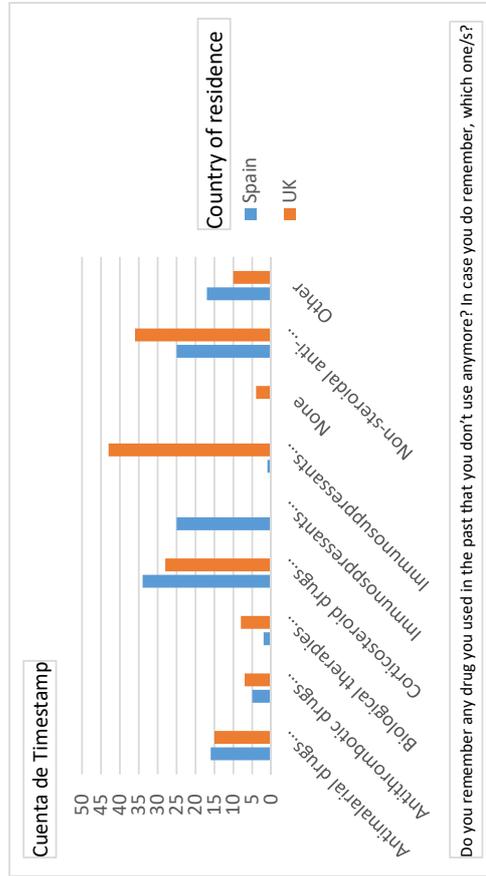
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	Total
I do not remember	16	10	26
No	91	60	151
Yes	51	88	139
Total	158	158	316

	Spain	UK
Yes	32,28%	55,70%
No	57,59%	37,97%
I do not remember	10,13%	6,33%



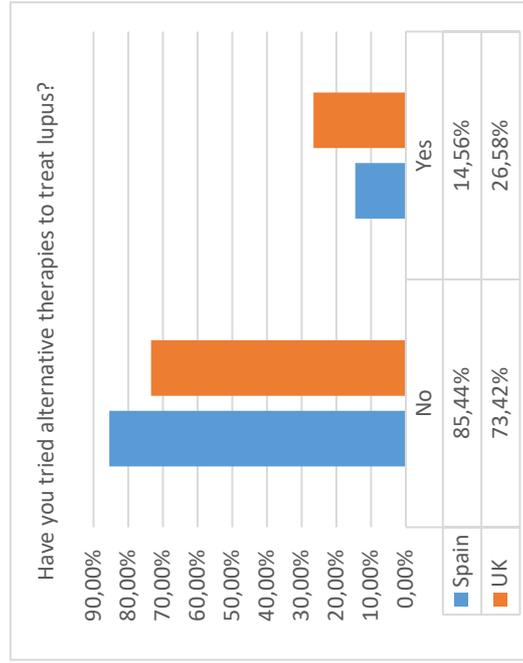
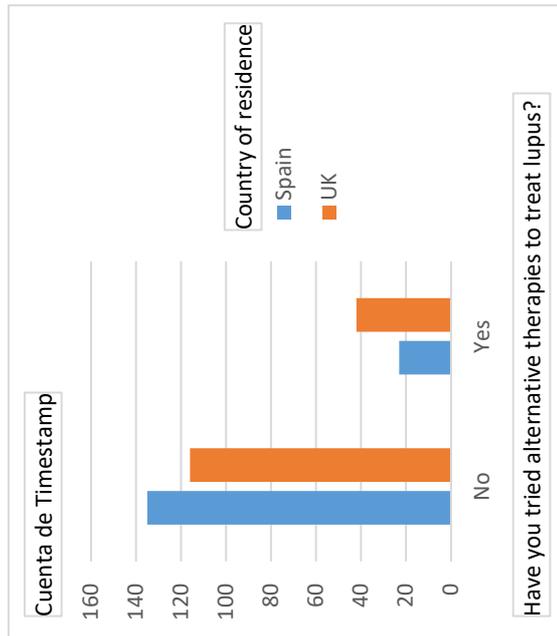
Cuenta de Timestamp	Etiquetas de columna		
	Spain	UK	Total
Antimalarial drugs (hidroxicloroquine, cloroquine...)	16	15	31
Antithrombotic drugs (acetylsalicylic acid, synthrome...)	5	7	12
Biological therapies (belimumab, rituximab...)	2	8	10
Corticosteroid drugs (prednisolone...)	34	28	62
Immunosuppressants (methotrexate, azathioprine...)	25	25	25
Immunosuppressants (methotrexate, azathioprine...)	1	43	44
None		4	4
Non-steroidal anti-inflammatory drugs (ibuprofen, naproxen...)	25	36	61
Other	17	10	27
Total	125	151	276

	Spain	UK
Antimalarial drugs	12,80%	9,93%
Antithrombotic drugs	4,00%	4,64%
Biological therapies	1,60%	5,30%
Corticosteroid drugs	27,20%	18,54%
Immunosuppressants	20,00%	0,00%
Immunosuppressants	0,80%	28,48%
Anti-inflammatory drugs	20,00%	23,84%
None	0,00%	2,65%
Other	13,60%	6,62%



Cuenta de Timestamp	Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total
No	135	116	251
Yes	23	42	65
Total	158	158	316

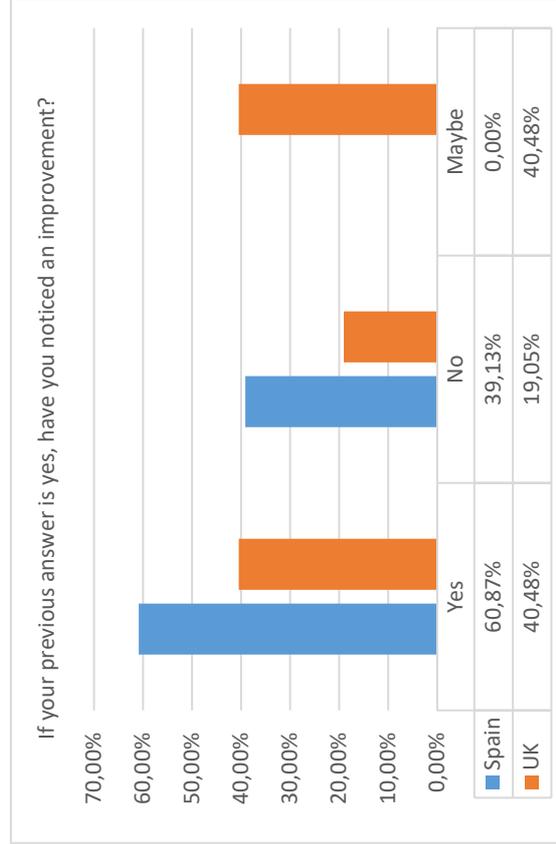
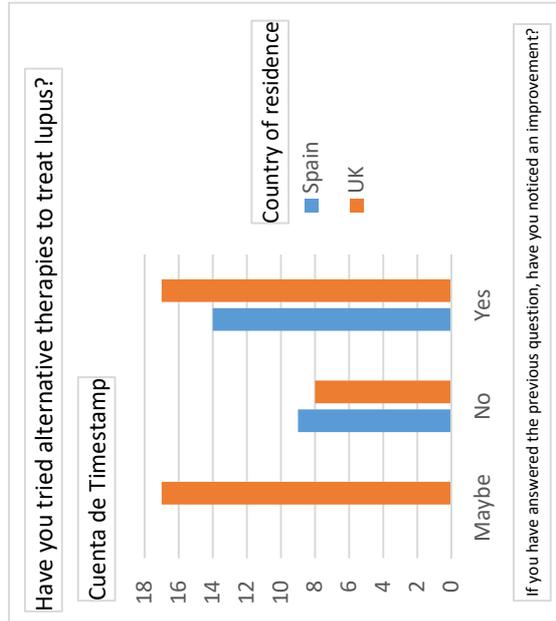
	Spain	UK
No	85,44%	73,42%
Yes	14,56%	26,58%



Have you tried alternative therapi Yes

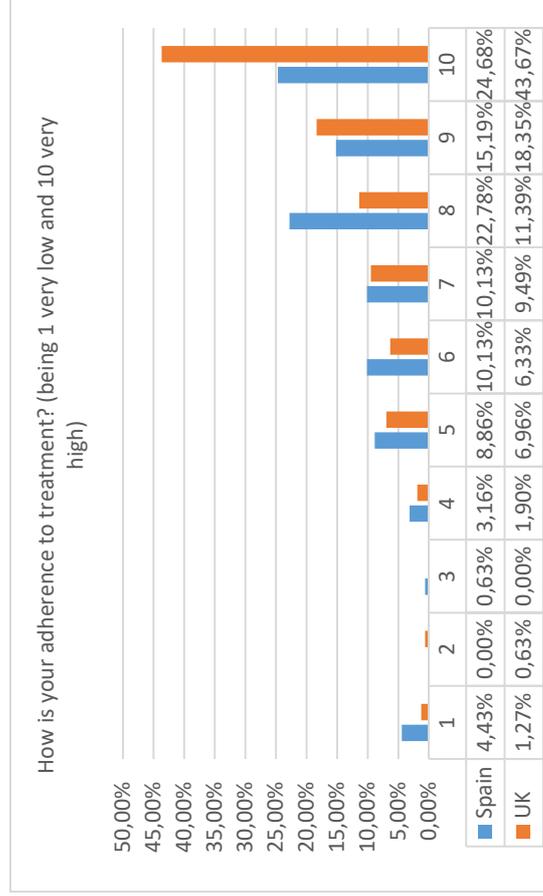
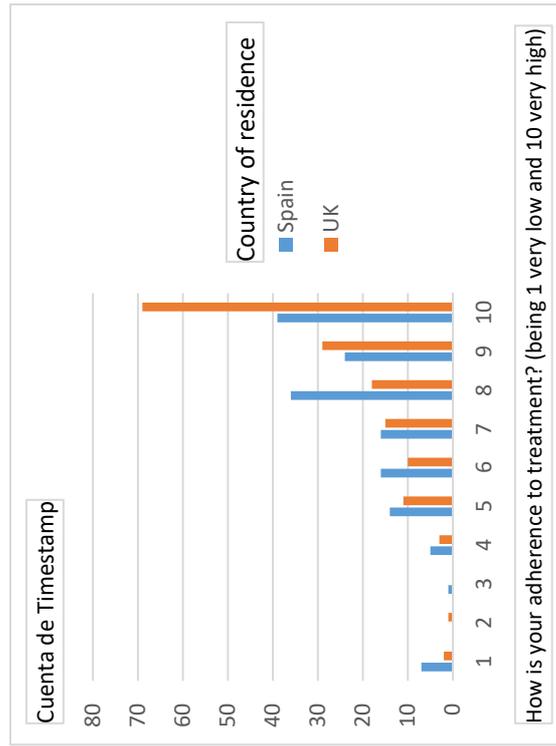
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
Maybe		17	17
No	9	8	17
Yes	14	17	31
Total	23	42	65

	Spain	UK
Yes	60,87%	40,48%
No	39,13%	19,05%
Maybe	0,00%	40,48%



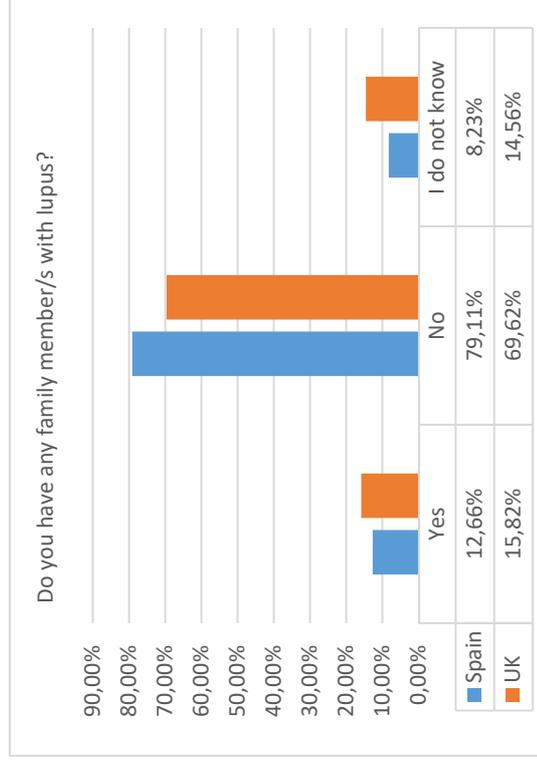
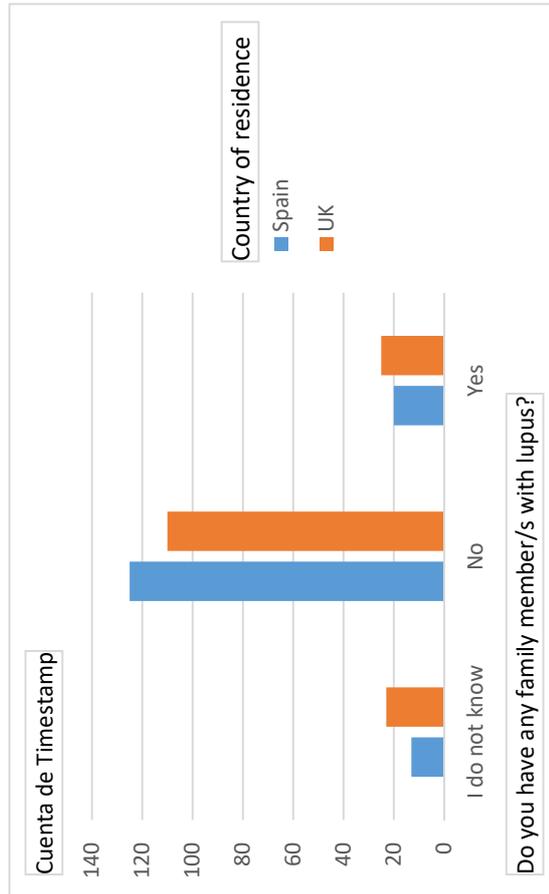
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	Total
1	7	2	9
2		1	1
3	1		1
4	5	3	8
5	14	11	25
6	16	10	26
7	16	15	31
8	36	18	54
9	24	29	53
10	39	69	108
Total	158	158	316

	Spain	UK
1	4,43%	1,27%
2	0,00%	0,63%
3	0,63%	0,00%
4	3,16%	1,90%
5	8,86%	6,96%
6	10,13%	6,33%
7	10,13%	9,49%
8	22,78%	11,39%
9	15,19%	18,35%
10	24,68%	43,67%



Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
I do not know	13	23	36
No	125	110	235
Yes	20	25	45
Total	158	158	316

