**SURVEY ON THE PERCEPTIONS OF PATIENTS WITH ULCERATIVE COLITIS IN SPAIN. UC-LIFE PROJECT**

**1. Demographics and general data**

* **Gender and age**

|  |  |
| --- | --- |
| Man | ❑ |
| Woman | ❑ |
| Age |  Years |

* **Current marital status**

|  |  |
| --- | --- |
| Single | ❑ |
| Married or partner | ❑ |
| Divorced | ❑ |
| Widow/Widower | ❑ |
| Others | ❑ |

* **Education (please check only one, the highest achieved level)**

|  |  |
| --- | --- |
| Non studies | ❑ |
| Primary education | ❑ |
| Secondary education | ❑ |
| Technical studies | ❑ |
| Higher education (university degree or more) | ❑ |
| Others | ❑ |

* **Employment status (please check only one, the one that best reflects your current situation)**

|  |  |
| --- | --- |
| Student | ❑ |
| Active worker | ❑ |
| House-holding | ❑ |
| Retired | ❑ |
| Unemployed | ❑ |
| Temporary leave of absent due to UC | ❑ |
| Permanent leave of absent due to UC | ❑ |
| Leave of absent due to others | ❑ |
| Others | ❑ |

* **Where does the support for your ulcerative colitis come from?. Please indicate only one, the one that best reflects your current situation**

|  |  |
| --- | --- |
| Family | ❑ |
| Care givers | ❑ |
| I take care of myself alone | ❑ |

**2. Data about ulcerative colitis and flares**

* **How many years ago was your ulcerative colitis diagnosed?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_years

* **Which of the following statements better define the evolution of your ulcerative colitis since diagnosis?. Please check only one.**

|  |  |
| --- | --- |
| I debuted with a strong flare but then I haven't had any more | ❑ |
| I have a flare or more every year alternating with asymptomatic periods | ❑ |
| I have constant symptoms throughout the year | ❑ |
| I debuted with mild symptoms but I have more severe flares over time | ❑ |
| I am not sure | ❑ |

* **Do you know the extension of your ulcerative colitis?**

|  |  |
| --- | --- |
| Yes* I have the entire colon affected
* I have roughly half of the colon affected
* I have only the last part of the colon affected
 | ❑❑❑❑ |
| No | ❑ |

 \*Colon = large intestine

* **How long have you experienced your last flare or sustained worsening of ulcerative colitis symptoms?**

|  |  |
| --- | --- |
| I am having now a disease flare | ❑ |
| Less than 6 months | ❑ |
| Between 6-12 months | ❑ |
| Between 1-3 years | ❑ |
| More than 3 years | ❑ |
| I am not sure | ❑ |

* **How many flares or sustained worsening of your disease had you last year?**

|  |  |
| --- | --- |
| Number of flares:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |
| I do not remember | ❑ |

* **How many weeks one of your flares or ulcerative colitis worsening usually last?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ weeks

* **Which of the following symptoms did you experienced during last year? You can check more than one.**

|  |  |
| --- | --- |
| Diarrhea | ❑ |
| Abdominal pain and/or stinging | ❑ |
| Flatulencies | ❑ |
| Rectal bleeding | ❑ |
| Urgency of defecation | ❑ |
| Incontinence | ❑ |
| Joint pain | ❑ |
| Fatigue or tiredness | ❑ |
| No symptoms | ❑ |

* **How many times did you need hospital admission due to UC worsening during the past year?**

Number of admissions: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* **How many times did you need attending the hospital emergency room due to UC worsening during the past year?**

Number of times:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* **How many times did you need moving ahead your scheduled outpatient appointment due to UC worsening during the past year?**

Number of times: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**3. Symptoms associated to ulcerative colitis**

* **How would you rate your ulcerative colitis at this moment?**

|  |  |
| --- | --- |
| Mild | ❑ |
| Moderate | ❑ |
| Severe | ❑ |

* **Which statement best describe the behaviour of your ulcerative colitis during last year?. Please check only one.**

|  |  |
| --- | --- |
| I have had my symptoms controlled or nearly controlled | ❑ |
| I have had symptoms but not impairing my everyday-life | ❑ |
| I have had symptoms impairing my everyday-life | ❑ |

**4. Knowledge about ulcerative colitis**

* **Which are your main sources of information about ulcerative colitis?. Which is for you the most important one?**

|  |  |  |
| --- | --- | --- |
|  | **Sources of information (you can check more than one)** | **The most important one (check only one)** |
| Primary care doctor | ❑ | ❑ |
| Specialist doctor | ❑ | ❑ |
| Nurse | ❑ | ❑ |
| Pharmacist | ❑ | ❑ |
| Web pages specialised in ulcerative colitis | ❑ | ❑ |
| Blogs related to ulcerative colitis or health | ❑ | ❑ |
| Friends or relatives | ❑ | ❑ |
| Mass Media | ❑ | ❑ |
| Leaflets for patients | ❑ | ❑ |
| Patients’ associations | ❑ | ❑ |
| Other patients | ❑ | ❑ |

