

# Understanding Lupus

A Lupus training program for  
Community Health Workers

Facilitator's Guide



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## Introduction

Welcome to *Understanding Lupus*: A lupus training program for community health workers. This training program aims to increase community health workers' (CHWs): (1) knowledge about the signs and symptoms of lupus, lupus health disparities, lupus clinical trials and clinical trial disparities; and (2) skills to increase lupus awareness, and support clients with potential and diagnosed lupus.

Here are a few key points about lupus:

- Lupus is a chronic, autoimmune disease that can cause inflammation in almost every organ, caused by the autoimmune system attacking its own cells and tissues.
- Minority populations are disproportionately impacted by lupus.
- Lupus is more common in women than in men.
- Women are often diagnosed between ages 15 and 44.
- Although there is no cure for lupus, there are medications and lifestyle changes that can help people with lupus manage the disease so that they feel better.

## Why use *Understanding Lupus*?

The *Understanding Lupus* program provides CHWs with knowledge and skills to raise lupus and lupus clinical trial awareness. While lupus is more common among minority groups than Whites, many minority communities may be unaware of lupus and its consequences. CHWs play an important role in addressing lupus and lupus clinical trial health disparities by educating and conducting outreach to reduce health barriers for their communities.

After participating in *Understanding Lupus*, CHWs will be able to:

- Explain what lupus is, describe signs and symptoms, and identify types of medical providers (providers) that treat lupus
- Define lupus health disparities, understand which populations are affected the most by lupus, understand the importance of clinical trials and minority participation, and describe barriers to participation.
- Understand the importance of raising awareness about lupus and clinical trials, describe the role of CHWs in reducing and navigating barriers to clinical trial participation, and describe the barriers of lupus patients participating in clinical trials.
- Explain the process of diagnosis, understand how to support clients with lupus, discuss the importance of support systems and support groups, and understand how to connect a client to a medical home.
- Understand the importance of listening to persons with lupus, describe lifestyle changes that benefit persons with lupus, and learn about self-management tools and information to recommend to persons with lupus.

## Who is *Understanding Lupus* for?

*Understanding Lupus* is designed to train CHWs in hospital-, clinic-, and community-based environments. A facilitator or CHW trainer should deliver the *Understanding Lupus* training. This program should not be used independently, as it is not a self-guided program. This program contains all the necessary instructions needed for implementation in English and includes handouts for distribution to the community in English, Spanish, and **simplified** Chinese.

## How is *Understanding Lupus* implemented?

*Understanding Lupus* consists of five sessions of approximately six hours of training. Sessions range in length from one hour to one hour and fifteen minutes and may be implemented in-person or virtually. We suggest short breaks between sessions for CHWs and a longer break of 15 minutes between Session 3 and Session 4. Additionally, we recommend around 15 CHWs participate in the training at a time. A small training class allows for CHWs to ask questions and participate in activities and provides the opportunity for in-depth discussions.

## About *Understanding Lupus*

*Understanding Lupus* includes this detailed, step-by-step Facilitator's Guide, PowerPoint slides, activity sheets, and handouts for the community. During the sessions, CHWs will participate in activities and role plays to provide CHWs with detailed knowledge on lupus, while also providing the opportunity to practice outreach techniques and skills. Each session begins with a brief overview of the learning objectives, the necessary support materials, and teaching materials. While *Understanding Lupus* may be implemented in-person or virtually, you will notice that the Facilitator's Guide default direction is for in-person implementation. We provide suggestions for virtual implementation in boxes labeled "Virtual session note" throughout the guide, where applicable.

## Teaching documents

*Understanding Lupus* uses four types of teaching documents:

- PowerPoint slides display information and illustrations for all participants to see. The PowerPoint slides can be used in rooms with computers and projectors. If you do not have computers and projectors, you may print copies of the slides for each participant.
- Activity sheets contain information for CHWs. Examples of activity sheets include fact sheets, role play scenarios, and information to use during the training.
- Handouts are materials that CHWs can share with their clients.
- Video clips as short clips accessible via URL noted in the Facilitator's Guide.