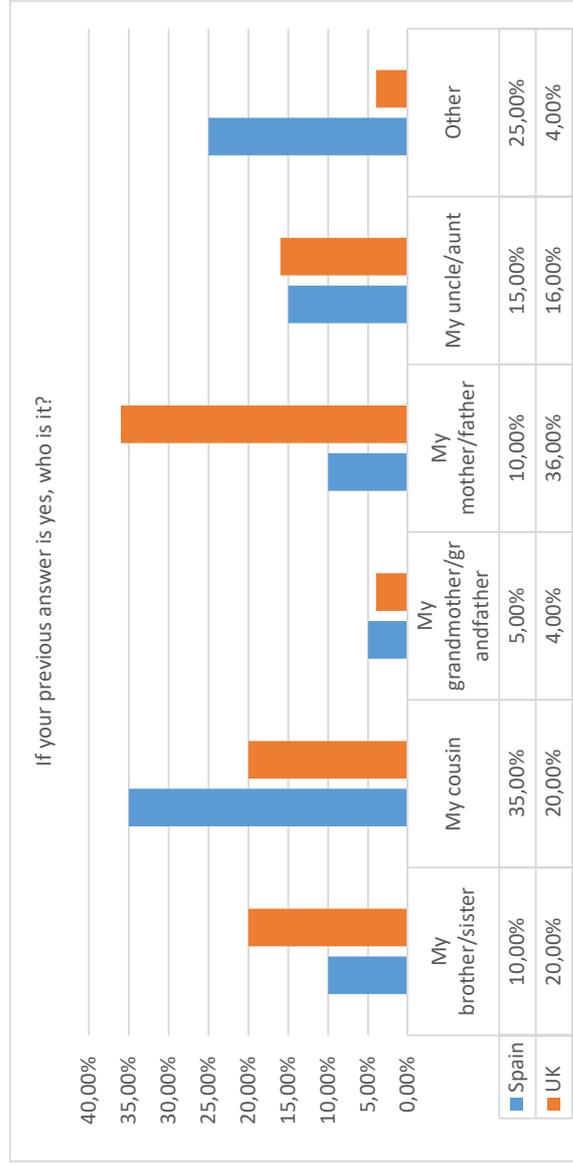
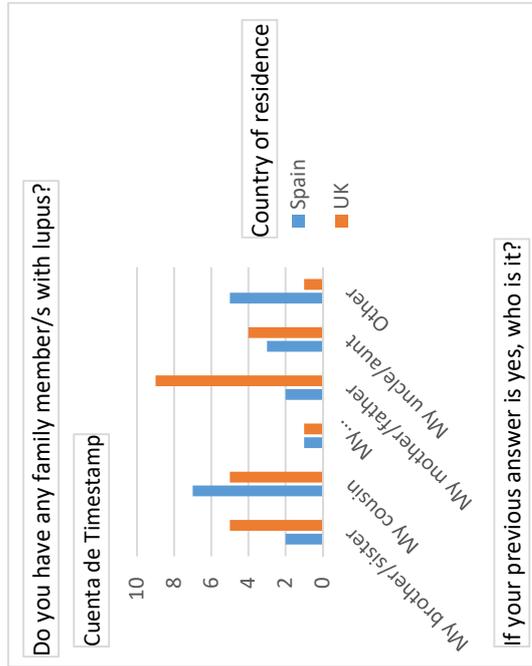
	Spain	UK
Yes	12,66%	15,82%
No	79,11%	69,62%
I do not know	8,23%	14,56%



Do you have any family member/s with lupus?

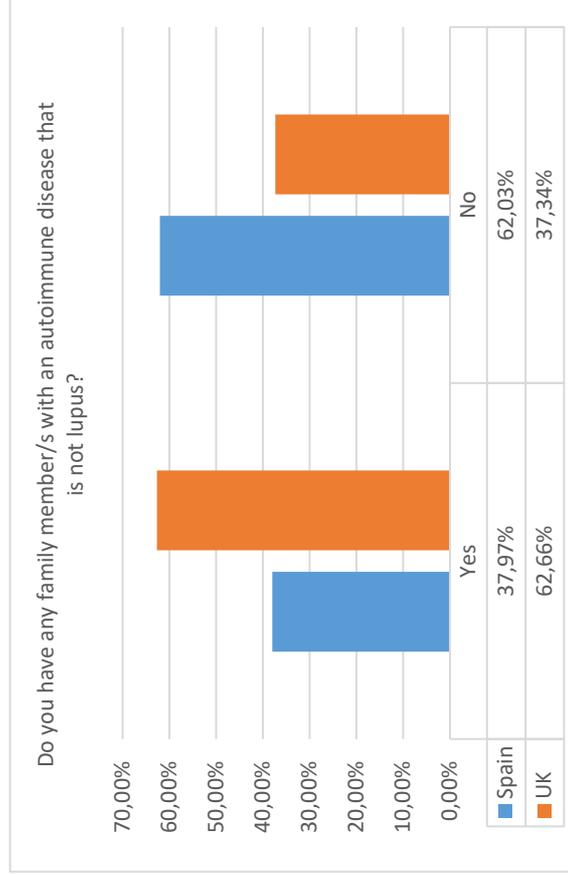
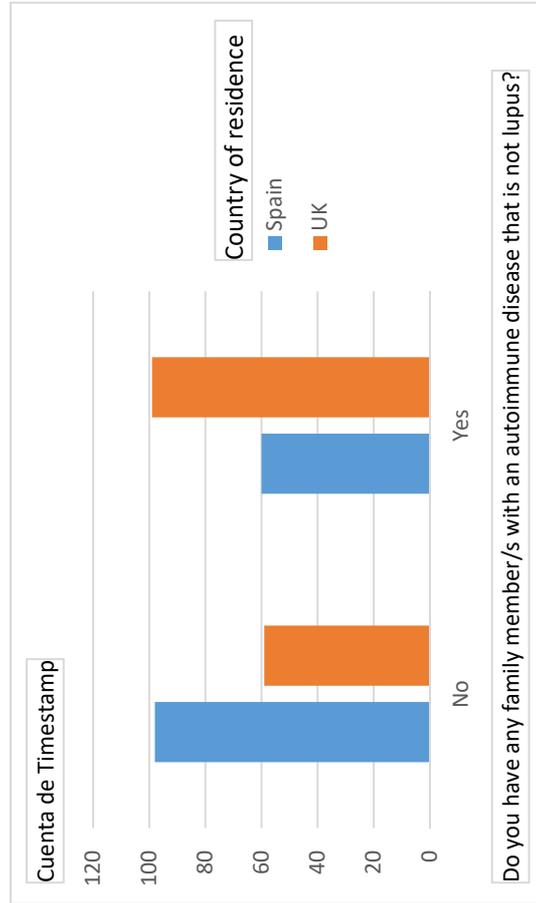
Cuenta de Timestamp	Etiquetas de columna	Spain	UK	Total
My brother/sister		2	5	7
My cousin		7	5	12
My grandmother/grandfather		1	1	2
My mother/father		2	9	11
My uncle/aunt		3	4	7
Other		5	1	6
Total		20	25	45

	Spain	UK
My brother/sister	10,00%	20,00%
My cousin	35,00%	20,00%
My grandmother/grandfather	5,00%	4,00%
My mother/father	10,00%	36,00%
My uncle/aunt	15,00%	16,00%
Other	25,00%	4,00%



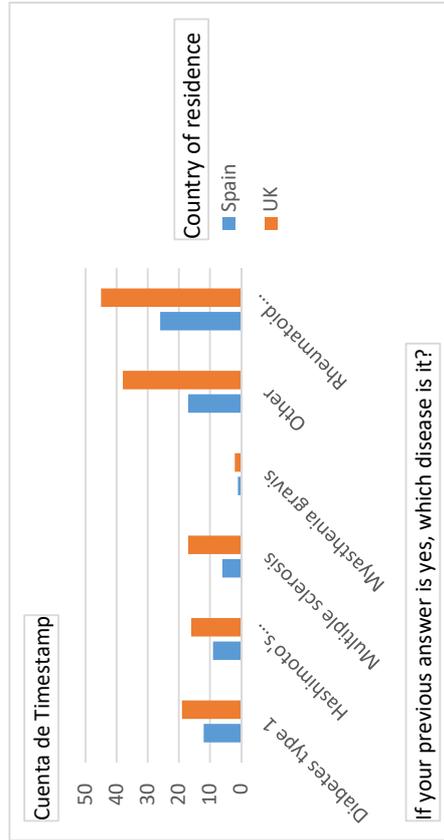
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	98	59	157
Yes	60	99	159
Total	158	158	316

	Spain	UK
Yes	37,97%	62,66%
No	62,03%	37,34%



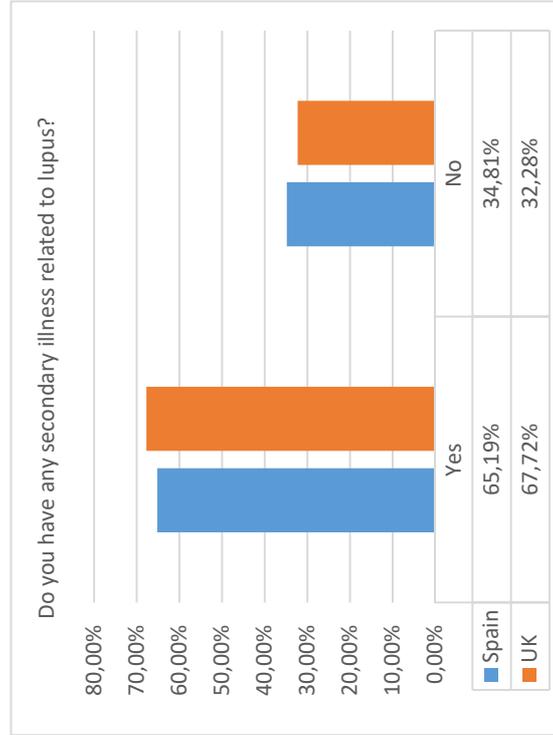
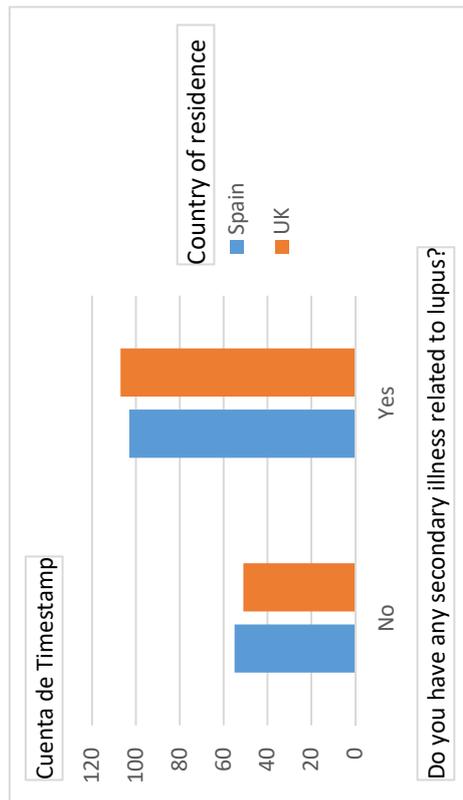
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
Diabetes type 1	12	19	31
Hashimoto's thyroiditis	9	16	25
Multiple sclerosis	6	17	23
Myasthenia gravis	1	2	3
Other	17	38	55
Rheumatoid arthritis	26	45	71
Total	71	137	208

	Spain	UK
Diabetes type 1	16,90%	13,87%
Hashimoto's thyroiditis	12,68%	11,68%
Multiple sclerosis	8,45%	12,41%
Myasthenia gravis	1,41%	1,46%
Rheumatoid arthritis	36,62%	32,85%
Other	23,94%	27,74%



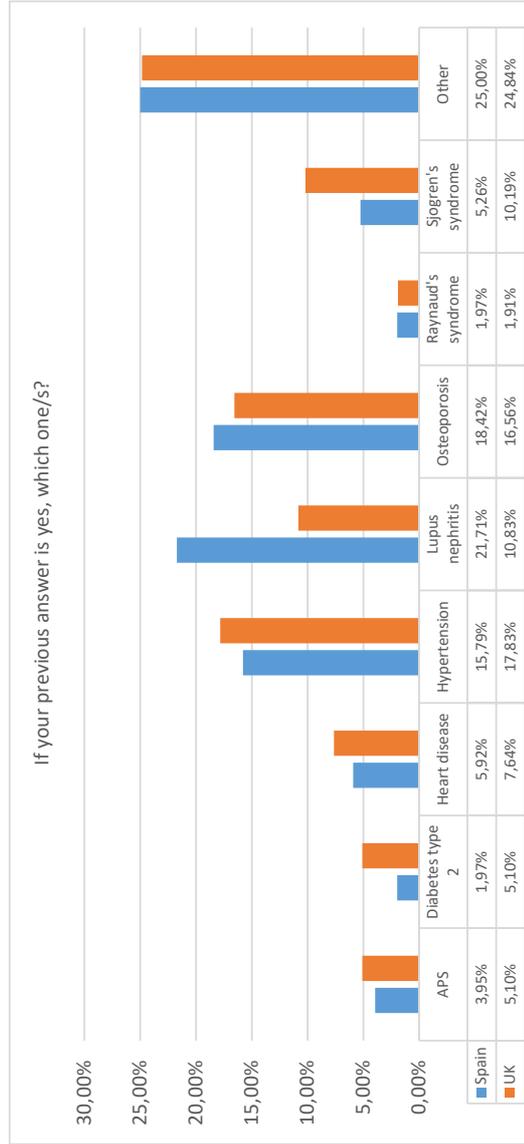
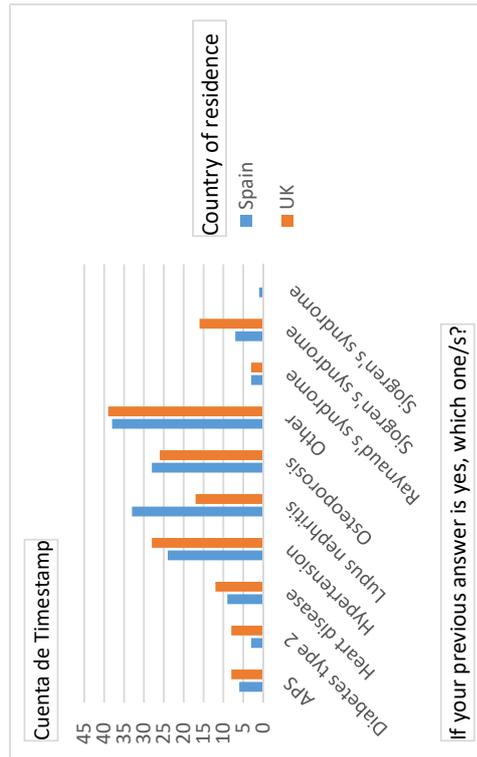
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	55	51	106
Yes	103	107	210
Total	158	158	316