* **Please indicate if you agree or not which the following statements about ulcerative colitis**

|  |  |  |
| --- | --- | --- |
|  | **I agree**  | **I disagree** |
| It is a chronic disease in which symptomatic and asymptomatic periods alternate | ❑ | ❑ |
| It is an incurable disease | ❑ | ❑ |
| It is a disease due to an inadequate diet  | ❑ | ❑ |
| It is a hereditary disease | ❑ | ❑ |
| It is a disease that can affect other organs besides the intestine ,such as joints, skin or eyes  | ❑ | ❑ |
| It is a disease due to stress | ❑ | ❑ |
| It is a disease that needs lifelong treatment | ❑ | ❑ |
| It is a contagious disease | ❑ | ❑ |

**5. Impact of ulcerative colitis on your everyday life**

1. **Impact of symptoms on quality of life and work**
* **Please indicate those symptoms that worsen your quality of life (QoL) the highest**

|  |  |  |
| --- | --- | --- |
|  | **Symptoms with higher impact on your QoL (you can tick more than one)** | **Indicate the two symptoms with the highest impact on your QoL**  |
| Diarrhea | ❑ | ❑ |
| Abdominal pain and/or stinging | ❑ | ❑ |
| Flatulencies | ❑ | ❑ |
| Rectal bleeding | ❑ | ❑ |
| Urgency of defecation | ❑ | ❑ |
| Incontinence | ❑ | ❑ |
| Joint pain | ❑ | ❑ |
| Fatigue or tiredness | ❑ | ❑ |

* **How often does your disease prevent you from doing a normal life?**

|  |  |
| --- | --- |
| Never | ❑ |
| Sometimes | ❑ |
| Frequently | ❑ |
| Always or mostly | ❑ |

* **How often do the symptoms of your disease affect the quality of your sleep?**

|  |  |
| --- | --- |
| Never | ❑ |
| Sometimes | ❑ |
| Frequently | ❑ |
| Always or mostly | ❑ |

* **Have you ever find yourself in any of these situations?**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **No** | **Yes** | **This option does not apply me** |
| Your illness has conditioned the kind of work you perform | ❑ | ❑ | ❑ |
| You have rejected a job you were interested in due to UC  | ❑ | ❑ | ❑ |
| You have had sick-leaves due to UC  | ❑ | ❑ | ❑ |
| You have lost a job due to UC | ❑ | ❑ | ❑ |
| You have had problems with your studies due to UC | ❑ | ❑ | ❑ |
| You have had to leave your studies due to UC  | ❑ | ❑ | ❑ |

1. **Emotional aspects**
* **Order from 1 (higher) to 4 (lower) which of these situations generates more fear**

|  |  |
| --- | --- |
|  | **Order from 1 (higher) to 4 (lower)**  |
| To need a surgical intervention | ❑ |
| Faecal incontinence in public | ❑ |
| The disease could cause colon cancer | ❑ |
| To have a colostomy | ❑ |

* **Order from 1 (higher) to 6 (lower) which of these situations generates more concern**

|  |  |
| --- | --- |
|  | **Order from 1 (higher) to 6 (lower)**  |
| The disease prevents me from achieving my goals in life | ❑ |
| The disease affects my personal relationships | ❑ |
| The disease affects my sexual relationships | ❑ |
| The disease interferes with my work | ❑ |
| The disease does not allow me to enjoy my leisure time | ❑ |
| Having to be admitted to hospital due to my illness | ❑ |

* **In case you are currently working, do your superiors know you suffer from ulcerative colitis?**

|  |  |
| --- | --- |
| Yes | ❑ |
| No | ❑ |
| It does not apply to me (I am not working or I have not superior) | ❑ |

* **Do your friends or relatives know you suffer from ulcerative colitis?**

|  |  |
| --- | --- |
| Yes | ❑ |
| No | ❑ |
| It does not apply to me | ❑ |

* **Do you feel that suffering from ulcerative colitis reduce your self-confidence?**

|  |  |
| --- | --- |
| Yes  | ❑ |
| No | ❑ |
| It does not apply to me | ❑ |

* **How often do you feel the following sensations do to ulcerative colitis?**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Never** | **Sometimes** | **Frequently** | **Always or mostly** |
| Unmotivation | ❑ | ❑ | ❑ | ❑ |
| Anxiety | ❑ | ❑ | ❑ | ❑ |
| Anger | ❑ | ❑ | ❑ | ❑ |
| Depression | ❑ | ❑ | ❑ | ❑ |
| Frustration  | ❑ | ❑ | ❑ | ❑ |
| Embarrassment | ❑ | ❑ | ❑ | ❑ |

1. **Social life aspects**
* **Please indicate the frequency, if any, with which you have lived any of these situations**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Never** | **Sometimes**  | **Frequently** | **Always or mostly**  | **This option does not apply to me** |
| I take into account whether a WC is closer when I plan my leisure activities | ❑ | ❑ | ❑ | ❑ | ❑ |
| My illness have influenced the kind of friendships I have | ❑ | ❑ | ❑ | ❑ | ❑ |
| I have lost touch with friends due to my illness | ❑ | ❑ | ❑ | ❑ | ❑ |
| I have lost couples due to my illness | ❑ | ❑ | ❑ | ❑ | ❑ |
| My illness influences the kind of activities I do in my leisure time | ❑ | ❑ | ❑ | ❑ | ❑ |
| I have refused participation in recreational or professional activities due to my illness | ❑ | ❑ | ❑ | ❑ | ❑ |

