

## *It's Rare for Me* project Official guidelines for interviews

### Introduction

The *It's Rare for Me* project includes the filming of patients and/or caregivers in the rare diseases area.

The outcome of the interviews consists of two videos: a long video, about 10 minutes, and a shorter one about 3 minutes length that will be used both on the dedicated campaign website and eventually for the creation of materials to be used both at congress booths and for internal events.

For this reason, we need to maintain a standard and structured approach for the interviews.

Following, you can find the guidelines that we ask you to follow as much as possible, given the circumstances you will be in.

### Technical guidelines

Interview:

- 2 cams
- 4K resolution
- Frontal frames/shooting
- Locations with as less background noises as possible
- Shooting: high resolution, at least 10-12 photos per patient, including close-ups

Mandatory:

- Location, patient while alone, interaction between patient and caregiver.
- Backstage photos

Please note that all the materials must not include the presence of Chiesi people, otherwise they cannot be included in the final video/photos.

### Interview guidelines

The interviewer will have to use the following questions to start the interview. These can be adapted following the patient's answers, to follow their flow of information and thought.

Please note that the questions are included in the Chiesi presentation for patients, that has to be shared with them by their Chiesi contacts beforehand.

The agency responsible for the European interviews will be available for a call in advance, to support with its organization.

- **Personal Background:**
  - Could you start by telling us a bit about yourself?
  - If you had to choose something or somebody that is rare and precious for you, what would that be?
  - In addition to what is rare and precious for you, is there any hobbies, passions or interests that bring you joy or help you manage the difficulties?
  
- **Diagnosis:**
  - How did you decide you needed to get help? What were the first symptoms?
  - How long until you got the correct diagnosis? Please share your diagnostic journey
  - How did you feel when you learned you had to live with this rare disease?
  - How was it when you shared it to your family and friends?
  
- **Experiences and insights:**
  - Can you describe your day-to-day life?
  - How have your relationships been impacted by the disease?
  - Could you please describe your experience with the medical community? Is there some kind of medical support that is missing?
  - Is there any other need of yours that is not being addressed?
  - What have been some of the biggest challenges in living with the condition, and how do you manage them?
  - Do you feel there are misconceptions or misunderstandings people may have about rare diseases? What would you suggest to change that?
  - Do you feel that the language used to talk about rare diseases has a role in building an inclusive society? Do you feel people normally use appropriate language to talk about rare diseases?
  - Are there specific people in your life who have been particularly supportive in helping you face this journey?
  
- **Becoming a rare disease advocate and/or raising awareness:**
  - What is the impact of the rare disease on the quality of your life?
  - What are your hopes and fears?
  - What led you to the decision to share your story?

- Is networking with the rare patient community important to you?
- What do you wish more people understood about your rare disease and the challenges it presents?
- What do you think it should be done to increase awareness around rare diseases and around your condition specifically?
- What are the most important messages that you would like to share to the people who listen to your story?

### Guidelines for Chiesi people

- The interview will be led by a ~~journalist~~ or third-party person.
- Please remember that the location must be chosen together with the patient, who must feel comfortable with it.
- If the location is outside, it must be in a place where there is no passage of people and with as less background noises as possible.
- Chiesi people:
  - At each interview, the number of people from the Company must be limited (max. 2 people).
  - The Company representatives must not interact with the patient during the interview but must always check that the patient feels comfortable.
  - The Company representative and the crew must inform the patient beforehand that he/she can ask for a break and freely express any concern or discomfort they feel at any time.