# ONLINE SUPPLEMENTARY DATA

## Appendix 1. Video-recording patient consent form

* Patients were asked to provide two permissions:
  + Permission for the raw, unedited video footage to be analyzed and stored securely, and for clips to be used to form a summary DVD for the study sponsor
  + Permission for the summary DVD to be shared with the study sponsor’s research and development, marketing, and sales teams, and with healthcare professionals for educational purposes

## Appendix 2. Patient information

* Information provided to patients before enrollment was tailored to the individual countries involved in the study
* The information introduced the company conducting the research and the overall aims of the study, i.e., to understand the experiences of people with diffuse cutaneous systemic sclerosis (dcSSc), specifically understanding the events that took place, how the patient felt at key points in their journey, and to understand the impact of living with dcSSc
* The interviews, ethnography sessions, and video diaries were described (as applicable to the different countries in the study), along with the uses to which the recordings and other information were to be put

## Appendix 3. Sixty-minute patient interview

* The moderator guidelines for the 60-minute interview were divided into four modules:
  + A: Introduction (5 minutes)
    - Summary of the interview format and the intended use of the video footage collected
    - Patients were reminded of the requirement to report adverse events and were asked for consent to continue
  + B: Warm-up and support/educational resources used (15 minutes)
    - Personal introductions
    - Patient’s description of their condition
    - Information sources, support services, and patient associations used by the patient
    - Interest in new treatments
  + C: Associations and living with diffuse cutaneous systemic sclerosis (dcSSc) (15–20 minutes)
    - Patient’s experiences of living with the condition
    - Symptoms experienced and their impact
    - Patient’s responses to pre-defined scenarios and images
    - Patient’s perceptions of stigma
    - Communication with others about the patient’s condition
    - Impact of disease on life, relationships, family, and employment
  + D: Understanding the management of dcSSc
    - Age at diagnosis and initial symptoms
    - Experience of being diagnosed, including time taken
    - Evolution of disease over time
    - Treatments being received and their impact (positive and negative) on symptoms and daily life
    - Relationship with healthcare professionals and frequency of follow-up
    - Treatment compliance and overall satisfaction with management
    - Worries about the future

## Appendix 4. Patient screener

* Detailed instructions were provided to recruiters tasked with recruiting patients from healthcare professionals and patient associations
* The instructions specified that patients with diffuse cutaneous systemic sclerosis (dcSSc) should be recruited and **not** patients with limited systemic sclerosis
* A script was provided, tailored to the requirements of each participating country
* Patients were informed as to the intended uses of the material collected, consistent with the consent form described above. They were also informed that the research was non-promotional, would adhere to local market research codes of conduct, and that they had the right to withhold information or withdraw from the interview at any time
* Given the research was sponsored by a pharmaceutical company, patients were informed of the requirement to report adverse events or product technical complaints related to products manufactured by the study sponsor and consent to participate on this basis was captured
* Patients were asked about several demographic and disease characteristics to confirm their eligibility, including:
  + Sex
  + Age
  + Diagnosis of dcSSc
  + Prescription medications being taken for dcSSc
  + Highest education level
  + Living status
  + Employment status

## Appendix 5. Interview pack for patients participating in the 7-day research

* A printed pack of materials was provided for each patient
  + Video diary instructions
    - Expectations of the video diary
    - Suggestions for issues to discuss (e.g., daily activities and disease impact, symptoms, medication)
    - Operation of the video camera and contact details for technical support
  + Instructions for self-completion exercises
    - Expectations for the three exercises (note: options were provided to patients with reduced dexterity)
    - Task 1: preparation of a collage, collection of items, or filming of a video recording, representing/describing what dcSSc meant to them
    - Task 2: completion of a picture or description of a room showing how they felt about their condition
    - Task 3: illustration of their emotional journey on a timeline or a description of their emotional highs and lows

## Appendix 6. Ethnography moderator guide for the 7-day research

* A detailed guide was provided for moderators of the ethnography research, divided into five sessions over a 7-day period
  + 1. Structured in-depth interview: understanding patient perspective (Day 1)
    - Introduction
    - Current diffuse cutaneous systemic sclerosis (dcSSc) condition
    - Understanding the dcSSc patient journey (e.g., diagnosis, evolution of symptoms over time, healthcare professionals, treatments)
  + 2. Ethnography session: observe how patients live with dcSSc and the impact of dcSSc (Day 1)
    - General observations around the patient’s home and specific prompts (e.g., treatments, hygiene, food and drink, preparing to go out, general housework, employment, relaxing/socializing, fatigue, preparing for bed)
  + 3. Materials for video diary sessions: understand the daily impact/considerations of living with dcSSc (Days 2–6)
    - Introducing the patient materials described in Appendix 5
  + 4. Ethnography session: observe how patients live with dcSSc and the impact of dcSSc (Day 7)
    - To involve the patient leaving the house (e.g., to a supermarket or their place of work) and, if possible, interacting with a friend or family member involved in the patient’s care
    - Specific prompts for the patient in this session related to interactions with family and other carers, and support services
    - Questions for family members/carers relating to the patient’s condition and the burden of providing care and emotional support
  + 5. Structured in-depth interview: understand patient associations with dcSSc and the emotional impact of the condition, with reference to the ethnography studies and video diary tasks (Day 7)
    - Impact of dcSSc on daily living and quality of life
    - Emotional impact of living with dcSSc
    - Use of education and support services

## Appendix 7. Interview pack for moderators

* To support moderators in the activities during the study, a PowerPoint presentation was provided, containing:
  + Images to show the patient suggesting responses such as distress, isolation, burden, etc. to illustrate their response to their disease and their relationships with others
  + Record sheets to note treatments taken and compliance
  + Background information on systemic sclerosis symptoms and treatments for reference
  + Chart for patients to record their journey and feelings over time
  + Descriptions of activities of daily living and charts for patients to prioritize individual activities