* **Do you think that your disease have influenced your decision about having children?**

|  |  |
| --- | --- |
| Yes | ❑ |
| No | ❑ |
| It does not apply to me | ❑ |

* **In case of having children, do you feel that your disease have influenced or influence on your vitality for taking care of them?**

|  |  |
| --- | --- |
| Yes | ❑ |
| No | ❑ |
| It does not apply to me | ❑ |

**6. Satisfaction with ulcerative colitis treatment**

* **What is the degree of satisfaction with your current ulcerative colitis treatment?**

|  |  |
| --- | --- |
| Very satisfied | ❑ |
| Satisfied | ❑ |
| Neither satisfied nor dissatisfied | ❑ |
| Dissatisfied | ❑ |
| Very Dissatisfied | ❑ |

* **Order from 1 (most important) to 5 (less important) the following aspects for an ulcerative colitis treatment in general**

|  |  |
| --- | --- |
|  | **Order from 1 (higher) to 5 (lower)**  |
| Continuous control of symptoms | ❑ |
| Good tolerability | ❑ |
| Speed of action | ❑ |
| Easiness of administration | ❑ |
| Normalization of my Quality of life | ❑ |

* **Assess your current treatment**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Very satisfied** | **Satisfied** | **Neither satisfied nor dissatisfied** | **Dissatisfied** | **Very dissatisfied** |
| Continuous control of symptoms | ❑ | ❑ | ❑ | ❑ | ❑ |
| Good tolerability | ❑ | ❑ | ❑ | ❑ | ❑ |
| Speed of action | ❑ | ❑ | ❑ | ❑ | ❑ |
| Easiness of administration | ❑ | ❑ | ❑ | ❑ | ❑ |
| Normalization of my Quality of life | ❑ | ❑ | ❑ | ❑ | ❑ |

**7. Physician-patient communication and disease follow-up**

* **Please indicate how is your case:**

|  |  |  |
| --- | --- | --- |
|  | **Yes** | **No** |
| Primary care doctor diagnosed my ulcerative colitis | ❑ | ❑ |
| Primary care doctor initiated my treatment | ❑ | ❑ |
| Primary care doctor referred me to the specialist | ❑ | ❑ |
| Primary care doctor participates in the follow-up of my disease | ❑ | ❑ |

* **During the last year, how many times did you attend to your gastroenterologist clinic?**

|  |  |
| --- | --- |
| Number of times:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |
| I do not remember | ❑ |

* **Please, indicate the behaviour of your physician during your regular appointments:**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Never or hardly ever** | **Sometimes** | **Frequently** | **Always or mostly** |
| Listen to me | ❑ | ❑ | ❑ | ❑ |
| Cares for me | ❑ | ❑ | ❑ | ❑ |
| Answers to my questions | ❑ | ❑ | ❑ | ❑ |
| Devotes me enough time | ❑ | ❑ | ❑ | ❑ |
| Involves me in treatment decisions | ❑ | ❑ | ❑ | ❑ |
| Asks me how I feel emotionally | ❑ | ❑ | ❑ | ❑ |
| Asks me about my symptoms | ❑ | ❑ | ❑ | ❑ |
| Asks me about the impact of my disease on my work  | ❑ | ❑ | ❑ | ❑ |
| Asks me about the impact of my disease on my personal relationships  | ❑ | ❑ | ❑ | ❑ |
| Listens to me when I need it | ❑ | ❑ | ❑ | ❑ |
| Gives me information about the causes of my disease | ❑ | ❑ | ❑ | ❑ |
| Gives me information about the evolution of my disease | ❑ | ❑ | ❑ | ❑ |
| Gives me information about the different treatment options for my disease | ❑ | ❑ | ❑ | ❑ |
| Reassures me | ❑ | ❑ | ❑ | ❑ |

* **Did your physician explain you the aims of the treatment for your ulcerative colitis?**

|  |  |
| --- | --- |
| No | ❑ |
| Yes, my physician | ❑ |
| Yes, other health professional | ❑ |
| I do not remember | ❑ |

* **How often do you attend to routine visits with your physician?**

|  |  |
| --- | --- |
| Every 2-3 months | ❑ |
| Every 6 months | ❑ |
| Every year | ❑ |
| We do not agree routine visits | ❑ |
| Normally I do not attend routine visits | ❑ |

* **In case of sudden worsening of your disease, which options are available to talk with your physician?. You can check more than one**

|  |  |
| --- | --- |
| I can phone him / her | ❑ |
| I can communicate by email | ❑ |
| I can get a visit at the gastroenterology clinic the same day | ❑ |
| I have to get an appointment and wait for doctor’s availability | ❑ |
| I have to go to emergency room | ❑ |