	Spain	UK
Yes	65,19%	67,72%
No	34,81%	32,28%



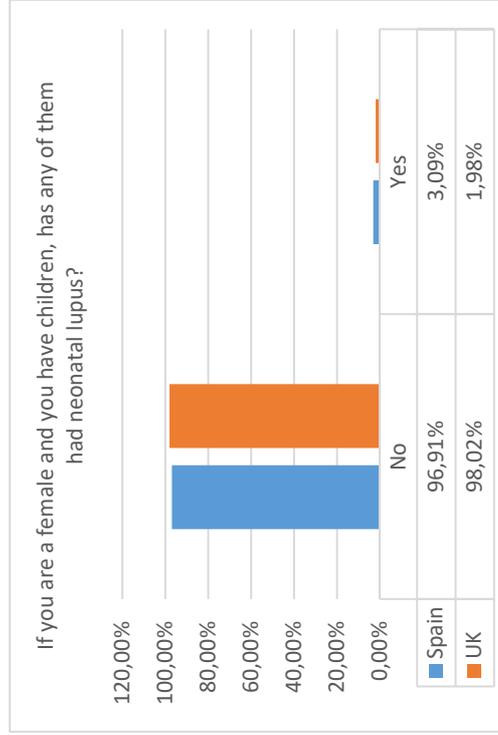
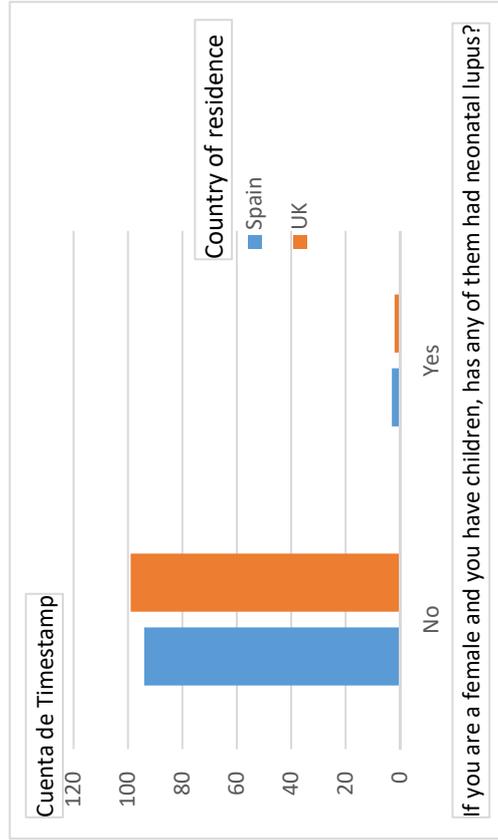
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
APS	6	8	14
Diabetes type 2	3	8	11
Heart disease	9	12	21
Hypertension	24	28	52
Lupus nephritis	33	17	50
Osteoporosis	28	26	54
Other	38	39	77
Raynaud's syndrome	3	3	6
Sjogren's syndrome	7	16	23
Sjogren's syndrome	1		1
Total	152	157	309

	Spain	UK
APS	3,95%	5,10%
Diabetes type 2	1,97%	5,10%
Heart disease	5,92%	7,64%
Hypertension	15,79%	17,83%
Lupus nephritis	21,71%	10,83%
Osteoporosis	18,42%	16,56%
Raynaud's syndrome	1,97%	1,91%
Sjogren's syndrome	5,26%	10,19%
Other	25,00%	24,84%



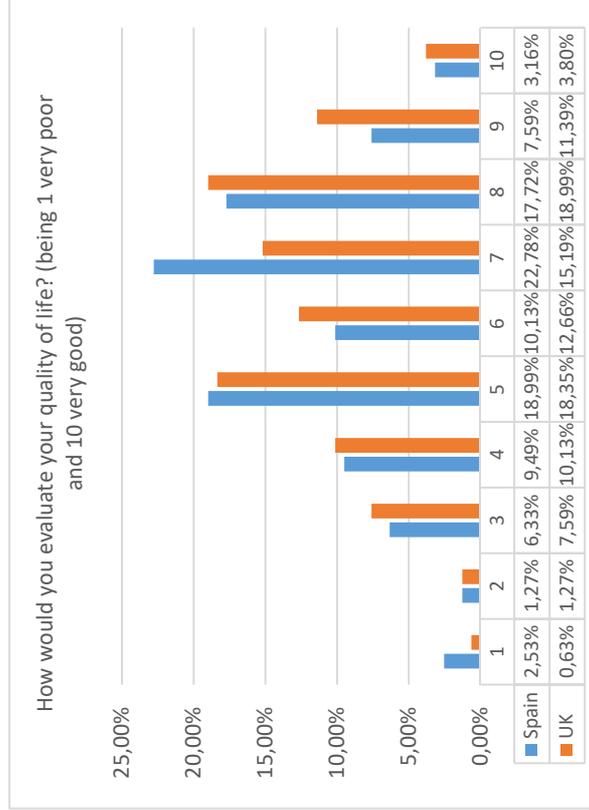
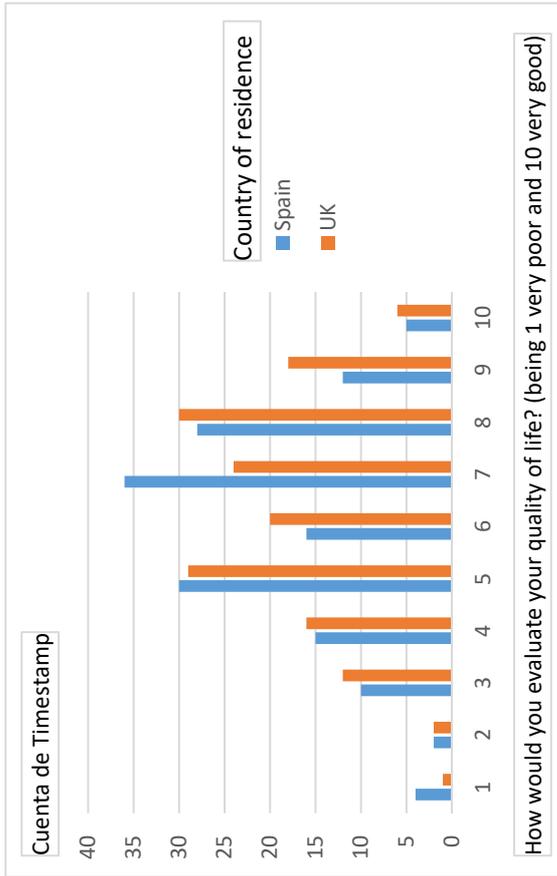
Cuenta de Timestamp	Etiquetas de columna			Total
Etiquetas de fila	Spain	UK		
No	94	99		193
Yes	3	2		5
Total	97	101		198

	Spain	UK
No	96,91%	98,02%
Yes	3,09%	1,98%



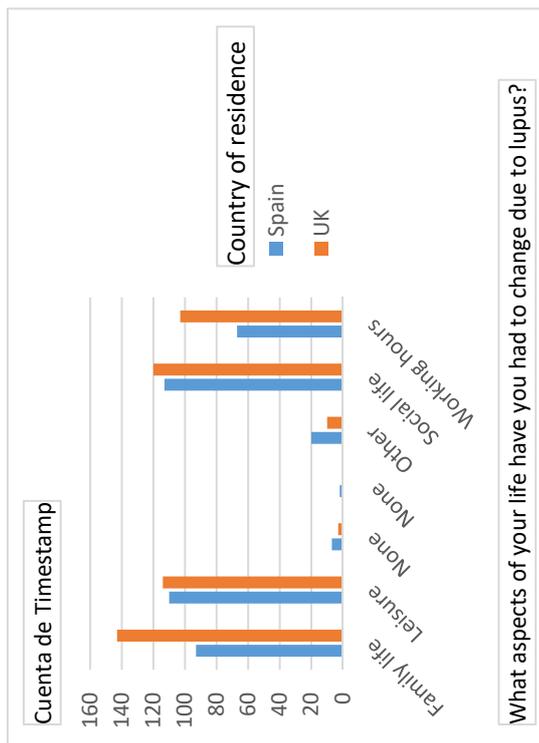
Cuenta de Timestamp	Etiquetas de columna			Total
Etiquetas de fila	Spain	UK		
1	4	1		5
2	2	2		4
3	10	12		22
4	15	16		31
5	30	29		59
6	16	20		36
7	36	24		60
8	28	30		58
9	12	18		30
10	5	6		11
Total	158	158		316

	Spain	UK
1	2,53%	0,63%
2	1,27%	1,27%
3	6,33%	7,59%
4	9,49%	10,13%
5	18,99%	18,35%
6	10,13%	12,66%
7	22,78%	15,19%
8	17,72%	18,99%
9	7,59%	11,39%
10	3,16%	3,80%



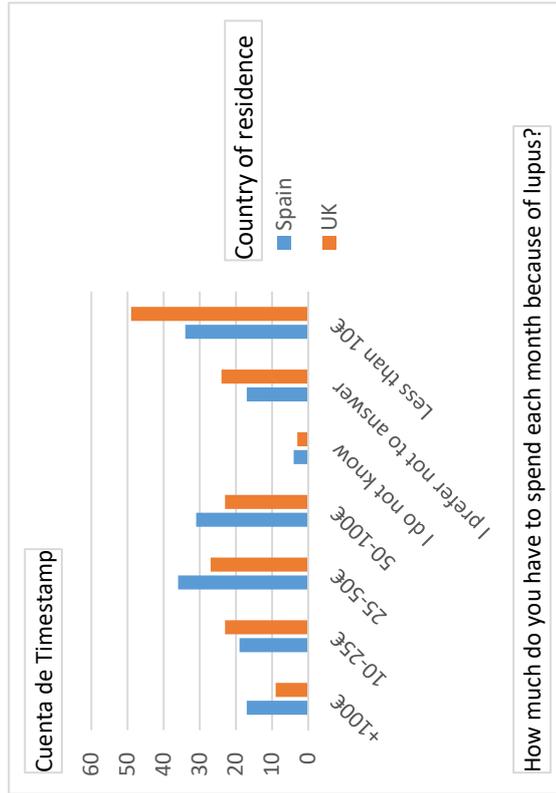
Cuenta de Timestamp		Etiquetas de columna		Total
Etiquetas de fila	Spain	UK		
Family life	93	143		236
Leisure	110	114		224
None	7	3		10
None	2			2
Other	20	10		30
Social life	113	120		233
Working hours	67	103		170
Total	412	493		905

	Spain	UK
Family life	58,86%	90,51%
Leisure	69,62%	72,15%
Social life	71,52%	75,95%
Working hours	42,41%	65,19%
Other	12,66%	6,33%
None	5,70%	1,90%



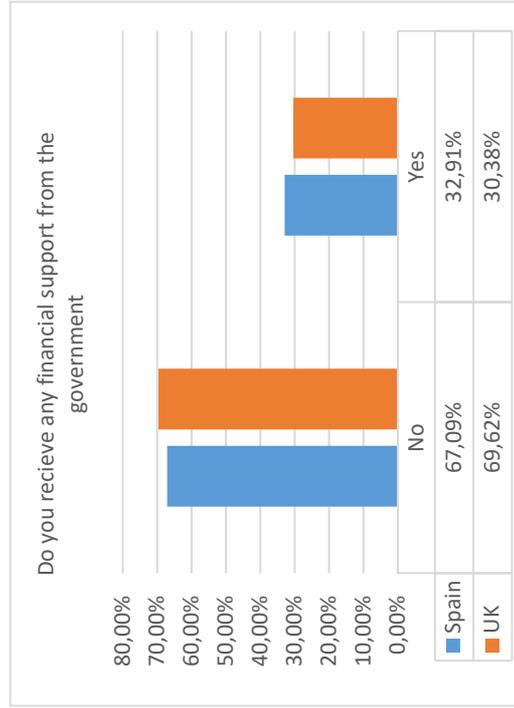
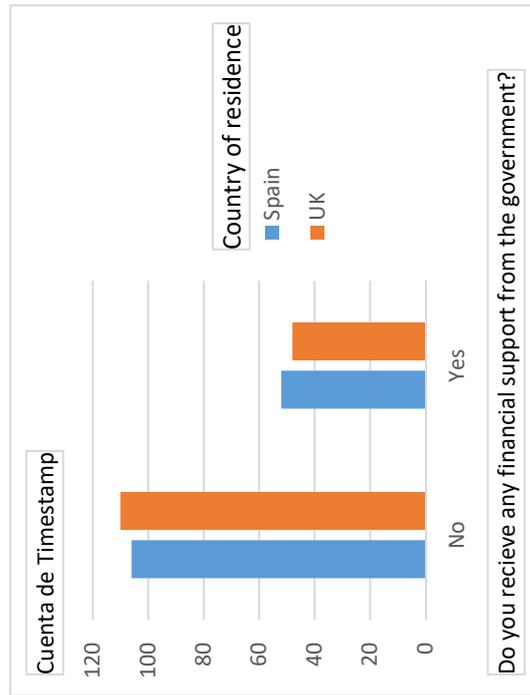
Cuenta de Timestamp				Etiquetas de columna		Total
Etiquetas de fila	Spain	UK		Spain	UK	Total
+100€	17	9		26		26
10-25€	19	23		42		42
25-50€	36	27		63		63
50-100€	31	23		54		54
I do not know	4	3		7		7
I prefer not to answer	17	24		41		41
Less than 10€	34	49		83		83
Total	158	158		316		316

	Spain	UK
Less than 10€	21,52%	31,01%
10-25€	12,03%	14,56%
25-50€	22,78%	17,09%
50-100€	19,62%	14,56%
+100€	10,76%	5,70%
I do not know	2,53%	1,90%
I prefer not to answer	10,76%	15,19%