## Materials

*Understanding Lupus* does not require any special materials. For in-person sessions, you will need the following supplies:

- Pens and markers: Participants can use pens and markers to take notes and complete activity sheets.
- Thick paper or card stock: Ask participants to make name plates when they arrive for the sessions.
- LCD projector for PowerPoint slides: Set up the projector before beginning the program.
- Small, lightweight beach ball to complete group activity in Session 1.

For virtual sessions, you will need the following supplies:

- Access to the Internet
- Access to a video platform such as Zoom or Ring Central
- Knowledge about how to navigate the chosen platform

## SESSION ONE

# Lupus basics

## Overview

In Session 1, facilitators will introduce the major goals and guidelines of *Understanding Lupus*, particularly the critical role of community health workers (CHWs) in increasing lupus awareness and supporting people living with lupus in their community. CHWs will learn what lupus is, how to recognize the signs and symptoms of lupus, and how lupus is diagnosed. CHWs will then practice applying the information they learned and using the resources provided during a role play with a person who may have undiagnosed lupus.

## Learning objectives

After completing Session 1, participants will be able to:

- Explain what lupus is
- Describe the common signs and symptoms of lupus
- Understand lupus flares and common triggers for lupus flares
- Identify the types of medical providers who treat lupus

## Materials needed

- Small, lightweight beach ball
- Thick paper or cardstock for name plate (one per participant)
- PowerPoint projector or laptop if using PowerPoint slides.
- Equipment to show video clips

## Teaching documents

- PowerPoint 1. Lupus Basics
- Activity sheet 1.1. Lupus signs and symptoms
- Activity sheet 1.2. Lupus talking points
- Handout 1.1. Lupus fact sheet
- Handout 1.2. Symptom tracker
- Video Clip 1.1. [Ivana and Michelle](#)

## Before the session

- Gather all the materials you will need for the session (listed above)
- Assemble all the documents (including PowerPoint slides and the video clips) you will need for the session (listed above)
- Make copies of Activity sheets 1.1, 1.2, and 1.3 (one per participant)
- Make copies of Handouts 1.1. and 1.2. (one per participant)
- If you will be conducting the session in an unfamiliar room, visit the room to make sure it has
  - adequate space and enough chairs and tables to accommodate your participants
  - a screen on which to project the PowerPoint slides and show the video clips
  - a working electrical outlet (older buildings may require an extension cord)
- If you will be conducting the session in an online software, conduct a test run to make sure you know how to:
  - Share your screen to present the PowerPoint slides and show the video clip, including how to share your computer sound
  - Create and admit participants to breakout rooms for activities



## Virtual Session Note

If hosting a virtual session, the facilitator may consider emailing the activity sheets and handouts to participants or posting links to the documents in the chat.

## SESSION ONE AGENDA

# Total time: 75 minutes

ACTIVITY	TOTAL TIME
<p>Activity 1: Welcome and introductions</p> <ul style="list-style-type: none"><li>• Instructor welcome</li><li>• Participant introductions</li><li>• Session guidelines</li></ul>	15 minutes
<p>Activity 2: Lupus, the immune system, and autoimmune diseases</p> <ul style="list-style-type: none"><li>• Did You Know?</li><li>• What is lupus?</li><li>• Immune system and autoimmune diseases</li></ul>	15 minutes
<p>Activity 3: Lupus signs and symptoms</p> <ul style="list-style-type: none"><li>• Did You Know?</li><li>• Activity sheet 1.1. Lupus signs and symptoms</li><li>• Visible and invisible signs and symptoms</li><li>• Video Clip 1.1. Ivana and Michelle and discussion</li></ul>	20 minutes
<p>Activity 4: Diagnosis and flares/remission</p> <ul style="list-style-type: none"><li>• Did You Know?</li><li>• Lupus diagnosis</li><li>• Who is a rheumatologist?</li><li>• Lupus flares and remission</li></ul>	10 minutes
<p>Activity 5: Role play and teach back</p> <ul style="list-style-type: none"><li>• Role play – talking to a person who may have undiagnosed lupus</li><li>• Activity sheet 1.2. Lupus talking points</li><li>• Activity sheet 1.3. Lupus assessment tool</li><li>• Handout 1.1. Lupus fact sheet</li><li>• Handout 1.2. Symptom tracker</li><li>• Teach back</li></ul>	15 minutes