Chiesi

IT'S RARE for Me

Chiesi
global rare diseases

"It's Rare for Me" project

Guidelines for participants

Introduction

"Where should I begin? How do I communicate what is going on with my friends, family, or healthcare providers? How will my life change?"

These are only some of the questions that arise to anyone that gets a rare disease diagnosis. **Many within the rare disease community do not know how great an impact they can have by sharing their story.** The isolated nature of many rare diseases **makes it essential to speak up**, any **individual story could be invaluable to someone still searching**. Not only sharing a story can lessen feelings of isolation and promote new avenues of support: it can also offer vital diagnostic clues when others are searching for answers. These stories can shed light on a condition's symptoms, prognosis, and other details for those still searching for the correct diagnosis or for someone who knows their disease firsthand.

Telling a story can be tough! **These guidelines are intended to help you overcome the difficulties** by offering advice on ways to get started.

Getting started

Sharing a personal story can be scary, cathartic, emotional, simple, or extremely difficult all of these are understandable and important feelings. For this reason, here are some advices on how to encourage people in sharing their rare, unique stories most spontaneously without being afraid of their own emotions.

Photo Project

The aim of these pictures will be to **show the uniqueness of each person** who will **pose with something or someone that they are particularly tied to or that they perceive as precious or rare**. Is not the object itself that needs to be rare, but it might also represent a passion or hobby, anything that is rare and precious.

Video Project

The aim is to create a series of videos where people living with rare disease and/or their caregivers **share their life as an intimate, direct, unfiltered story**.

Putting together the stories

PERSONAL BACKGROUND AND LIFE STORY

- 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? Is not the object itself that needs to be rare, but it might also represent a passion or hobby, anything intangible that is rare and precious.
- 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?

Putting together the stories

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 think 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?

Putting together the stories

BECOMING A RARE DISEASE ADVOCATE / RAISE 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? Why?
- 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?

Conditions of use and disclaimer

- If the storyteller is enrolled in a clinical trial, please ensure they **do not share information about** or related to **the trial** experiences.
- **Avoid** any kind of **reference to drugs** or to their **commercial name**.
- If any **medical questions arise**, please advise the storyteller to **direct them to their physician.**

Go at your pace

Knowing that sharing your personal story can be a very stressing experience, we sympathize with you. **Go at your pace, feel absolutely free to ask for a break** at any time. Some open-ended questions might help you.

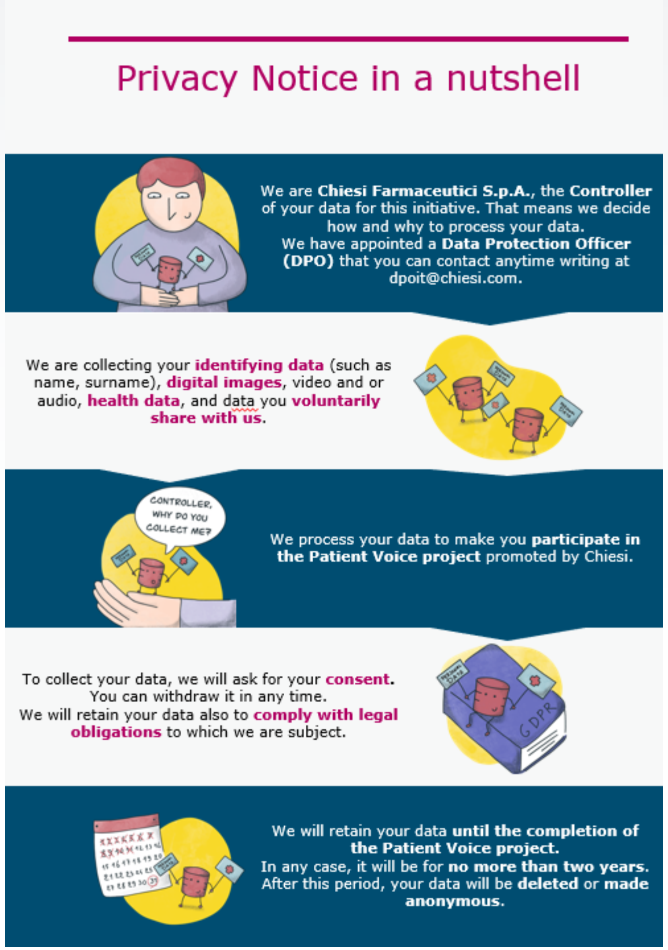
Please consider the following as an example:

- Talk a little about yourself: what do you like to do on your free time? (not related to the disease or the pain you are experiencing)
- How do you feel right now?
- What are your thoughts?
- What does the future look like?

Privacy is of utmost importance

Only **the storytellers can decide** what's most appropriate to share from their personal experience

Privacy Notice in a Nutshell



Privacy Notice in a nutshell

We are **Chiesi Farmaceutici S.p.A.**, the **Controller** of your data for this initiative. That means we decide how and why to process your data.
We have appointed a **Data Protection Officer (DPO)** that you can contact anytime writing at dpoit@chiesi.com.

We are collecting your **identifying data** (such as name, surname), **digital images**, video and or audio, **health data**, and data you **voluntarily share with us**.

We process your data to make you **participate in the Patient Voice project** promoted by Chiesi.

To collect your data, we will ask for your **consent**.
You can withdraw it in any time.
We will retain your data also to **comply with legal obligations** to which we are subject.

We will retain your data **until the completion of the Patient Voice project.**
In any case, it will be for **no more than two years.**
After this period, your data will be **deleted** or **made anonymous**.

We **share** your data with **Public Authorities** (where requested), **service providers** and our **affiliates**, that may be **outside the EEA**.
In such case the transfer is subject to **appropriate safeguards**, so that your data are secured.

You can exercise your rights anytime writing at dpoit@chiesi.com.
You are not required to pay any charge for exercising your rights. We have one month to respond to you.

Right to access
You have the right to ask us to access and receive a copy of your personal data.

Right to object
You have the right to stop or prevent us from processing your personal data in our legitimate interests.

Right to erasure
You have the right to ask us to erase your personal data in certain circumstances.
You may have heard of this right also as the "right to be forgotten".

Right to restrict processing
You have the right to ask us to restrict the processing of your personal data.
That means we can still store your personal data, but not use it.

Right to data portability
You have the right to ask us that we transfer the personal data you gave us to another organisation or to give it to you.

Right to rectification
You have the right to ask us to rectify personal data you think is inaccurate.
You also have the right to ask us to complete personal data you think is incomplete.

Right to lodge a complaint with a Supervisory Authority

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Guidelines from the provider

- For the photo project, **the storyteller can choose something or someone (an object, a person, a passion or hobby) that is considered ‘precious' and 'rare’**
- For the photo shoot and interview, the storytellers should feel comfortable (be **in their everyday look)**

- Consider **one day** will be needed for the photo shoot and interview. This can be adapted based on participants’ needs and availability.
- There will be **no need to choose and prepare a set** beforehand, the crew will provide the correct lighting and sound

Useful Contacts

In case of questions and doubts please contact:

- SGRÒ Sonia sa.sgro@chiesi.com

  for issues related to patient advocacy

- Di Rosario Giada g.dirosario@chiesi.com

  for issues related to patient advocacy

- Locciola Jessica j.locciola@chiesi.com

  for issues related to patient advocacy

Let’s Make The World
Feel Better

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