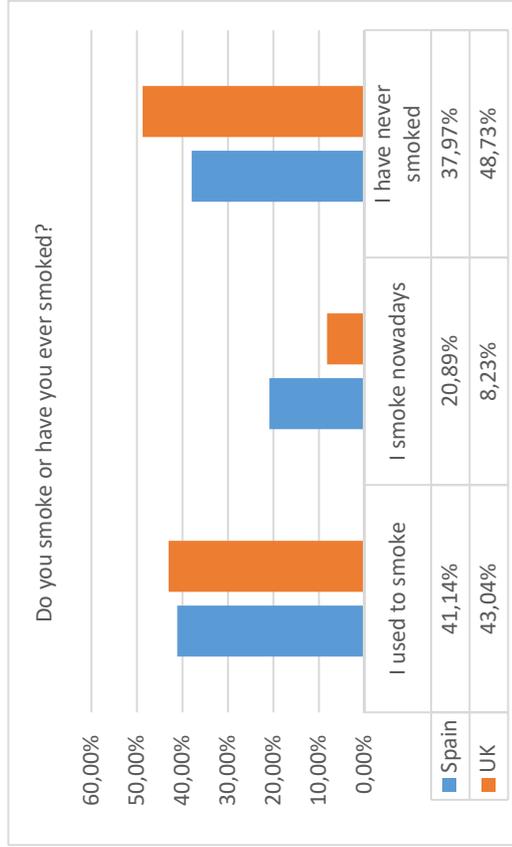
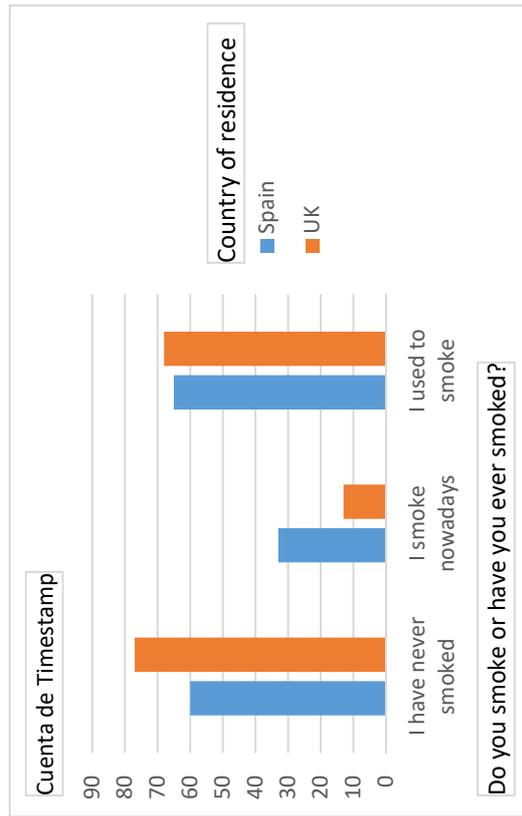
Cuenta de Timestamp	Etiquetas de columna			Total
Etiquetas de fila	Spain	UK		
No	106	110		216
Yes	52	48		100
Total	158	158		316

	Spain	UK
No	67,09%	69,62%
Yes	32,91%	30,38%

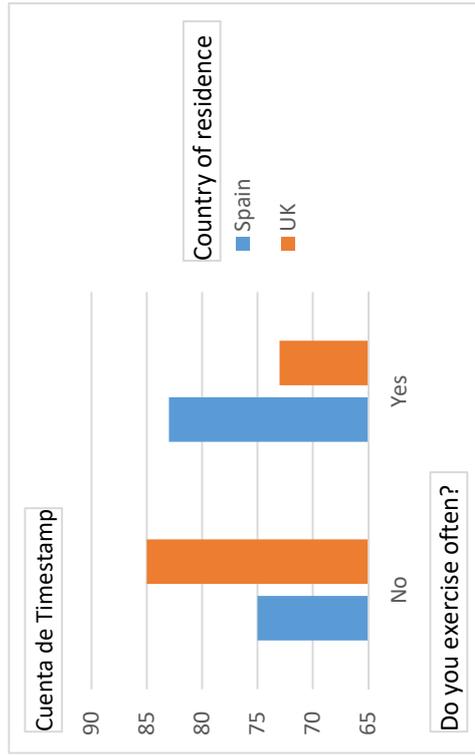


Cuenta de Timestamp				
Etiquetas de fila	Etiquetas de columna			Total
	Spain	UK		
I have never smoked	60	77		137
I smoke nowadays	33	13		46
I used to smoke	65	68		133
Total	158	158		316

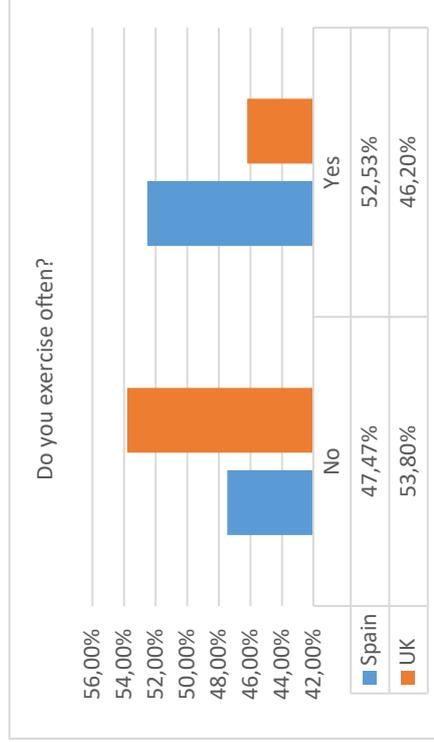
	Spain	UK
I used to smoke	41,14%	43,04%
I smoke nowadays	20,89%	8,23%
I have never smoked	37,97%	48,73%



Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	75	85	160
Yes	83	73	156
Total	158	158	316

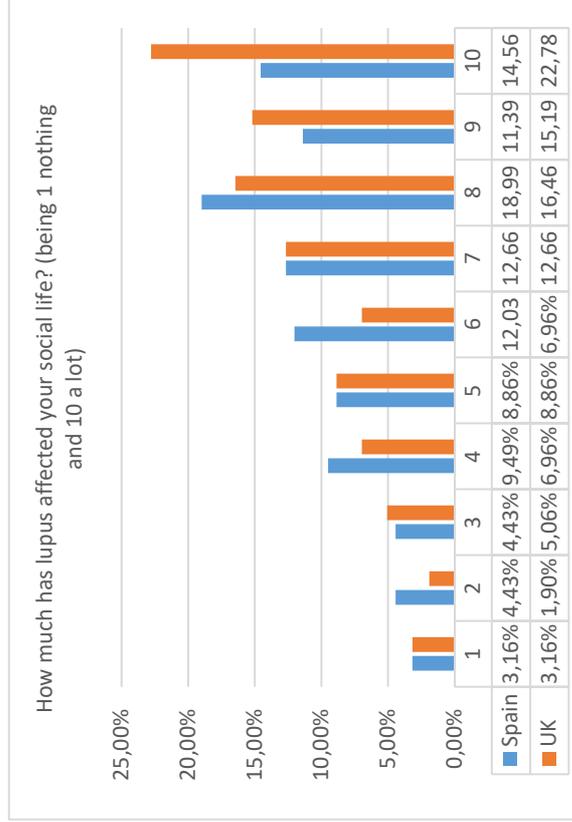
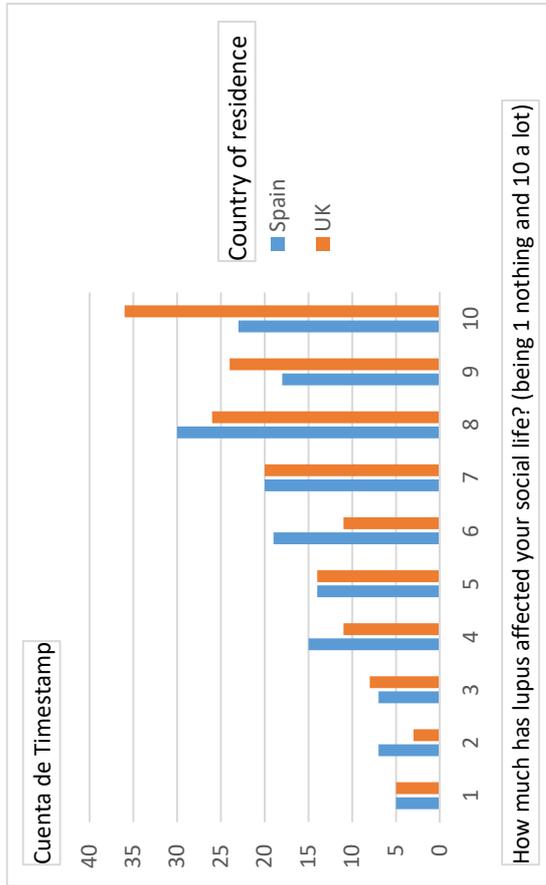


	Spain	UK
No	47,47%	53,80%
Yes	52,53%	46,20%



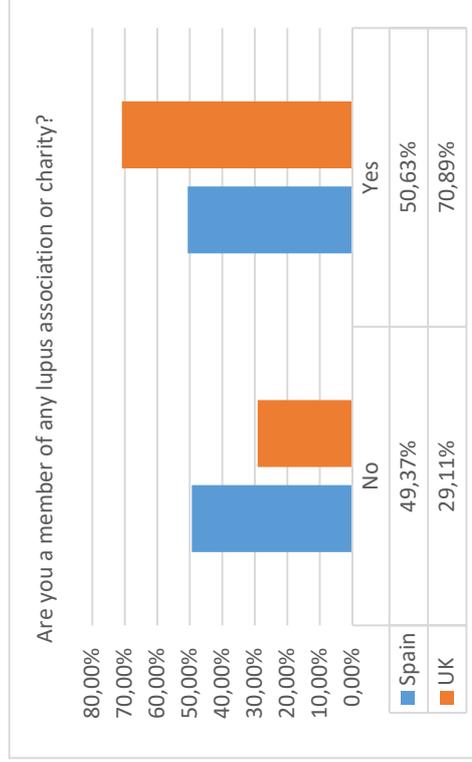
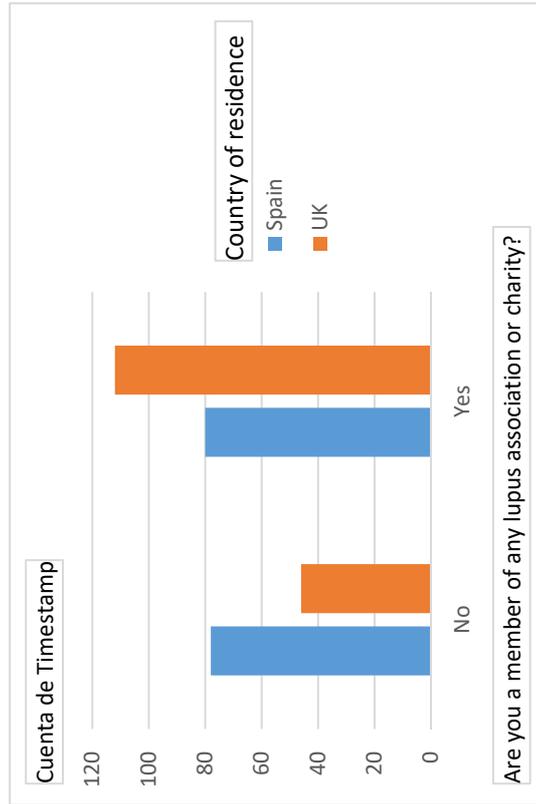
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	Total
1	5	5	10
2	7	3	10
3	7	8	15
4	15	11	26
5	14	14	28
6	19	11	30
7	20	20	40
8	30	26	56
9	18	24	42
10	23	36	59
Total	158	158	316

	Spain	UK
1	3,16%	3,16%
2	4,43%	1,90%
3	4,43%	5,06%
4	9,49%	6,96%
5	8,86%	8,86%
6	12,03%	6,96%
7	12,66%	12,66%
8	18,99%	16,46%
9	11,39%	15,19%
10	14,56%	22,78%



Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	78	46	124
Yes	80	112	192
Total	158	158	316

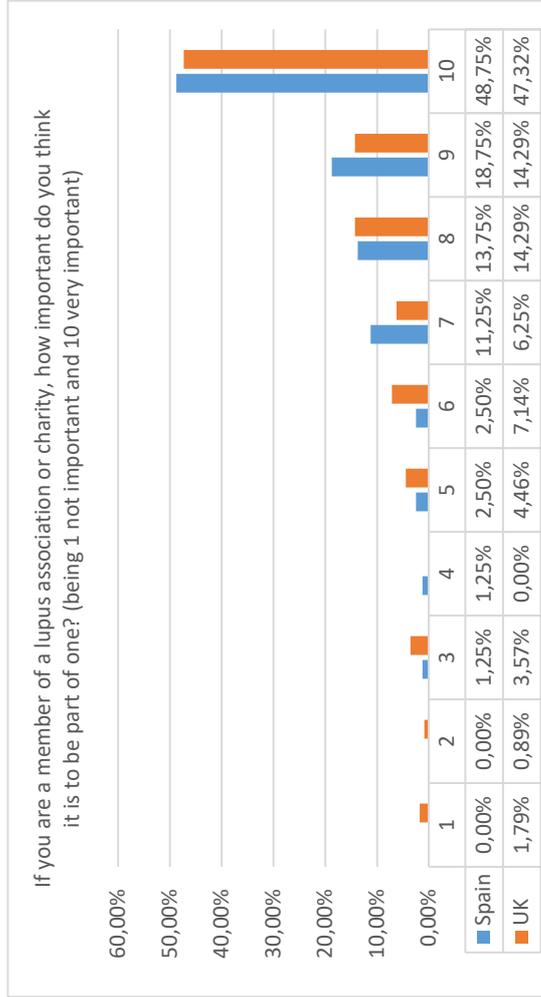
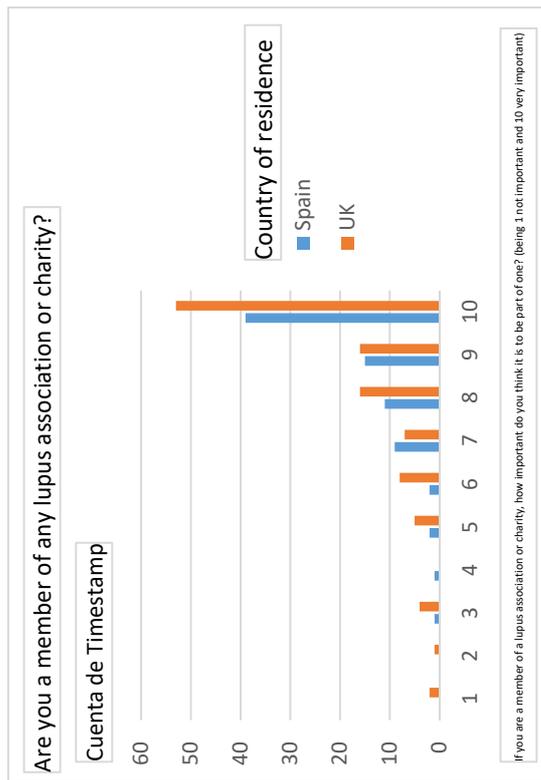
	Spain	UK
No	49,37%	29,11%
Yes	50,63%	70,89%



Are you a member of any lu Yes

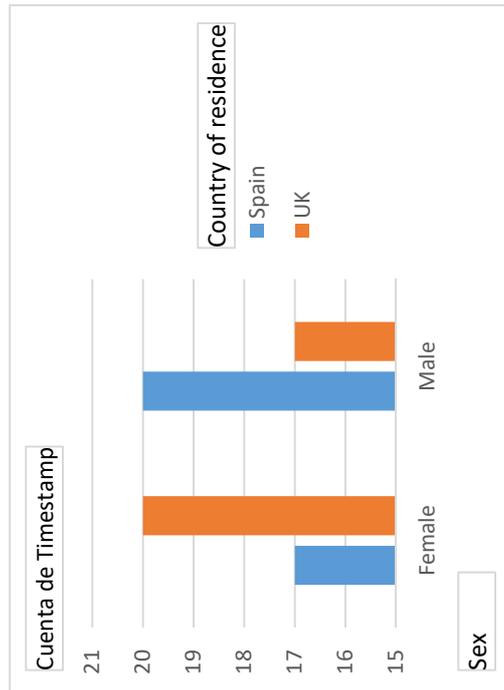
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
1		2	2
2		1	1
3	1	4	5
4	1		1
5	2	5	7
6	2	8	10
7	9	7	16
8	11	16	27
9	15	16	31
10	39	53	92
Total	80	112	192

	Spain	UK
1	0,00%	1,79%
2	0,00%	0,89%
3	1,25%	3,57%
4	1,25%	0,00%
5	2,50%	4,46%
6	2,50%	7,14%
7	11,25%	6,25%
8	13,75%	14,29%
9	18,75%	14,29%
10	48,75%	47,32%

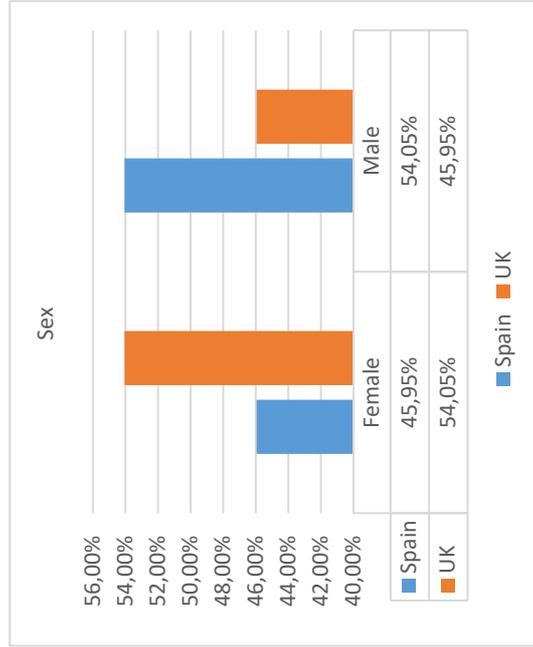


ANNEX IX. DYNAMIC GRAPHICS AND DYNAMIC TABLES USED TO ANALYSE THE DATA FROM
THE FAMILY MEMBERS TO LUPUS PATIENTS' POLL

Cuenta de Timestamp		Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	UK	Total
Female	17	20		37
Male	20	17		37
Total	37	37		74

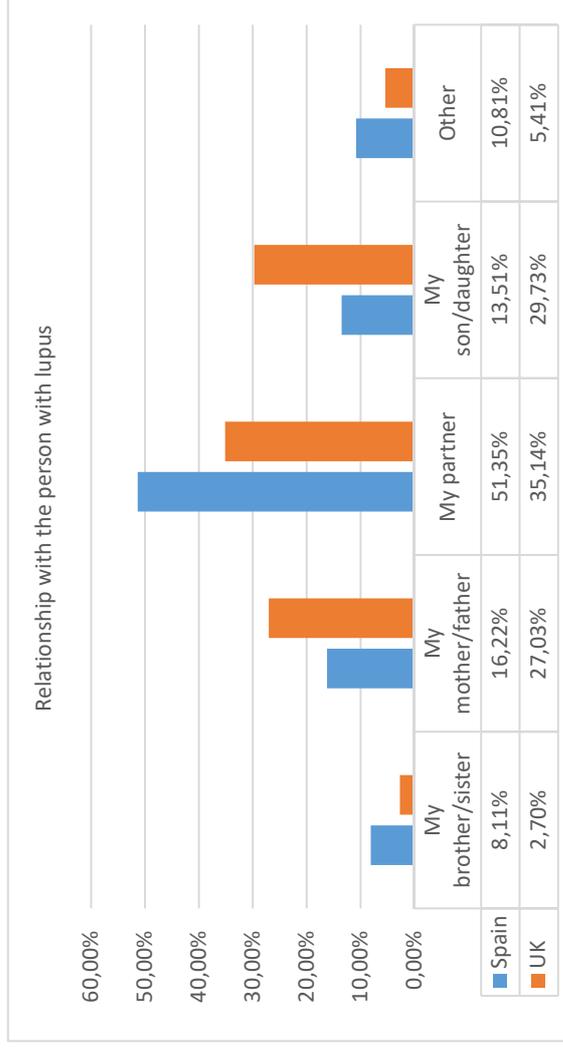
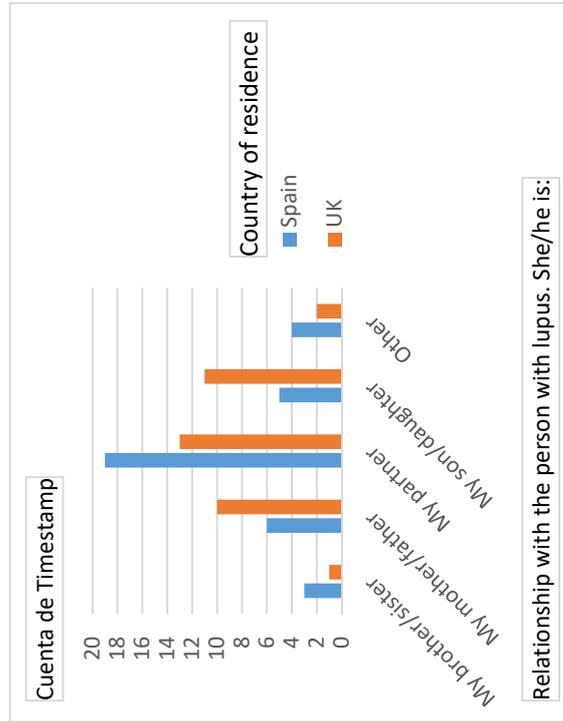


	Spain	UK
Female	45,95%	54,05%
Male	54,05%	45,95%



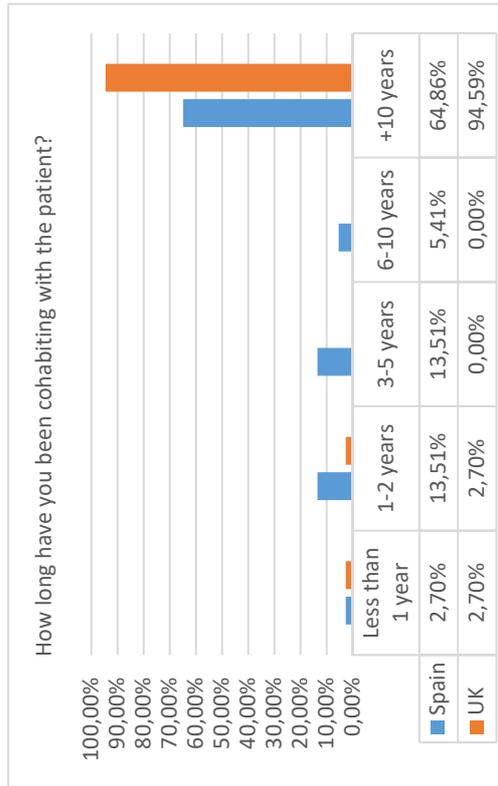
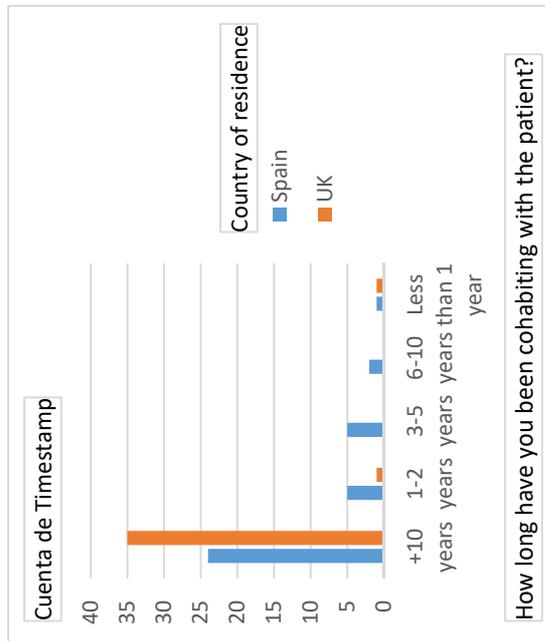
Cuenta de Timestamp		Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total	
My brother/sister	3	1	4	
My mother/father	6	10	16	
My partner	19	13	32	
My son/daughter	5	11	16	
Other	4	2	6	
Total	37	37	74	

	Spain	UK
My brother/sister	8,11%	2,70%
My mother/father	16,22%	27,03%
My partner	51,35%	35,14%
My son/daughter	13,51%	29,73%
Other	10,81%	5,41%



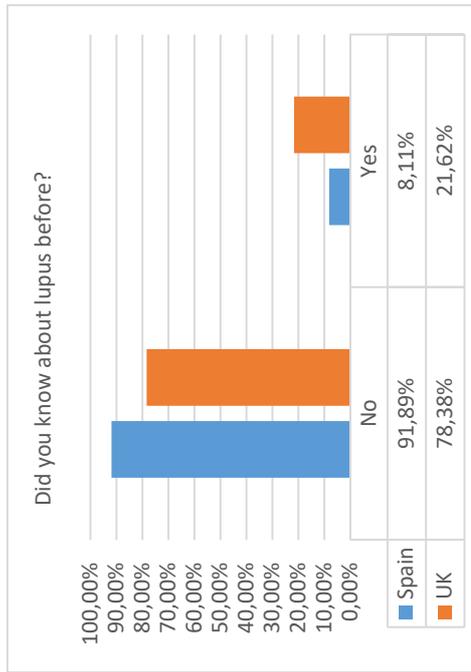
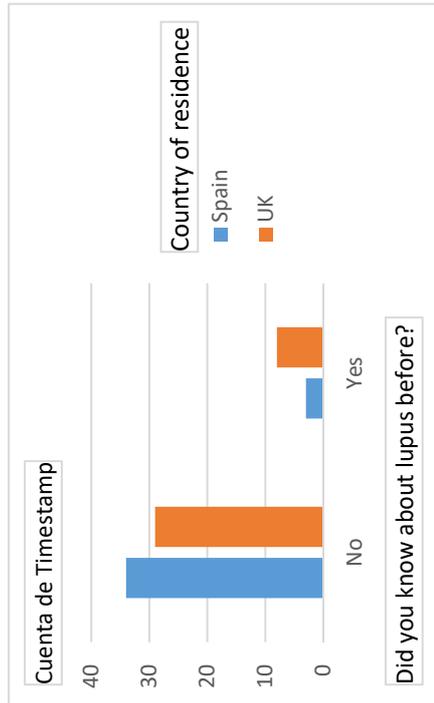
Cuenta de Timestamp	Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total
+10 years	24	35	59
1-2 years	5	1	6
3-5 years	5		5
6-10 years	2		2
Less than 1 year	1	1	2
Total	37	37	74

	Spain	UK
Less than 1 year	2,70%	2,70%
1-2 years	13,51%	2,70%
3-5 years	13,51%	0,00%
6-10 years	5,41%	0,00%
+10 years	64,86%	94,59%



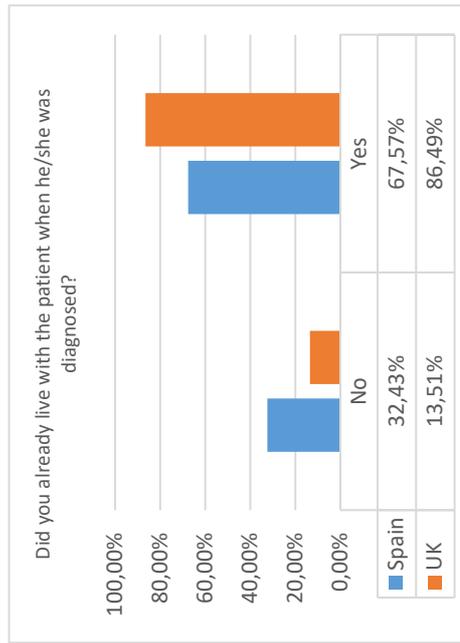
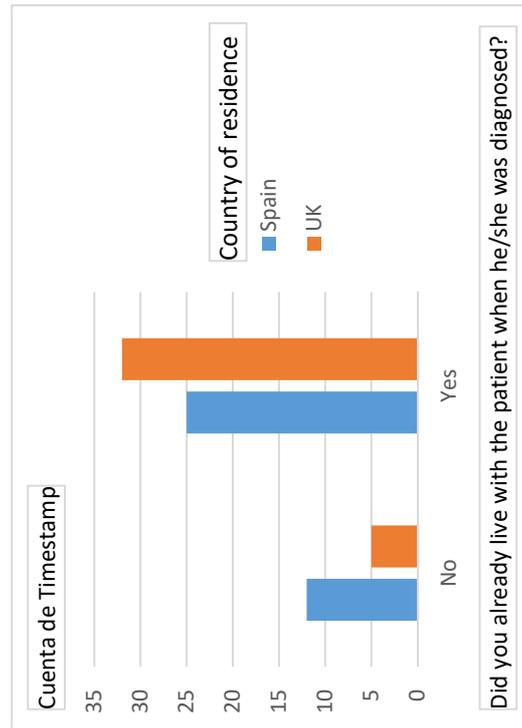
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	Total
No	34	29	63
Yes	3	8	11
Total	37	37	74

	Spain	UK
No	91,89%	78,38%
Yes	8,11%	21,62%



Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
No	12	5	17
Yes	25	32	57
Total	37	37	74

	Spain	UK
No	32,43%	13,51%
Yes	67,57%	86,49%

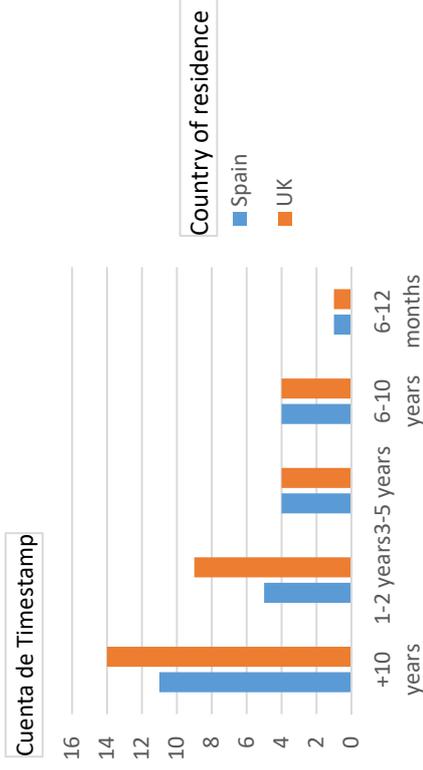


Did you already live with the patie Yes

Cuenta de Timestamp		Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total	
+10 years	11	14	25	
1-2 years	5	9	14	
3-5 years	4	4	8	
6-10 years	4	4	8	
6-12 months	1	1	2	
Total	25	32	57	

	Spain	UK
6-12 months	4,00%	3,13%
1-2 years	20,00%	28,13%
3-5 years	16,00%	12,50%
6-10 years	16,00%	12,50%
+10 years	44,00%	43,75%

Did you already live with the patient when he/she was diagnosed?



How long has it been since the diagnosis?

How long has it been since the diagnosis?

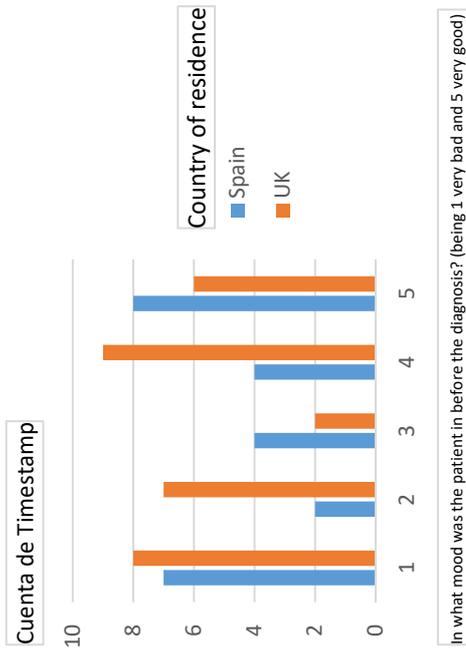


Did you already live

Did you already live with the patient when he/she was diagnosed?

Cuenta de Timest: Etiquetas de columna				
Etiquetas de fila	Spain	UK	Total	
1	7	8	15	
2	2	7	9	
3	4	2	6	
4	4	9	13	
5	8	6	14	
Total	25	32	57	

What mood was the patient in before the diagnosis?



In what mood was the patient in before the diagnosis? (being 1 very bad and 5 very good)

	Spain	UK
1	28,00%	25,00%
2	8,00%	21,88%
3	16,00%	6,25%
4	16,00%	28,13%
5	32,00%	18,75%

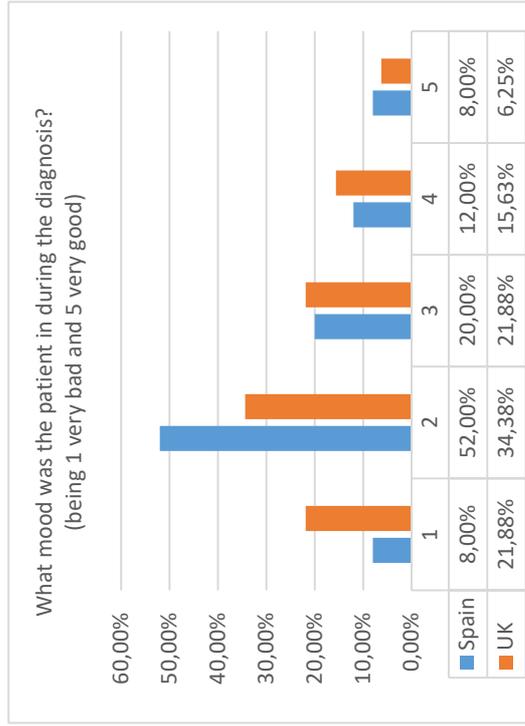
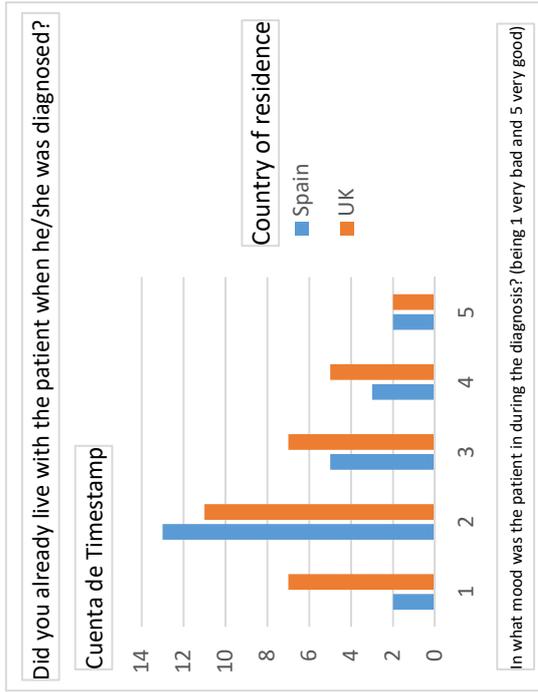
What mood was the patient in before the diagnosis?
(being 1 very bad and 5 very good)



Did you already live Yes

Cuenta de Timesta Etiquetas de columna			
Etiquetas de fila	Spain	UK	Total
1	2	7	9
2	13	11	24
3	5	7	12
4	3	5	8
5	2	2	4
Total	25	32	57

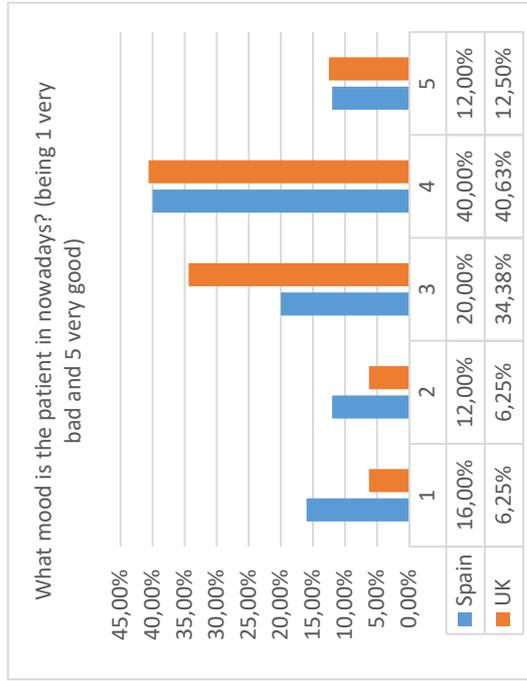
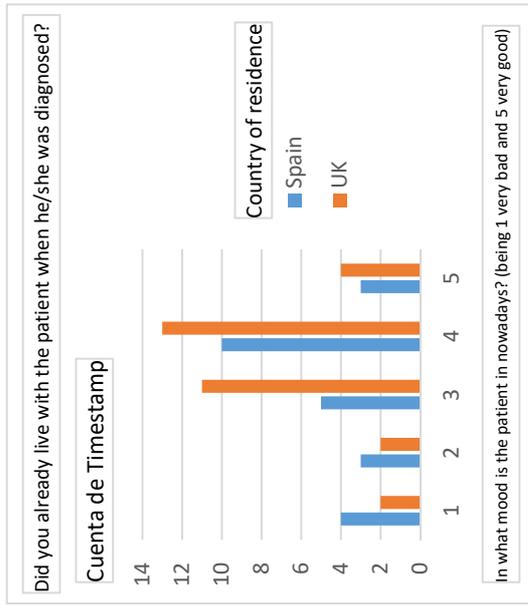
	Spain	UK
1	8,00%	21,88%
2	52,00%	34,38%
3	20,00%	21,88%
4	12,00%	15,63%
5	8,00%	6,25%



Did you already live Yes

Cuenta de Timesta Etiquetas de columna			
Etiquetas de fila	Spain	UK	Total
1	4	2	6
2	3	2	5
3	5	11	16
4	10	13	23
5	3	4	7
Total	25	32	57

	Spain	UK
1	16,00%	6,25%
2	12,00%	6,25%
3	20,00%	34,38%
4	40,00%	40,63%
5	12,00%	12,50%

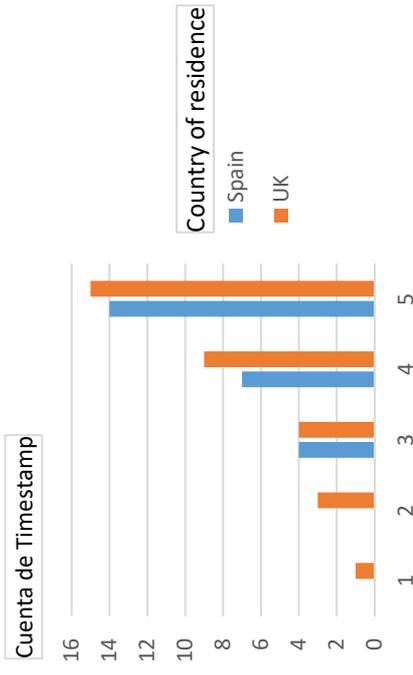


Did you already live Yes

Cuenta de Timesta Etiquetas de columna			
Etiquetas de fila	Spain	UK	Total
1		1	1
2		3	3
3	4	4	8
4	7	9	16
5	14	15	29
Total	25	32	57

	Spain	UK
1	0,00%	3,13%
2	0,00%	9,38%
3	16,00%	12,50%
4	28,00%	28,13%
5	56,00%	46,88%

Did you already live with the patient when he/she was diagnosed?



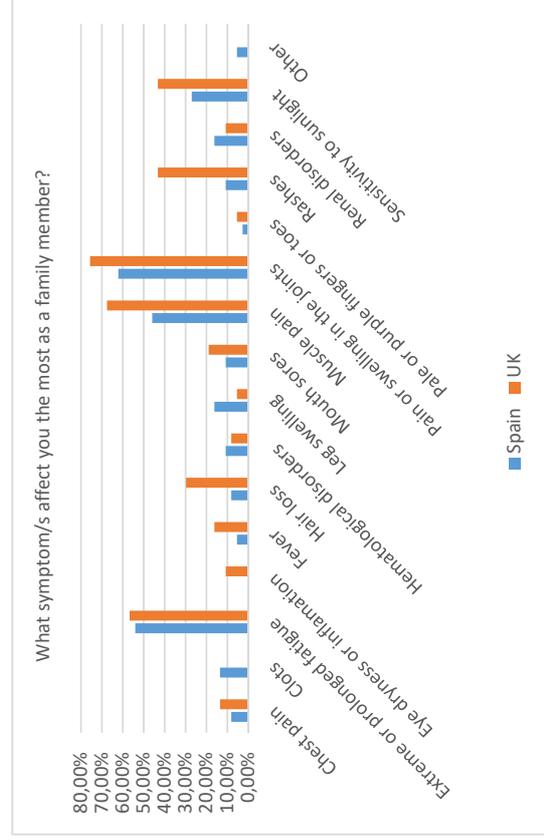
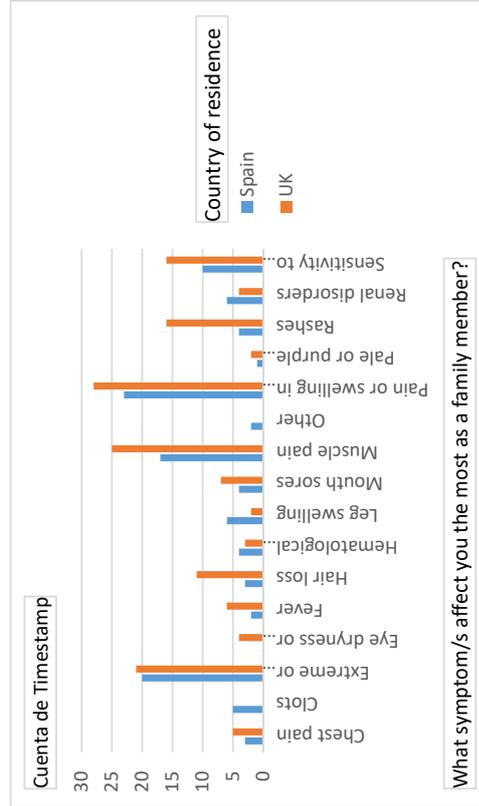
How much has the lifestyle of the patient changed since before the diagnosis? (being 1 nothing and 5 a lot)

How much has the lifestyle of the patient changed since before the diagnosis? (being 1 nothing and 5 a lot)



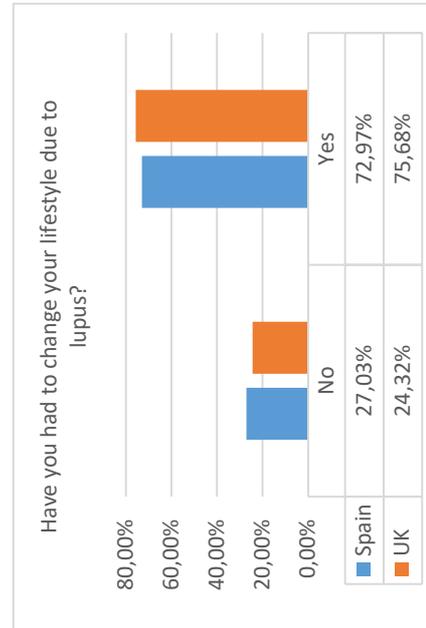
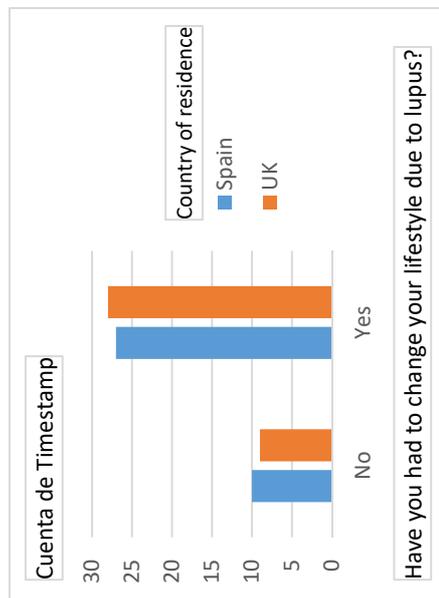
Cuenta de Timestamp	Etiquetas de columna		Total
	Spain	UK	
Chest pain	3	5	8
Clots	5		5
Extreme or prolonged fatigue	20	21	41
Eye dryness or inflammation		4	4
Fever	2	6	8
Hair loss	3	11	14
Hematological disorders (e.g. anemia)	4	3	7
Leg swelling	6	2	8
Mouth sores	4	7	11
Muscle pain	17	25	42
Other	2		2
Pain or swelling in the joints	23	28	51
Pale or purple fingers or toes	1	2	3
Rashes	4	16	20
Renal disorders	6	4	10
Sensitivity to sunlight or fluorescent light	10	16	26
Total	110	150	260

	Spain	UK
Chest pain	8,11%	13,51%
Clots	13,51%	0,00%
Extreme or prolonged fatigue	54,05%	56,76%
Eye dryness or inflammation	0,00%	10,81%
Fever	5,41%	16,22%
Hair loss	8,11%	29,73%
Hematological disorders	10,81%	8,11%
Leg swelling	16,22%	5,41%
Mouth sores	10,81%	18,92%
Muscle pain	45,95%	67,57%
Pain or swelling in the joints	62,16%	75,68%
Pale or purple fingers or toes	2,70%	5,41%
Rashes	10,81%	43,24%
Renal disorders	16,22%	10,81%
Sensitivity to sunlight	27,03%	43,24%
Other	5,41%	0,00%



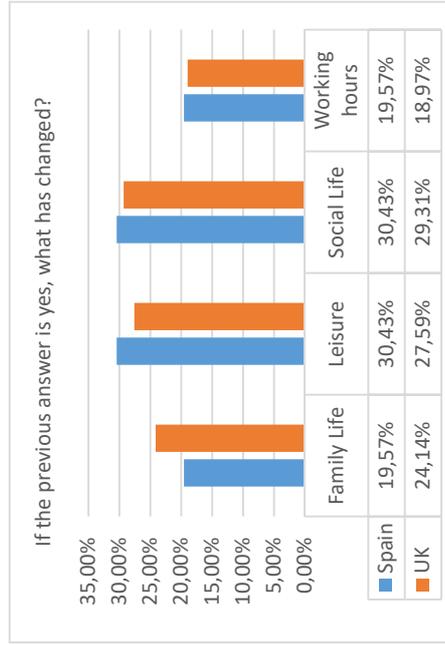
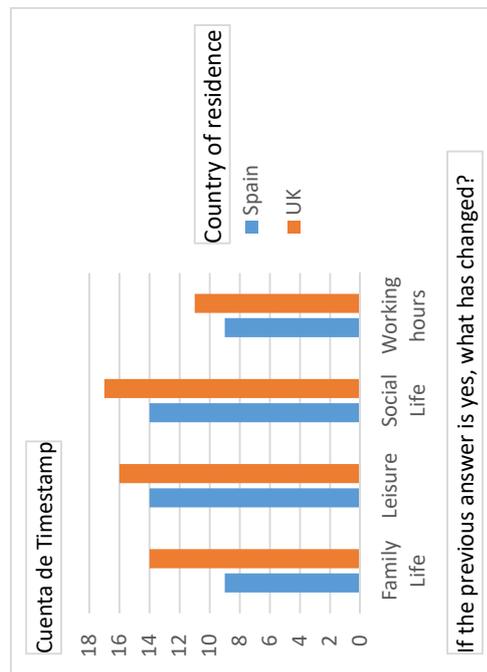
Cuenta de Timestamp		Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total	
No	10	9	19	
Yes	27	28	55	
Total	37	37	74	

	Spain	UK
No	27,03%	24,32%
Yes	72,97%	75,68%



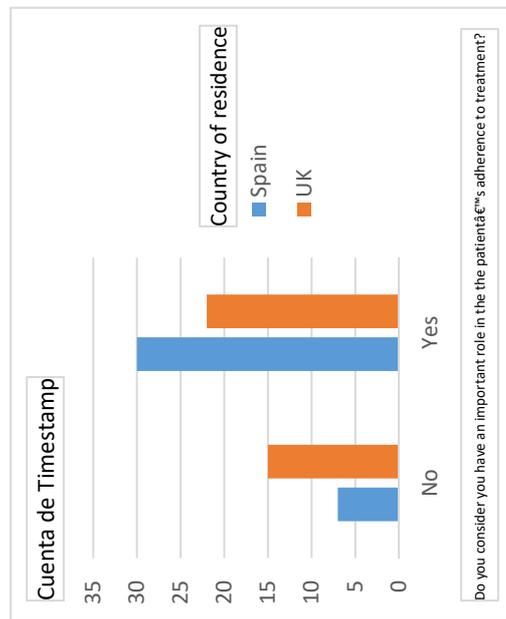
Cuenta de Timestamp	Etiquetas de columna		Total
Etiquetas de fila	Spain	UK	
Family Life	9	14	23
Leisure	14	16	30
Social Life	14	17	31
Working hours	9	11	20
Total	46	58	104

	Spain	UK
Family Life	19,57%	24,14%
Leisure	30,43%	27,59%
Social Life	30,43%	29,31%
Working hours	19,57%	18,97%

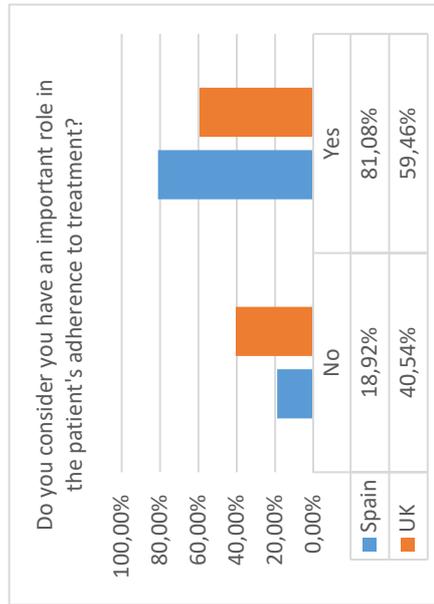


If the previous answer is yes, what has changed?

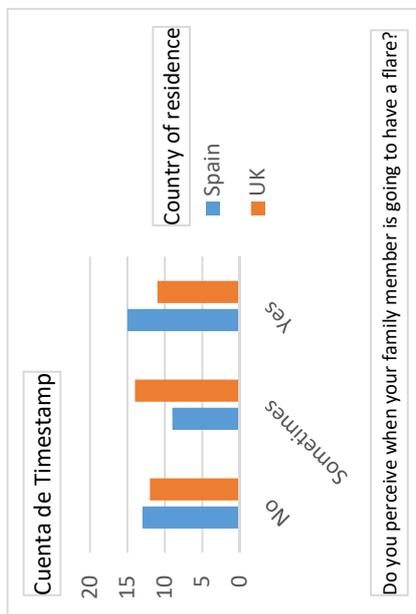
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No	7	15	22	
Yes	30	22	52	
Total	37	37	74	



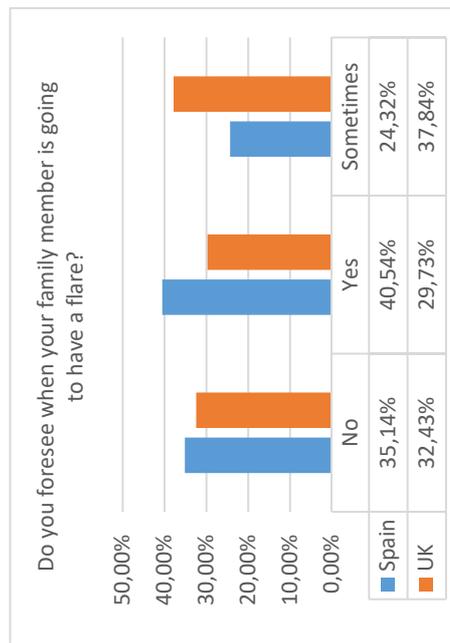
	Spain	UK
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Yes	81,08%	59,46%



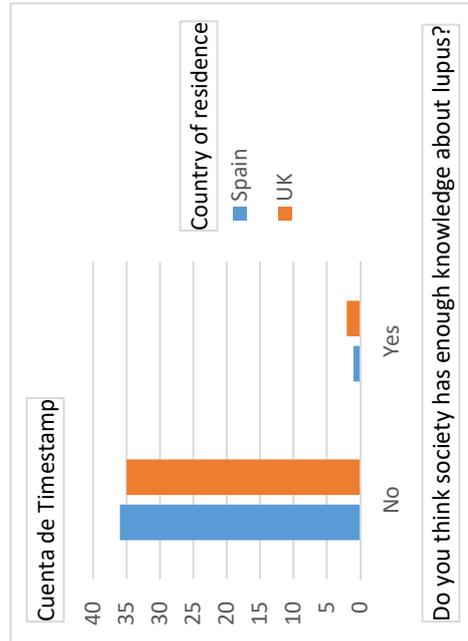
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Sometimes	9	14	23
Yes	15	11	26
Total	37	37	74



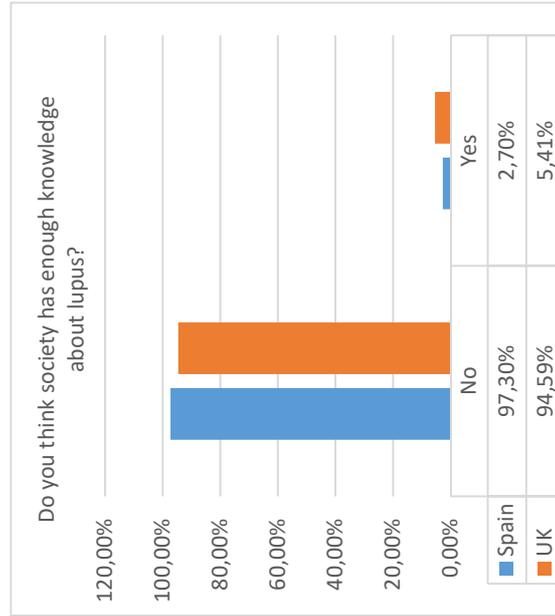
	Spain	UK
No	35,14%	32,43%
Yes	40,54%	29,73%
Sometimes	24,32%	37,84%



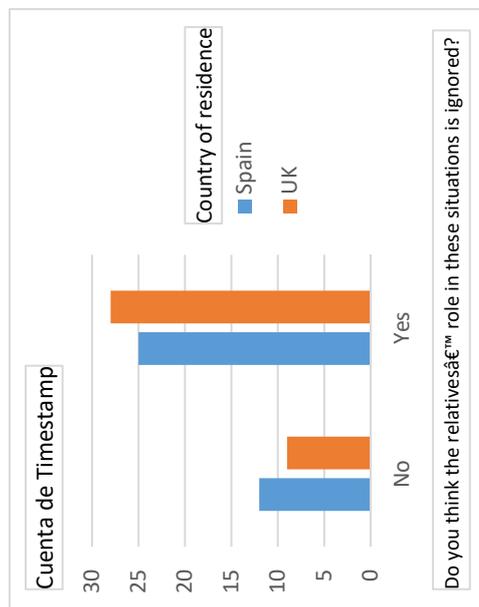
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Yes	1	2		3
Total	37	37		74



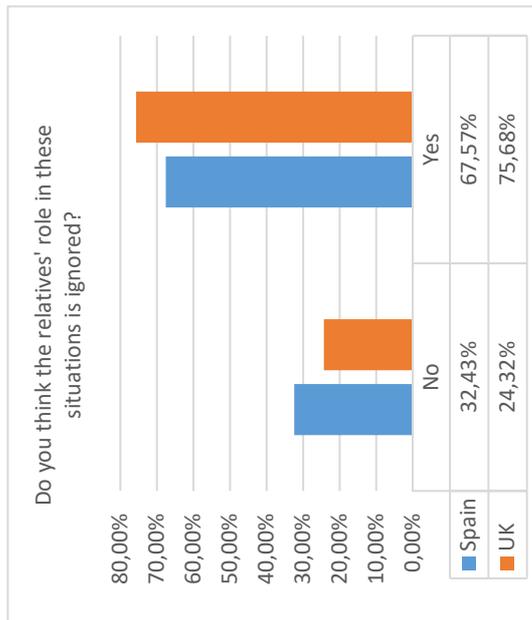
	Spain	UK
No	97,30%	94,59%
Yes	2,70%	5,41%



Cuenta de Timestamp	Etiquetas de columna		
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Yes	25	28	53
Total	37	37	74

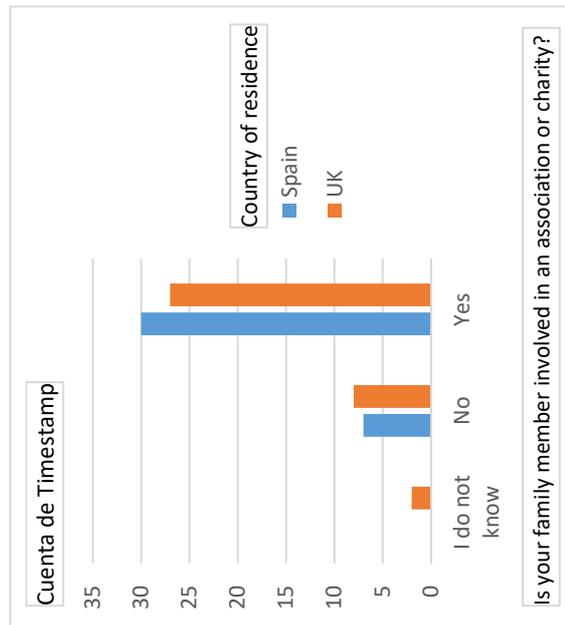


	Spain	UK
No	32,43%	24,32%
Yes	67,57%	75,68%



Cuenta de Timestamp					Etiquetas de columna		
Etiquetas de fila	Spain	UK	Total				
I do not know		2	2				
No	7	8	15				
Yes	30	27	57				
Total	37	37	74				

	Spain	UK
No	18,92%	21,62%
Yes	81,08%	72,97%
I do not know	0,00%	5,41%



ANNEX X. INTERVIEWS TO LUPUS CHARITIES' STAFF MEMBERS

10. 1. INTERVIEW TO PILAR LUCAS, FOUNDER AND CEO OF ACLEG

Good afternoon Pilar,

First of all I wanted to thank you for your help and kindness, and for agreeing to answer the questions of this interview. I also wanted to say how incredible your job as the CEO of an association that is able to help so many people is.

I will start the interview with some very short questions about the association. So let's start.

What year was ACLEG founded in?

ACLEG was founded on June, the 21st, 1999, in Barcelona.

How many members does ACLEG have?

We are not too many actually, we are rather few. For some unknown reason, people don't usually become members of associations when they are diagnosed.

And well, ACLEG has about 180 members, which is a very small number of people if you think about the fact that in Catalonia there are more than seven thousand people with lupus. But hopefully lupus patients and family members will realise how valuable and necessary the work of ACLEG is, and then they will become members, as they will see all the pros of being one. As I always say: one person alone can't do anything, but many people together can do a lot.

What does it mean/entail to be a member of ACLEG?

It means being part of a group of people that feels like a second family, which I think is very important. Being a member of ACLEG also means that you help the lupus community by making the disease more known, by pressuring the state, pharmaceutical companies, and others to ask for clinical trials... and many other things. So it is a mutual help.

It basically means strength and support, and being all together to help each other.

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?

So, as I said, ACLEG is strength, effort, constancy...

Being a member of ACLEG will cost you 40€ every year, which is not a lot of money but it isn't a small amount of money either. But it is worth it, because ACLEG also gives a lot to members, like being able to be part of projects I will talk about later on.

Who is involved in the ACLEG's staff?

Well, there are a few people involved. First of all we have the people like me who are in charge of ACLEG and everything we do. Then we also have a scientific advisory committee, whose president is Dr. Cervera. In this scientific committee there are some internists and some rheumatologists who can help members with any doubt they may have. However, they never make any decisions related with what we do as an association, as this is done by the people like me who are in charge of ACLEG.

What is your main aim?

Our main aims are to make lupus more known around Catalonia and Spain and to make sure that patients are feeling fine. We also need to make sure that the treatments we need are available at all times and that clinical trials are done.

We are also trying to make it possible that lupus patients are well cared for when they need to see the GP (General Practitioner) or any other doctor who doesn't treat lupus often.

Now I am going to ask you some questions through which you will be able to explain how you work and what you are working in nowadays.

What projects or acts are you working in nowadays?

Something we have been doing for the past years is to fund money for research in Hospital Clínic de Barcelona. This is possible thanks to the help and initiative of our members.

However, right now we are in a so-called “stand-by” moment, as we aren’t working in any new projects. What we are doing now is to make sure that the projects we carried out a while ago are still functioning well. And another thing we are doing is helping our members get some financial support from the government.

Could you tell me about a project or act you have carried out recently?

We have carried out a lot of projects which we are really proud of. One that helped us a lot economically is the one I am about to explain. It is called “Frena el sol, frena el lupus”, which means: “Stop the sun stop, the lupus”. As lupus patients can’t be exposed to the sun for too long, they need to use a lot of sunscreen, which turns out really expensive if you have to buy a lot. In order to help, ACLEG, the pharmacies’ association and labs from Catalonia came to an agreement that all members of ACLEG could have a 50% discount for every sunscreen they bought from the brand “Isdin”. Nowadays ACLEG is currently trying to make this discount possible for everyone in Spain, not only for Catalans, and they have already been able to make it possible in about 10 other Autonomous Communities.

Another thing we managed to make possible is to have a researcher doing only lupus research in Hospital Clínic de Barcelona, which I mentioned before. To make it possible we also had to fund money, which we got thanks to a beautiful project carried out by Pep Vega, whose mother died due to lupus. His project is called “Kilometros por el Lupus”, in which he does a lot of sport and raises money.

We also organise conferences, cooking workshops and other things that lets lupus patients get to know each other.

How has the charity evolved since it was founded until nowadays?

When we first started with the association we thought about quitting so many times, as it was very hard to make it work the way we wanted. It has been very tough and hard to make it work as we wished, because, as I said earlier, people who are diagnosed with a disease do not usually become members of associations. But we are very happy now seeing how we are able to help so many people.

Have you felt supported by government entities, associations, institutions, etc.?

Well, it depends how you look at this. Basically, government entities, institutions and others have never come to us and asked: how can we help? It is us who have to go up to them and ask for help. This is something that

definitely needs to change in the next few years.

What challenges have you faced as a charity?

We have faced many challenges during the existence of our association. For example, when we first founded ACLEG, it was very hard for us to find our place in the world of associations in Spain. It was also hard, as I said earlier, to become a proper association with members and staff that were able to help one another. But all those challenges we have faced have made us become an enterprising association, so we are glad about who we have become.

Why is it so important to be member of a charity like yours?

It is very important to be member of ACLEG because the union of people creates strength. A lupus patient finds himself or herself alone when diagnosed, as it is a very unknown and rare disease. So if they become a member of ACLEG they will get to know people who are experiencing the same as them, and this will help them a lot and will give them a lot of hope.

What does it mean to you to be a staff member of a charity like ACLEG?

It means I have lot of headaches (laughs). This is because it requires a lot of time and dedication. But I must say that being able to help people makes me feel very happy.

And finally, I wanted to ask you one last question:

How do you see the future of lupus?

I suppose it will get much better. I mean, lupus is still going to be there, but if research is done, there will obviously be a breakthrough. I must say I have a lot of hope. I have been diagnosed with lupus for almost 40 years, and I have seen how it has been getting better and better, and I think it will continue this way.

And that's it for the interview, thank you very much for everything.

10. 2. INTERVIEW TO CHANPREET WALIA, SOCIAL MEDIA & PROJECTS OFFICER AT LUPUS UK

Good morning Chanpreet,

First of all I wanted to say thank you for answering this interview and for all the help provided from Lupus UK. I also wanted to say how incredible everything you do is.

I am going to ask you some questions about your charity. So let's start with some very short ones:

What year was Lupus UK founded in?

LUPUS UK was founded in 1990 and it was registered as a National Charity on 29th of December 1995.

How many members does Lupus UK have?

We have around 5,000 members. We have both UK-based and international members.

What does it mean/entail to be a member of Lupus UK?

To me, it means to provide the best possible care, support and non-medical advice to every single lupus patient, health care worker and family member or friend we speak to. We also need to ensure we raise awareness of lupus amongst the public and medical profession.

Who is involved in the Lupus UK staff?

We have eight staff members, including one staff member who has lupus.

What is your main aim?

The charity's vision is a world where people with lupus can live full and active lives. LUPUS UK's mission is to empower people by providing them with information about lupus and offering support, so their voices are heard alongside their condition being diagnosed and managed effectively.

The charity funds medical research looking into potential causes and treatments of lupus, supports lupus patients in desperate need of help with the purchase of equipment and it also funds Specialist Lupus Nurses in NHS hospitals.

The charity believes that people with lupus are entitled to specialised care and treatment, whilst also informing and educating the medical profession and the public about lupus and its effects. LUPUS UK has worked with the NHS to establish ten LUPUS UK Centres of Excellence around the country who offer a high-quality care for people with lupus.

LUPUS UK believes in bringing people with lupus together so they are not isolated and have the best possible information about their condition. For that reason, the charity has over 20 Regional LUPUS UK Groups based all across the country supporting our members and those yet to be diagnosed within their communities. Alongside this, the charity has an online HealthUnlocked Community Forum for those who are unable to go out into their community.

Now I am going to ask some questions through which you will be able to explain how you work and what you are working in:

What projects or acts are you working in nowadays?

The charity is working towards funding a new Specialist Lupus Nurse in an NHS Hospital. The charity aims to fund a new Specialist Lupus Nurse every year and has recently welcomed two new nurses in Northern Ireland and Scotland.

Could you tell me about a project or act that you have carried out recently?

As a consequence of the COVID-19 pandemic, LUPUS UK created a Coronavirus Emergency Assistance Fund where lupus patients in crisis can apply for a one-off cash grant to help with financial uncertainty and current hardships.

What is the first thing you do as a charity when a recently diagnosed person contacts you?

We firstly check if they are under the care of a rheumatologist. We also provide them with literature about lupus, being newly diagnosed, lupus-related symptoms booklets and factsheets are very helpful. We provide them with trained LUPUS UK telephone contacts who they can speak with over the telephone for non-medical advice and support. They are given details of any LUPUS UK groups that may be in their area and they are encouraged to join our online HealthUnlocked forum and to become a LUPUS UK member.

What are the most common problems patients face? How can you help them?

There are a range of different scenarios we come across, from people waiting for years for a diagnosis to people who are looking for specific advice regarding certain symptoms, a common one being skin rashes. We address people to our LUPUS UK Centres of Excellence who offer a high quality care for people with lupus as well other relevant sources of information.

How has the charity evolved since it was founded until nowadays?

The charity has had to update ways in which members and non-members receive the latest information and news. Before, patients heavily relied on speaking to LUPUS UK via the telephone and ordering awareness materials and merchandise through the post. Now, a majority of people contact us through email and social media. This is also the same for ordering awareness materials and merchandise. Since the very beginning, LUPUS UK has a News & Views magazine which is sent to members three times a year, and although we still send it, we have had to adapt to new times and offer an email-newsletter alongside with our physical magazine. Our first E-Newsletter was published in August 2020. The charity has always been a patient-focused charity and this is something that will not change.

Have you felt supported by government entities, associations, institutions, etc.?

LUPUS UK does not receive government support. However, we do apply to Trusts, Foundations and companies for grants and donations to help us maintain our vital work. The three main sources of income for LUPUS UK are donations, individuals fundraising events and grants from Trusts/Foundation and companies.

What challenges have you faced as a charity recently?

Due to the COVID-19 pandemic, a majority of the LUPUS UK team had to work from home from March until August except for Paul Howard, CEO; and Chris Maker, Finance Manager. Although initially it felt strange for the team to be split-up and work from home, it was not a problem. All staff members had a virtual coffee meeting once a week and ensured we all kept up-to-date with the latest lupus-news and were able to still provide support from wherever we were working.

Why is it so important to be member of a charity like yours?

LUPUS UK is a patient-focus charity who puts patients at the forefront of what we do. Without their support we would not be able to fund medical research looking into the potential causes and treatment of lupus or fund Specialist Lupus Nurses around the UK. We help provide lupus patients in desperate need of help with much-needed equipment such as stair lifts, electric wheelchairs and TEN's pain machines. We want all lupus patients to live a full and active life and the way we can achieve this is through our incredible supporters.

LUPUS UK is one of the founding members of the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA) and we will continue to work with our partner organisations that are supporting people with related health conditions. By coordinating our response we prevent any duplicated efforts and provide a stronger, unified message.

What does it mean to you to be a staff member of a charity like Lupus UK?

I love working for the charity, the LUPUS UK Head Office is like a family. This charity provides important and vital work and working for the charity shows me how much our work makes a difference to the lives of people with lupus, their family and friends. LUPUS UK goes above and beyond to provide care for every person that contacts the charity.

And finally, I wanted to ask you one last question:

How do you see the future of lupus?

I think we should remain hopeful, there are so many research projects looking into new causes and treatments of lupus which will hopefully result in a cure one day in the future. We are seeing a lot more awareness of lupus from articles, celebrities raising awareness and special days/months like World Lupus Day and Lupus Awareness Month which is all helpful in raising awareness of lupus and its symptoms.

And that's it for the interview, thank you very much for everything.

ANNEX XI. INTERVIEWS TO LUPUS SPECIALISTS

11. 1. INTERVIEW TO DR. RICARD CERVERA, SPANISH LUPUS SPECIALIST

Good morning Dr. Cervera,

Before anything else, I wanted to say thank you for answering my interview and for all your help.

First of all I am going to ask you some questions about your experience with lupus. So let's start:

How long have you been working with lupus for?

Since I started MIR residency in Internal Medicine, in 1984.

Why did you decide to specialise in lupus?

In the Internal Medicine Service of the "Hospital Clínic de Barcelona", where I did the MIR residency, there was a lot of research and investigation going on related with lupus, and I found it very interesting.

You do research at IDIBAPS: what projects is your team working in?

We are currently working on more than 50 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).

Could you explain me the progress of the projects since you started working in them until nowadays?

One of the most personal projects I am working in is the "CAPS Registry Project": In the early 90's we described a rare disease (catastrophic antiphospholipid syndrome) that often accompanies lupus, and thanks to an international registry that we coordinated we have been able to know better its clinical characteristics and the most appropriate treatment, having been able to decrease mortality from 70% to 30%.

What are you currently working towards?

We continue on searching better treatments for autoimmune diseases; for example, so-called biological treatments, which are more effective and less toxic than those currently used (especially corticosteroids and immunosuppressants).

Now I will proceed to ask you some questions about research and the evolution of lupus:

What do you think has been the most important discovery or advance in lupus in the last few years?

From a clinical point of view, I think it was very important to discover, in 1983, the antiphospholipid syndrome (autoimmune disease that causes thrombosis and abortions), as it is a disease that occurs in 30-40% of patients with lupus. However, it requires very different treatment from the usual ones in lupus: antithrombotic drugs instead of immunosuppressive drugs.

Since you work with lupus, what do you think has evolved the most (diagnosis, treatment, lifespan...)?

In recent years, progress has been made in treatment with biological drugs (rituximab, belimumab, anifrolumab, etc.).

I have been informed that lupus doctors work in networks, how does this help when it comes to lupus?

It is fundamental, as all these studies that I have mentioned are the result of working in international networks.

Your profession requires you to stay up to date. How do you make it possible?

Networking is associated with participating in multiple meetings, conferences, courses, etc. In this way, what is being researched and its results is always almost immediately shared.

What is being studied in Spain about lupus?

Several Spanish research groups participate in the aforementioned networks and participate in many of the studies previously discussed.

And finally, I wanted to ask you a question that has a lot of lupus patients intrigued:

How do you see the near and not so near future of lupus?

We will soon have some new biological treatments that will allow us to treat lupus better, especially the cases which are more difficult to control nowadays.

Thank you very much.

11. 2. INTERVIEW TO PROF. DAVID D'CRUZ, BRITISH LUPUS SPECIALIST

Good morning Professor D'Cruz,

Before anything else, I would like to say thank you for answering my interview.

First of all I am going to ask you some questions about your experience with lupus. So let's start:

How long have you been working with lupus for?

I have been working with SLE since 1987, when I joined Professor Graham Hughes at St Thomas' Hospital in London as a junior doctor.

Why did you decide to specialise in lupus?

In 1987 when I started to work with Professor Hughes.

Could you talk about a research project about lupus you are currently working in?

I am currently working in a project with colleagues who are expert in qualitative research on the adverse impact of Covid-19 on the care of lupus patients. During pandemic many lupus clinics have had to cancel or defer many patient appointments due to medical staff being re-deployed to acute medicine duties. As a result, many patients have had poor or no care for their lupus and rheumatologists are really struggling to see these patients and provide them with high quality care. This has had huge physical and psychological impacts on lupus patients.

What are you currently working towards?

We have analysed the data and we are preparing to submit our manuscript to a journal for publication.

Now I will proceed to ask you some questions about research and the evolution of lupus:

What do you think has been the most important discovery or advance in lupus in the last few years?

There have been many advances in the understanding of the pathobiology of SLE that have led to new treatments. The most important advances have include the development of biological treatments such as belimumab, which is now licensed in many countries to treat active SLE. A recent trial has demonstrated that belimumab is also a potentially useful treatment for kidney diseases in lupus. This is a major advance as

there are no specific treatments that have been licensed to treat lupus nephritis. We hope this will be the first such treatment.

Since you work with lupus, what do you think has evolved the most (diagnosis, treatment, lifespan, etc.)?

There have been dramatic improvements in the reduction in mortality in SLE patients. This used to be considered a fatal disease in the 1950's and patients are now living much longer with better life quality but there is still a long way to go. There is no cure for SLE yet.

I have been informed that lupus doctors work in networks, how does this help?

We work in the British Isles Lupus Assessment Group (BILAG) in the UK. This is a critically important forum for discussion for managing lupus patients, designing new research projects and helping to train young rheumatologists. I have also been part of the EuroLupus consortium where we have designed new trials to successfully treat lupus kidney disease.

Your profession requires you to stay up to date. How do you make it possible?

I keep up to date by attending international conferences such as the American College of Rheumatology and the EULAR. I also read important journals such as "LUPUS" and other major rheumatology journals.

What is being studied in the UK about lupus?

There is a huge spectrum of research in the UK including clinical trials of new treatments containing new biologic agents. There is also a lot of basic science research into the mechanisms of how the abnormal immune system causes lupus. By understanding these processes, we can develop new treatments.

And finally, I wanted to ask you a question that has a lot of lupus patients intrigued:

How do you see the near and not so near future of lupus?

We are on the cusp of a revolution in the treatment of lupus with potentially many new biological treatments being approved. We currently only have two biologics namely belimumab and rituximab, but across the world there are many clinical trials of new agents that are potentially very exciting.

Thank you very much.